



Chapter 7

Walking with children in the shadow of death

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These are the words of a seven-year-old boy:

My mum said she was sad because her friend was Pastor Way. I didn't know ... who was Pastor Way? I thought Pastor Way was a man, but her friend was a lady. I thought my mum [had] gone mad! (Drane & Fleming Drane, 2009:212).

Introduction

When I asked a mother whether anyone was discussing her son's imminent death with him, she got very upset with me and answered that we were not there yet and that she would talk to him when he is actually dying. He passed away less than 24 hours later.

Few adults are willing to discuss the difficult topic of death with children, especially when the child has a life-limiting condition. People should be able to live full lives until their golden years, and the diagnosis of a terminal illness in a child goes against everything we believe in. In her book, *The Private Worlds of Dying Children*, Myra Bluebond-Langner describes this as follows:

There they all were: children with futures to be moulded; parents charged with this responsibility; medical practitioners trained to cure. Leukaemia now threatened everyone's ability to fulfil their socially defined roles. Moreover, it threatened their ability to carry on social interaction. (Bluebond-Langner, 1978:321)

Although children would welcome opportunities to reflect on matters of life and death (Bates & Kearney, 2015), they will sense immediately if a topic is making an adult uncomfortable and will refrain from starting a discussion or asking questions about it. Damsma Bakker et al. (2018:e109) explain that children want to protect their parents from pain and suffering and that they tend to avoid difficult spiritual questions. For this reason, many children are often stuck with numerous unanswered questions, and theology students should be prepared to address these questions and support children in the religious communities where they are involved.

Therefore, the learning outcomes at the end of this module could be:

- Students will be able to understand the developmental stages of children and how their understanding of death changes at different ages.
- Students will be able to promote a supportive environment for children when a parent or significant other is terminally ill.
- Students will be able to facilitate open and honest communication with children about death and dying when they are critically ill.
- Students will be able to critically reflect on personal biases and fears about death and dying.

Children's understanding of death and dying

The limited life experience of children could lead to a variety of misconceptions. This was the case for a six-year-old boy who had to go for a minor operation. He was trembling with fear, and when I talked to him to explain what was going to happen, I realised that he thought he had come to the hospital to die. His mother then confirmed that a few months ago, his father had passed away in the same hospital where this little boy was now waiting to go for an operation. The same happened when a five-year-old girl thought she was going to be euthanised by her immunisation injection – just because

that was what happened to her dog a few weeks before her healthcare experience!

The way children understand death and dying is not only determined by their developmental age but also by their experience of the concepts of death and dying. If they've previously had to deal with the death of a pet or a loved one, they were exposed to the finality of death and had the chance to experience that once someone is dead, they will never return. Children in an oncology unit are often exposed to friends dying and have a different concept of death than their peers at the same age. Mdleleni-Bookholane, (2003:163) concludes that children who are exposed to an environment where it is distasteful to speak about death, are not on the same cognitive level as their peers with regards to their conceptualisation of death.

Although it is important not to generalise, a look at the different developmental stages of children will give a better understanding of the reasoning of children with regard to death and dying.

0–2 years

Object permanence is not yet developed in babies, and they can't understand that an object or person exists when out of sight. However, they know their parents or primary caregivers and can get very upset when separated from them. During this stage, they learn to trust other people and having their basic needs met is an important part of developing trust. Physical closeness is central for trust to develop, and abuse or insufficient caregiving can damage this process of learning to trust others. Trusting other people is the foundation of trust in God. When the parent is terminally ill, adequate loving care should be available for babies and small children and their routine should be kept as consistent as possible. From one year of age, the loss of a parent will be felt even more, but small children cannot give meaning to the loss and might get depressed.

When one of these small ones is dying, close physical contact with the parents or primary caregivers should be encouraged as much as possible. If that is not possible, someone else should stand in for the parents to ensure constant care.

2–3 years

One of the biggest fears of children during this early stage is separation from their parents or primary caregivers, and it is therefore very traumatic for these children when they are separated due to illness, hospitalisation (of either the child or one of the parents) or death. They have a natural fear of monsters, ghosts, and mutilation of the body, and all these fears have the potential to escalate when the child is faced with illness, hospitalisation, and/or death. Small children still don't understand the irreversibility and permanence of death and might confuse it with sleep. They might think that they've done something wrong to have caused the illness or death and that they are being punished. They are not able to understand abstract concepts and will form a literal picture in their minds of everything being said to them. We should, therefore, use concrete examples when talking to them.

3–7 years

Preschool children still fear separation from their parents and might become fearful of being separated from them. They have a vivid imagination and respond well to stories of good and evil, but some television programmes and animated movies might give them the wrong idea of dying. They might be interested in investigating a dead animal and talking about death, but they are still not able to fully grasp the permanence of death. They might still believe that they are being punished by negative events as they don't understand the relationship between cause and effect.

These children are still not capable of abstract reasoning, and when they don't understand certain concepts or wording, they will create their own images or words that they can

understand. This might lead to many misunderstandings such as in the example in the introductory quote, where the concept of ‘pass away’ is unfamiliar to the child, and he therefore assumed it to be a person, Pastor Way.

7–12 years

School-age children may start to grasp the finality of death and they tend to stress about details, such as that the process of dying might be scary or painful. Their peers are very important to them, and they value their newly found independence and may fear the loss of control or becoming disabled. Abstract thinking starts to develop, and they have a more mature thinking about cause and effect. They also start to understand the finality of death, however, they still tend to personify death and might associate it with monsters or the bogeyman. School-age children rarely verbally express negative emotions, and when they are diagnosed with a chronic or life-threatening illness, they usually want to protect their parents and not upset them more than they already are by expressing their emotions. When terminally ill, young people often want to ‘live life to the fullest,’ but this should not be interpreted as that they don’t understand what is happening to their bodies (Bates & Kearney, 2015:5).

At this stage, children have a strong sense of justice and believe that goodness is rewarded, and evil is punished. This could lead to a spiritual crisis when they realise that bad things can happen to good people. One of the teenagers in the oncology ward was a star student, captain of the rugby team, leader in his school and very caring towards the other children in the ward. When he died, one of the other patients, a 10-year-old boy, became very depressed and admitted that, if the teenager whom he admired so much couldn’t survive a cancer diagnosis, there was no way that he would survive it.

When a parent or significant other is terminally ill

Too often we want to shelter children from the harsh realities of life by withholding information from them. What we tend

to forget, is that children are very susceptible to the feelings and body language of the adults around them and will know intuitively that something is wrong. Children often overhear adult conversations or telephonic discussions and might arrive at their own conclusions, which may be far from the truth. Eade (2009:190) points out the very uncomfortable truth that 'in trying to protect them [the children], we as adults are often protecting ourselves'. We need to brace ourselves for uncomfortable discussions with children because they also deserve to know the truth.

The sections that follow mention the things that a child should be told when a loved one is terminally ill.

That the person is ill

Children will know something is wrong and should be kept in the loop from the beginning. If the situation is not explained to them, their imagination might start to run wild, and they could imagine all sorts of scenarios that are far from the truth. Always get permission from the family to disclose the name of the illness to the child, especially if it is a sensitive issue such as in the case of HIV and AIDS. Children should be told the name of the illness in a controlled setting before hearing it from someone else.

Parents once wanted to protect their child by not telling her that her brother has cancer. Back at school, a concerned classmate, who overheard one of the teachers talking, approached her and asked: 'I hear your brother has cancer. My grandpa also had cancer and he is dead now. When is your brother going to die?'

That the illness might lead to death

Although it is important to keep hope alive (as discussed later in this chapter), the topic of death should be discussed with the child according to that child's understanding of death. Children also deserve time to say goodbye, time to build special memories and time to make the most of being together. Because sometimes, all we have left, is just a little bit of time.

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Kathleen McCue and Ron Bonn highlight the following as 'Something to think about':

All life is terminal. Even if one's own timetable is tragically shortened by a medical diagnosis, the end is not yet. There is still time, time for children and parents who love each other to make the most of. Don't try to shield your children from making the most of that time. (McCue & Bonn, 1994:21)

Whether the illness is contagious or not

Explain to children whether an illness is contagious or not. After COVID-19, children might assume that all illnesses are contagious. If the sick person is not contagious, assure children that they can safely interact with the sick person. If the person is contagious, explain the steps being taken to ensure that the rest of the family will not get ill.

What will happen in the near future

Children are focused on the here and the now and need to know what will happen in the near future. They might get concerned about who will fetch them from school when a parent is in hospital, or where the money is going to come from when the breadwinner can't go to work. Keep their routine as normal as possible and explain to them how it is going to work.

What was the cause of the illness or injury?

Children might blame themselves for any illness, pain, and suffering, and should be ensured that they didn't do anything wrong to have caused the illness or injury. However, if the child did cause the accident, do not avoid the issue, and discuss it with the child, addressing intent and forgiveness where necessary.

Children and hospitals

Should children visit a loved one in a hospital? This is a controversial topic, and the answer depends on who you're asking. Often, hospitals don't allow children to visit the sick due to the risk of infection to both the child and the patient, or they are not equipped to deal with the preparation and support of children visiting. Sometimes, the patient might be severely disfigured or too unstable to tolerate a visit from children, or parents might prefer not to be visited by their children.

However, if possible and with the necessary permissions from all involved, I believe that a child should be allowed to visit his or her loved ones in the hospital or even in the ICU, but it is very important to prepare the child for such a visit. Never insist if the child doesn't want to visit but try to determine the reason for this. Children often envision a scenario much worse than reality, and it might be a good starting point to show a child a picture of the sick person (with the necessary permissions). Ask the staff to assist so that you can explain to the child the purpose of all the medical equipment, lines, and tubes on the photo so that they know what to expect when the visit.

Explain to children what is expected of them, what they should or shouldn't do, and give them a purpose for visiting by explaining what their visit will mean to the patient. They can be encouraged to tell their loved one about their day or take a picture that they can leave next to the bed. Make sure that you do a debriefing session according to the age of the child afterwards so that the child can get a chance to express emotions and make sense of the visit.

After the death of a loved one

Be mindful of how children could misinterpret your words. If you tell a child that God wanted the person, the child might get angry at God. Encourage open and answer the children's questions truthfully. If children were praying for healing, don't avoid the subject, thinking it will go away and the child

will get over it. Discuss it with the child and ask them what they are thinking. Remember, it is okay to tell children that you don't know the answer.

Children should also be included in the planning of a funeral and can even be involved in the service. They sometimes have great ideas of how to honour and remember the life of a loved one and their input and wishes should be respected. Because rituals are concrete, they can be very meaningful to children, such as sending helium balloons with a message to heaven. Burrell and Selman (2020:376) conclude that rituals after the death of a loved one can be valuable for both children and adults, but they should be able to plan it according to what is meaningful to them. They also pointed out the importance of social support during a funeral. After the funeral, explore ways in which children can still honour and remember the person, such as making a scrapbook or having a special corner in the house with photos and memorabilia of the deceased.

If possible, children should get professional help after the death of a loved one. Be on the lookout for signs that a child is not coping, such as sleeping and eating disturbances, fears and extreme anxiety, regression of developmental milestones, and/or behaviour problems, and make sure that the child gets the help needed.

When their days are numbered

Myra: 'Jeffery, why do you always yell at your mother?'

Jeffery: 'Then she won't miss me when I'm gone.'
(Bluebond-Langner, 1978)

Children will always try to protect their parents and loved ones, even if it implies that they must be mean to them or refrain from asking burning questions when they realise it makes the adults around them uncomfortable. However, we as adults are the ones losing out when we refrain from talking to children at the end of their lives. As Clutter (2005:365) states: 'Those who

are dying can have quite a different spiritual reality, especially if they are suffering'. We can learn so much from children if we are brave enough to join them on their journey.

Not all children express their awareness of the fact that they are going to die in the same way. Bluebond-Langner (1978:165) explains that some children may be very direct, stating that they know they are going to die, while others are more subtle, making statements such as that they will not be able to back to school or attend someone's birthday party in the future. A 12-year-old describes his struggle with accepting his terminal diagnosis as follows:

I started to think about whether I was going to die. But I never really thought I was going to die. I thought about it in my mind like a film, my brother going into my room and me not being there, and about my dog and someone else taking him for a walk, but inside I didn't think I was going to die. (Drane & Fleming Drane, 2009:215)

According to Bates and Kearney (2015:2) children's understanding of their terminal illness is a 'fluctuating process,' and research into this is limited and outdated. However, it might be worth mentioning that Bluebond-Langner (1978:169) identifies the following stages of awareness when children learn that they are terminally ill:

- I am well.
- I am seriously ill.
- I am seriously ill and will get better.
- I am always ill and will get better.
- I am always ill and will never get better.
- I am dying.

Children deserve to know that they could die so that they have time to come to terms with it and plan for it. It can be very comforting for children to be able to express their own needs, dreams and wishes. Children often want to have a say in who will get their earthly possessions and toys, and they also need reassurance that someone will take care of their pet, that their

loved ones will be okay, and that they will not be forgotten. Children might find it comforting to draw a picture or make a piece of artwork, such as a candle holder, to give to each of their loved ones, serving as a reminder so that they will not forget about them.

However, talking to children about their wishes shouldn't focus only on dying, but rather on living life to its fullest, with as much fun as possible, and as normal as possible till the end. Their wishes should, therefore, also include things they still want to do and how they want other people to treat them. If possible, children should attend school and other social activities for as long as possible, and Bates and Kearney (2015:1) concluded that children 'show remarkable resiliency in the face of death and want to get the most out of the remaining time they have'.

Discussions about death and dying

Children know when something is wrong, and they are very perceptive to the mood and body language of the adults around them. When a child is dying, they often know it before it can be discussed with them. As adults, we often think we need to have all the answers, but if you can accept that we will never have all the answers to the difficult questions in life, you can start exploring these questions together with a child, and you might be surprised at how much you will be able to learn. When their second child died, Drane and Fleming Drane (2009:206) made the following comment about their oldest, who was 4 1/2 years old: 'In the midst of tragedy we learned more from his intuitive spirituality than from all the professional attention of clergy, medics and therapists'.

When talking about death and dying, keep cultural differences in mind. For instance, in the African languages, it is very disrespectful to refer to a person as being 'dead', and phrases such as 'he has breathed his last', 'he is dry as if from yesterday', 'going home', 'to follow the company of one's grandfathers', or 'to empty out the soul' are common (Mdleleni-Bookholane, 2003:7-8). People often refer to

someone as sleeping, that they've lost someone or that they've passed away, and children could easily misinterpret any of these expressions if not explained to them.

All indications are that children would welcome the opportunity to talk about spiritual issues, especially at the end of life. According to Ferrell et al. (2016), discussions with children revealed that they 'question God and the reason for their illness, have a desire to talk about the afterlife as a way of understanding their limited lifespan, and to share descriptions of an afterlife.'

Terminally ill children often reflect with great insight and acceptance on their short lives and listening to them can be an enriching experience (Marston, 2011:5). However, people generally find it very difficult to talk to children about death and dying, and there are only a few caregivers who are willing to walk with children through their terminal illness.

Play is the language of children, and they should be encouraged to express their feelings in other ways than talking about it. It might be helpful for children to project their emotions on a soft toy or to use a puppet through which they can communicate. Drawing or playing with playdough can be a great way of expressing what they are going through, while bigger children may find journaling, scrapbooking, or writing poems comforting. Drane and Fleming Drane (2009:221) reflect on the life of Jesus and his view of children when they concluded:

He also was more likely to address life's big questions by telling stories, drawing pictures, and invoking the imagination about the nature of God – all things that seem to come naturally to children.

Godfrey Kalake (2011:92–93), then 12 years old, mentioned how sad he was when a friend of his died in the hospice centre. He then drew a picture of the hospice, of his friend, and of his fears of death. Father Keith then sat down with him and addressed all his fears. These are his words:

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Moo Sunflower kene ke utlwile dohloko hobane Sthembile o ne a kula haholo e bile a hlokafala. Re ile ra lla kaofela. Ke ile ka taka ditshwantsho tsa Sunflower House, Sthembi le hore hobaneng ke tshaba ho swa. Father Keith o ne a bua lenna, fa re qeta ho bua, ha kesa tshaba ho swa.

Children often harbour a lot of misconceptions, and their ideas about death and dying can be influenced by fiction. Think for a moment about the way death is depicted in comic books and animations – characters might be blown to pieces, or their heads chopped off, just to be miraculously restored to life in the next scene. Discussions should therefore start by clarifying misconceptions. Children’s artwork can tell us a lot about their fears and interpretations of a situation, but don’t make your own conclusions – always ask children to tell you more about the picture. Also, ask them what they think is going to happen and listen carefully for any comments that don’t make sense and may indicate some misconceptions.

Try to find out more about the history of the child with regards to any experiences of death and dying and how different situations were addressed. For instance, if the death of a pet was previously diminished and not discussed with the child, the child might think that their death is also not a big deal and that they will be treated in an equal manner.

Use concrete examples when talking to children. A colleague, Vera van Dalen, uses the physical example of a plastic bottle, filled with water when talking to children about the process of dying and the afterlife. She compares the nature or essence of the child to the water, and the body to the plastic bottle. When the plastic bottle gets damaged up to the point where it can’t contain the water any more, the water is poured out painlessly into another container such as a glass. She emphasises that the water stays the same, but that it is now contained in a glass or different body.

There are also many books available on the internet with stories explaining death and dying to children. One little book, *Water Bugs and Dragonflies* (Stickney, 1997), tells the story of a water bug that changes into a dragonfly and is, for the first

time, able to fly around and experience the wonderful world outside of the water. However, once out of the water, his new body will not allow him to go back under the water again.

Keeping hope alive

Because of their vivid imagination, children are drawn to the prospect of heaven. They can get very excited and creative in imagining what it would be like, and when the end draws near, they are comforted and at peace. When talking about heaven, get creative and fantasise with the child, visualising all possibilities. You can say something like ‘I don’t know what heaven is like, but what do you think? What do you want to do in heaven? How do you want it to look?’

The saying, ‘Where there is life, there is hope’, might sometimes be overused to create false hope, but I’ve experienced the truth of this saying too many times. Miracles are possible, and I have personally witnessed patients who have recovered against all odds. However, it is not to say that we should disregard reality. To hope is not to deny the facts, but to hope despite the facts. Milona (2020:29) explains that, while secular philosophers tend to refer to hope in the likelihood that, what is hoped for, will not happen, Christianity associates hope with faith and confidence that what is hoped for, will happen. This author refers to the work done by Jeffrey (2019) when stating that ‘it is the intellectual confidence supplied by faith that gives rise to the Christian virtue of hope’.

Children might be dying, but they still have some living to do before they die. Their awareness of being alive may increase, prompting them to make the most of the time they have left (Bates & Kearney, 2015:5). Discuss their dreams and what they still want to do and focus on what is important to them and what gives them meaning.

Before his death, Johan Nieuwenhuis wrote that he had fought against cancer for seven years and had been through many things. He said that he was really glad he got sick because it made him much closer to the Lord. He then testified about what God has done for him, concluding that God is real,

and urging everyone else to also believe in Him. Being able to give his testimony was what gave meaning to his illness (Nieuwenhuis, 2011:77).

The rights of terminally ill children

The International Children's Palliative Care Network (ICPCN) published a 'Charter of Rights for Life Limited and Life Threatened Children' (ICPCN, 2008) As stated in this charter, the aim of palliative care is 'to relieve suffering and promote quality of life'. Other articles of the charter relevant to this discussion state that parents, legal guardians, as well as the child should be involved in all aspects of the child's care; communication with the child and family should be open and honest; they should be treated with dignity; and they should have access to support systems, including a multi-disciplinary care team and appropriate community resources. The charter also states that:

Every child and family member, including siblings, shall receive culturally appropriate, clinical, emotional, psychosocial and spiritual support in order to meet their particular needs. Bereavement support for the child's family shall be available for as long as it is required. (ICPCN, 2008)

As healthcare systems are overwhelmed, religious communities could play a major part in taking on the responsibility of walking with the dying child and providing the required care to these children.

A note on childhood euthanasia

Most people choose to avoid the topic of childhood euthanasia. Aristotle encouraged it when he wrote in *Aristotle's Politics* that 'as to the exposure and rearing of children, let there be a law that no deformed child shall live' (Aristotle & Jowett, 2015:199). However, childhood euthanasia is as relevant today as it was when Aristotle commented on this. The

Netherlands was the first country to regulate child euthanasia and developed the Groningen protocol to assist medical staff with the decision-making process during infant euthanasia. However, the criterion of 'hopeless and unbearable suffering' led to many debates, and according to Lindeman and Verkerk (2008), this definition is unclear and wide open for interpretation. Meanwhile, Singer (2016:83), a professor in bioethics, admits that physicians have confessed to him that child euthanasia is a reality in the US although they will never admit it openly for fear of prosecution as it is not legalised in the US. One can only speculate whether it is happening in South Africa or not.

What about the adults, walking with children in the shadow of death?

As you read through this chapter, carefully consider the thoughts and fears that you are experiencing right now. It is difficult to talk to children about death and dying, and there might be different reasons for that, usually stemming from our fears about death and dying. Start by reflecting on these questions, and write down any other questions that come to mind:

- Have you made peace with the fact that you too will die someday – maybe even soon?
- Why do you think children die?
- Why do bad things happen to good people?
- What happens after death?

Only when you are at peace with your own death, will you feel comfortable to discuss this difficult topic with other people and be able to truly accompany them on their journey in the shadow of death. However, taking this journey does not come without challenges and sacrifices. When writing to healthcare professionals about children's palliative care, Amery et al. (2009:351) cautions that

dealing with dying children and their families means sharing a painful and heavy burden, and occasionally that

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burden can begin to affect us, our work and ultimately our happiness itself.

These authors further concluded that they found happiness in the work that they do because of three vital aspects: their work gives them an opportunity to be challenged, they work together in a team and support each other, and they find meaning and purpose in the work that they do (Amery et al., 2009:352). Taylor and Aldridge (2017:5) also mention the importance of 'making a difference' in the workplace as a reward for working with children in palliative care. However, they refer to the increased risk of burnout and discuss the difficulties of obtaining adequate support for staff members outside of work. Patient confidentiality, the nature of their work, as well as people who lack understanding of the work being done, were mentioned as reasons for not being able to discuss their work with outsiders (Taylor & Aldridge, 2017:8).

When a child that I worked with died, my way of honouring the child's short life was to focus on at least one positive aspect or lesson that the child had taught me – and believe me, there was more than one to choose from. Other authors also commented that working with terminally ill children can be very enriching and that one can learn so much from these children (Marston, 2011:5). On the inside cover of the book, *Littlest Suffering Souls: Children Whose Short Lives Point Us to Christ*, the author explains that 'everyone with whom they [the children] came into contact...was profoundly affected by the encounter' (Ruse, 2017).

Whether the death of a loved one or the impending death of the child in front of you, you will be deeply affected, and it is essential to know your strengths and limitations before you start to walk with children in the shadow of death.

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