

## **Children's understanding of death**

Supporting a dying child and his or her family is one of the most difficult and emotional aspects of paediatric oncology.<sup>1</sup> Despite guidelines on how to discuss death with terminally ill children,<sup>2</sup> healthcare professionals (HCPs) may avoid doing so because of inexperience or discomfort, contributing to children's confusion, anxiety, and mistrust.<sup>3</sup> At other times, HCPs may have to balance the needs and rights of their patients with the wishes of parents/caregivers who do not want children to know their cancer is incurable.<sup>4</sup>

As HCPs, we can best serve terminally ill children and their families by gauging children's individual understanding of death and modelling direct, compassionate communication about painful feelings and issues.<sup>3</sup> By doing so, we can begin end-of-life discussions earlier, which can improve use of hospice, comfort and symptom control, and satisfaction with care.<sup>5</sup>

### ***Barriers to talking openly about death***

In 1929, developmental psychologist Jean Piaget contended that children could not fully understand the finality of death until age 11-16 years.<sup>4,6</sup> However, more recent research has shown that younger children with terminal illness sense changes in their bodies and notice the reactions of adults around them, enabling them to develop a complete or nearly complete understanding of death, dying, and limited time remaining.<sup>7-10</sup>

Nonetheless, several myths continue to deter some parents and HCPs from discussing death and end-of-life concerns with dying children. These include the mistaken beliefs that children:<sup>7</sup>

- Cannot understand death<sup>7</sup>
- Become severely depressed if asked to think about death or dying<sup>7</sup>
- Would rather pretend that everything is okay<sup>3</sup>

Our own feelings and those of parents/caregivers also can impede direct, skilled communication about death with dying children. These may include:<sup>7,8,11</sup>

- Guilt about not achieving a cure

- Helplessness as we watch a child get worse
- Anticipatory grief
- Emotional distancing to cope with these feelings

### ***Concepts of death***

Surmounting these communication barriers means understanding what children generally know about death and dying. Current developmental theory contends that as children develop and gain life experience, they gradually master concepts of:<sup>3,12,13</sup>

- Universality (all living beings die)
- Irreversibility (death cannot be undone)
- Nonfunctionality (all bodily functions stop in death)
- Causality (death has specific causes)
- Personal mortality

Children grasp these concepts at varying speeds, so it may be unhelpful to harbor too many preconceptions of what they know about death.<sup>13</sup> Nonetheless, it is useful to understand how concepts of death tend to develop. We can consider that children:<sup>14</sup>

- First understand the more concrete death concepts, such as irreversibility
- Later master more abstract concepts, such as causality

### ***Young children's understanding of death***

Infants and toddlers usually cannot grasp that death is irreversible, and therefore cannot distinguish it from separation.<sup>3</sup> Until they are at least 3 years old, they tend to think that death:<sup>15</sup>

- Is temporary
- Can be undone
- Is a different way of being alive (continuous with life)

However, even young children usually can understand concrete explanations about nonfunctionality if given time to talk and ask questions. They can be told that someone who has died (or is dying) cannot (or will not be able to):<sup>16</sup>

- Eat, sleep, play, or talk

- Feel heat, cold, sadness, or pain

Young children might feel anxious or confused as they try to understand the more abstract aspects of nonfunctionality. As a result, they might ask if:<sup>16</sup>

- A dead person can breathe
- You can feel things when you are dead
- They did something that caused (or will cause) death
- Parents/caregivers will leave them

Young children need comfort and honest reassurance as they incorporate new ideas about death.<sup>3</sup> Many can at least partially understand irreversibility and nonfunctionality by about age 4 years.<sup>15,16</sup>

### ***School-aged children's concepts of death***

By age 5-7 years, most children at least partially understand that death is universal, irreversible, and involves cessation of movement.<sup>3</sup> In one study, 60% of 5-year-olds fully or partially grasped universality, irreversibility, nonfunctionality, and causality, debunking previous ideas that this level of understanding only occurs in pre-adolescence.<sup>6,9</sup>

Keeping in mind that personal experiences, popular media, religion, and culture all affect death concepts, we can generalize that:<sup>3</sup>

- Most children understand the main characteristics of death by 10 years
- Children who have lost parents or other beloved caregivers may develop this understanding earlier in life

### ***How children revise ideas of causality***

By the time they are 7-10 years old, most children know that death is an irreversible shutdown of bodily functions.<sup>15</sup> But as they approach pre-adolescence, they usually revise ideas of causality to become less scientific and, in fact, more adult-like.<sup>3,14</sup> Depending on their age, children are most likely to describe death as caused by:<sup>3,14</sup>