

CHAPTER 5

Through the creative lens of the artist: society's perceptions of death in children

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*It is difficult
To get the news from poems
Yet men die miserably every day
For lack
Of what is found there.*

(William Carlos Williams, MD)

Introduction

These words of William Carlos Williams, a doctor and a poet, remind us that medical textbooks, professional journals, and the Internet are not the only sources of data that should inform our practice. Indeed, we need more than information alone to understand our patients, their families, and ourselves. By inviting contemplation of life's meaning when facing mortality, writers challenge us to go beyond society's commonly held perceptions, foremost among them being the dread of death. Shakespeare tells us that 'Death is a fearful thing', and Francis Bacon further specifies that 'Men fear death as children going into the dark.' In the winner of the Pulitzer Prize for General Non-Fiction, *The Denial of Death*, Ernest Becker (quoting Shaler) concludes that 'Heroism is first and foremost a reflex of the terror of death.'¹ And comic Woody Allen has the last word in telling us it's not that he's afraid of death—he just doesn't want to be there when it happens.

Sir William Osler once said that 'The practice of medicine is an art, not a trade; a calling, not a business; a calling in which your heart will be exercised equally with your head.'² It is not enough for physicians simply to understand the theories and principles that underlie their patients' bodily ailments. Samuel Taylor Coleridge remarked that such doctors 'are shallow animals, having always employed their minds about body and gut, they imagine that in the whole system of things there is nothing but gut and body.'³

One of the important themes of this textbook is to emphasize the need for an evidence-based approach to our practice of caring for children with life-limiting conditions. Another fundamental principle is to go beyond our analysis of paediatric palliative care, to be mindful that we are dealing not just with symptoms or diseases,

but with young human beings and their families. Patients cannot always articulate their experiences clearly. Simply communicating the presence of physical pain can be problematic enough, but describing aspects of anguish that arise from emotional or spiritual distress is even more difficult. Many patients can benefit from the insights, perceptions, and acuity of artists and poets, deriving relief and understanding from their words or images.

Often artists themselves have been patients—or parents, siblings, friends, or relatives of patients. Some have used their creative abilities to communicate characteristics of that experience. This chapter provides an introduction to accessing this rich and valuable source of data, and considers how a few representative artists have depicted the dying or death of a child. These artists speak from profound personal experience, having participated in the death as a family member (e.g. Edvard Munch), as a parent (e.g. Luke Fildes), or sometimes as a professional (e.g. William Carlos Williams).

Williams' poem is itself an illustration of the point that this chapter is making. He chooses the medium of a poem to teach us that important information can be gleaned by us as healthcare professionals from what artists create.

Art reflects the way that society thinks about death, and captures both the times and the timelessness of it. This chapter scrutinizes how society grapples with the meaning of death in children, especially as portrayed in the creative arts. Our assumption is that, by studying certain pertinent works of art, we shall learn something of value to paediatric palliative care.

Death in children: from commonplace to rarity

Although there are many works of art, both past and present, dealing with death in children, they tend to be marginalized these days as a 'special' subject. Art about dying children is now conspicuous by its scarcity, partly because confronting the reality of a dying child negates our culture's most important preoccupations, namely youth and happy endings. It is also true that many childhood illnesses and infections (e.g. scarlet fever, whooping cough, rheumatic fever, strep throat) have been largely controlled in the developed world as a result of medical advances. The death

of children is no longer the constant presence and threat that it was in previous centuries. Any walk through a nineteenth-century cemetery will reveal how precarious the existence of children used to be. Remarkably, we now take it for granted that such deaths are no longer commonplace.

Nevertheless, children continue to die of devastating diseases (e.g. cancers, cystic fibrosis, lissencephaly), and they and their families suffer. This chapter raises many questions with which those working in palliative care struggle, including how best to support the family during the time before the death, and how to prepare them for life without their child. We consider various perspectives—the doctor's uneasy role, the sibling's struggle, the father's consolation, and the mother's 'journey through grief.' Their views can provide us with much insight.

How society views the death of a child: the creative artist reacts

The heroic doctor as seen by the Victorian painter

Reproductions of one of today's most well-known paintings of a very sick child, a best-selling engraving of the Victorian era, have been used on postage stamps in Britain and the USA, and can still be found on the walls of almost all medical schools (see Figure 5.1). The canvas shows a concerned physician portrayed in profile, leaning forward in his chair at the bedside of the dying child, upon whom his attention is completely focused. Barely visible in the shadowed background are the parents. Gazing at the physician, the father stands helplessly, his hand on the shoulder of the mother, who is seated at a table with her face buried in her hands. Various titles have been given to the painting—*The Doctor*, *The Visit*, or *The Vigil*, the painting says much about our subject—the innocent child lying peacefully, glowing and almost angel-like in the light from a lamp on the table, sharing the spotlight and the centre of the canvas with the doctor, who has nothing more to offer medically. The doctor can only wait for the passage of time to find out whether the child will recover—or not.

There are differing accounts of the painting's origin. One version is that Henry Tate commissioned the fashionable artist, Sir Luke Fildes, in 1890 to paint a picture, the subject of which was to be

of the artist's own choosing, for the new National Gallery of British Art. Fildes' son, in a biography of his father, wrote that the painter's inspiration was the memory of the doctor attending his firstborn child, who had died in infancy.

By his presence, the physician as seen in the painting is the model of empathy and compassion. One doctor told his students that 'A library of books would not do what that picture has done and will do for the medical profession in making the hearts of our fellow men warm to us with confidence and affection.'⁴ And, of course, for those of us in palliative medicine, what is represented here—not abandoning a patient and family, challenging the stance that 'nothing more can be done', and attending to the end—makes this painting most poignant and meaningful.

This image of the ordinary family doctor's quiet heroism became a huge success with the late Victorian public when the painting was first exhibited in the 1890s. However, some present-day viewers consider the image to be sentimental, maudlin, and simplistic, and as pandering to stereotypes—the child being angel-like and innocent, the father being stoical, strong, and non-expressive, and the sobbing mother being emotional and grief-stricken.

When questioned about his intentions for the painting, Fildes answered:

At the cottage window the dawn begins to steal in, the dawn that is the critical time of all deadly illness, and with it the parents again take hope into their hearts ... the father laying his hand on the shoulder of his wife in encouragement of the first glimmerings of the joy which is to follow.⁵

Doubtless, Fildes envisioned a happy ending for his canvas and intended the child in his painting to recover. We may interpret this painting as the artist's wish-fulfilment, fixing in his art something that he wished had happened in real life to his own son.

Through society's lens: reason, logic, and religion

The psychiatrist Victor Frankl wrote that 'man is not destroyed by suffering; he is destroyed by suffering without meaning.'⁶ At the core of human identity is the need to make sense of things. The death of a child is unnatural in that it disrupts the life cycle—infancy, childhood, youth, maturity, old age, and finally death. It turns the world upside down, as parents are not supposed to



Figure 5.1 *The Doctor*, by Sir Luke Fildes (oil on canvas, 1891; ©Tate, London, 2003).

outlive their children. It goes against everything that parents, grandparents, caregivers, and society as a whole expect, wish, and fervently desire for every child. Reason and logic provide too few answers to those who have been crushed by a child's death. There is no timely death of a child.

Religion offers concepts that are not restricted by logic, reason, or scientific proof. When seeking answers to life's great questions, many people turn to belief in God, faith, prayer, and ritual, and to scriptures (e.g. the Koran, the Bible, the Torah). In the quest to answer the unanswerable and to provide solace, various religious dogmas and belief systems (e.g. astrology and numerology, superstitions, myths) all attempt to explain the inexplicable mysteries of human existence.

Various cultures and religions believe, as do some Native American tribes, that life is complete whether it lasts for two days or 80 years. The *Bhagavad Gita* asserts that death is as sure for that which is born, as birth is for that which is dead, closing with the words 'Therefore grieve not for what is inevitable.' Some of us may have heard the story of the woman who came to the Buddha in great anguish, carrying her dead child, and begging the Buddha to bring the child back to life. He instructed her to bring him a mustard seed from any household where no one had ever died, and then he would fulfil her wish. The woman searched in vain, and when she could not find any household in which no one had ever died, she suddenly realized the universality of death.

Bereaved families often ask whether, if God creates all life and if all life ultimately returns to God, parents should not rejoice in their child's reunification.⁷ The child can now enjoy immortality in heaven with the angels, as in the words of a folk tune called 'Daniel':

*You were closer to the angels
That's why they called you home ...
They took your tiny hand.*⁸

But can the faith that a child is with God fully satisfy a grieving parent? No matter how strong or comforting religious beliefs may be, they cannot deny the fact that death of a beloved child is heart-wrenching.

The Bible teaches that death can be a blessing (Revelation 14:13), yet we see Rachel grieving for her massacred children: 'A cry was heard in Rama/weeping and great lamenting/It was Rachel weeping for her children/And refusing all consolation because they were no more' (Jeremiah 31:15–17).

In Anthony Trollope's novel, *The Claverings*, a grieving father—who has just lost his only son—responds to his wife's uncertain reassurances about 'God's will' and their child's new home with the angels by saying 'That's all very well in its way, but what's the special use of it now?'⁹ The father is able to voice what the mother dares not express—that their professed faith is not enough in the face of such pain.

We human creatures recognize certain experiences as almost impossible to bear. One of these is the anguish of seeing a child die slowly of a terminal disease, and knowing that the child is cognizant of their impending death. Even if we disagree with the sentiment, we can sympathize with the expression of overwhelming grief felt by the individual who wrote: 'There is only one thing worse than a dying child—a child that knows he is going to die. This proves that there is no God.'¹⁰ Being human involves suffering, and no one is immune from this.

In addition to consolation that is provided by the clergy, many therapists are knowledgeable about the emotional roller-coaster

trajectories of grief, and can offer understanding of its course. The advent of support groups and chat rooms has also provided comfort for bereft individuals in their immediate and long-term struggle. The anniversary of death dates and holidays are especially distressing for the family, for many years after the death itself. Excellent information about bereavement and coping strategies exists in print and on the Internet, and many children's hospitals prepare their own brochures alerting families to this fact.^{11–13}

Through the lens of a writer: at a loss for words

Artists use their own medium, such as painting, music, photography, dance, or sculpture, to work out their questions or anguish following the death of a child. However, a contemporary American writer, Lisa Schnell, whose medium is language, noted how immediately after the death of her young child she was rendered totally speechless and wordless, wanting only to be dead.

Schnell, a grant recipient of a Project on Death in America Humanities Fellowship, produced a manuscript, *Learning How to Tell*,¹⁴ about the death of her baby daughter, Claire, and how she slowly regained her ability to find and express herself in words. When her baby, who was suffering from the rare and devastating birth defect lissencephaly, died at the age of 18 months, words were not forthcoming to this connoisseur of words—a literary critic, English professor, and writer. Schnell describes 'choking on' her grief, her vocal chords becoming metaphorically paralysed.

Words had turned on me ... they were language, a reminder of what Claire would never have; or they were just absent—the core of inarticulateness inside me, my helplessness, my inability to turn my grief and fear into a narrative with a happy ending.¹⁵

Incapacitated by grief, she wished only to be with her baby daughter: 'I just wanted to be dead with Claire. I wasn't suicidal. I didn't want to make myself dead, just be dead.' Ultimately, this grieving mother found the words for the 'lessons' that death had taught her.

Only later did I understand that Claire needed me to live; that her dying—and my not—hadn't been a flagrant violation of some sort of maternal symmetry. I am still Claire's mom.¹⁵

Moved by Lisa Schnell's writing, and with great trepidation, I invited her to take part in a visual case study exercise in which participants are asked to have a dialogue with a work of art. She was sent a photocopy of Deidre Scherer's fabric work, *Child* (see Figure 5.2 and Plate 2), together with the following broad 'probe question' to guide her: 'Please flesh out your reflections on this image with a story, vignette, title, quotation, or any commentary.'

Schnell responded both to the Scherer image and to how it felt to write about it. Here are her words describing how it felt to do the case study:

I was very struck by one particular part of the incredibly moving image you sent me, but in focusing on that I've tried to get across some of the complexity of my own experience of mothering a dying child. ... It was good to write it, a more powerful experience than I had anticipated.

Lisa Schnell responded to the visual case study, which centred on ordinary plastic tubing but blossomed into something quite extraordinary:

Clear plastic tubing; there was so much of it, and it was stiff and cumbersome in the cold December house at 3 a.m. But the pain of my engorged breasts was greater even than the discomfort of pumping

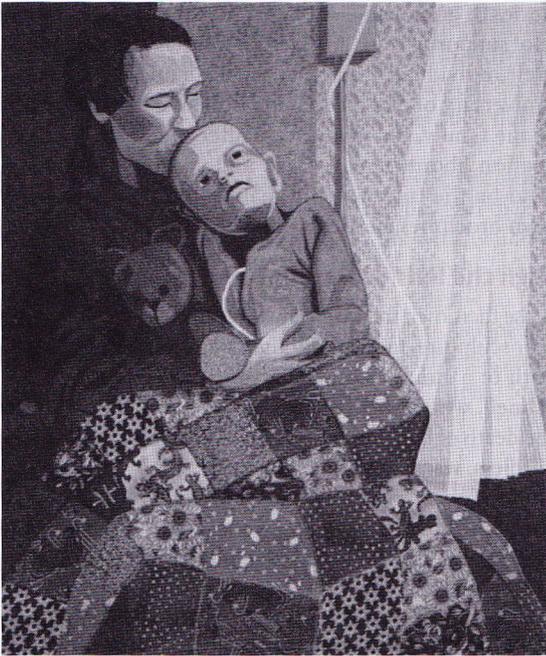


Figure 5.2 *Child*, by Deidre Scherer (36 x 30 inches, Thread on fabric. From the series *Surrounded by Family & Friends*, © Deidre Scherer, 2001, www.dscherer.com. See also Plate 2).

them out in the cold, quiet house. And so I would struggle with all that tubing, hooking up body to bottle to pump. ... The anxiety stayed inside, cold as the house, inhabiting the questions that rattled around inside my head: Why couldn't she nurse? Why wouldn't she wake up to eat? Why did she twitch all the time? But for a few moments as I felt the warm swoosh of my own milk, I would relish the dark calm of December and imagine that everything would be all right ...

Clear plastic tubing; months after the breast pump had been put away it reappeared, what seemed like miles of it, stretching from the tiny cannula in her nostrils to the big oxygen machine. It was May now, and the tubing was soft and flexible as we carried her from the living room to the bedroom, and sometimes even outside to the front porch. The gush of milk had long since ceded to the persistent leak of tears; the chill of anxiety was about to be replaced by the everlasting ache of grief. But there was an unmistakable calm in her wide gray eyes as she looked at me, tangled up in all that plastic tubing.¹⁶

Schnell read voraciously after her child's death, from Emily Dickinson to Freud, and was especially drawn to those authors, such as Christopher Noel, who also had taken 'a journey through grief.'¹⁷ In Schnell's words, 'all of the writers I was leaning on had learned not just what to tell, but how to tell.' Schnell gradually discovered the 'redemptive power of language.' She was helped both by reading other authors and by writing for herself: 'I found the process of writing profoundly enriching; in its simplest formulation I suppose it was a way I could continue to be Claire's mom.'¹⁵

Friedrich Rückert: missing a child in 400 poems

Writers who lose a child turn to their art to explain the loss to themselves, to describe it to others, and to struggle towards some understanding that enables them to continue. Friedrich Rückert (1788–1866), a German poet and Professor of Oriental Languages, wrote over 400 poems about the death of his son Ernst, which affected him as 'an overwhelming emotional upheaval.'¹⁸ The intense emotions remain in the poetry: 'When thy mother enters, her gaze does not go to me but to the spot where your face should

be... thou quickly extinguished ray of joy!', and 'One tiny lamp went out, my soul's delight.'¹⁹

The Austrian composer Gustav Mahler used five of these poems by Rückert as the setting for his *Kindertotenlieder* (*Songs on the Death of Children*). He wrote the first three songs as an 'artistic challenge' before he was married or had children of his own. His wife Alma was aghast that he could continue to complete the last two songs when he had his own young children playing outside. She later questioned Mahler's choice of text by comparing the artistic motivation of the two men: 'Rückert did not write these harrowing elegies out of his imagination; they were dictated by the cruelest loss of his whole life.' She had warned Mahler at the time, 'For heaven's sake, don't tempt providence.'¹⁸ When their oldest daughter died two years later, she was convinced that fate had indeed been tempted.

The early experiences of Edvard Munch: an artist remembers grief

Artists who have themselves suffered an earlier loss, especially that of a sibling or a child, often work through their response to that loss—perhaps years later—in their art. Borrowing their lenses, viewers can see that artists look deeply and often find profundity. The Norwegian painter Edvard Munch experienced multiple tragedies during his childhood. He lost his mother to tuberculosis when he was only 5 years old, at the age of 14 years he lost his sister Sophie to the same disease when she was 15, and he saw another sibling afflicted by severe mental illness, perhaps exacerbated by the deaths of her mother and sister.

In 1885, when Munch was a 22-year-old artist, Sophie's death 8 years earlier presented itself to him as a subject—a source of unresolved emotion—that he reflected on and wrestled with repeatedly in his art. His first version was a stunning oil painting, *The Sick Child* (painted around the time that Luke Fildes completed *The Doctor*). It shows the profile of his fragile, frail sister propped on a white pillow, looking steadily towards a window covered with dark drapes, perhaps representing the dark closed mystery of death (see Figure 5.3 and Plate 3). Aunt Karen (the woman who replaced their mother), her back bent over in inconsolable grief, is unable to look at the stricken girl. The sister and aunt grasp hands, their two hands painted together as one simplified form. Munch worked over the surface for years, scratching the paint, enhancing the colour, and creating a restless texture—perhaps attempting to capture, as well as to quiet, his inner unease with the subject.

Munch believed that this painting marked a maturation of his art, stating that it 'provided the inspiration for the majority of my later works.'²⁰ He returned to the theme of his dying sister over the years, painting it five more times in oils, and also rendering it in drypoint, lithograph, and etching. In a lithograph that he created 10 years later, also called *The Sick Child* (see Figure 5.4 and Plate 4), he concentrates on the profile of his sister's head, with her damp and curly reddish hair, as she gazes steadily at the dark window. This time he leaves out Aunt Karen altogether, and eliminates much of the surrounding space—as if to meditate on his sister's profile, searching for meaning in her unknowable thoughts.

As if he could not escape this theme and had to revisit it periodically, Munch detailed the progression of his sister's illness in his art—the fevers, the medicine bottles, the witnesses, and the identifiable family members. In *Death in the Sickroom* (1895), the dying Sophie is hidden from view, seated with her back to the viewer in

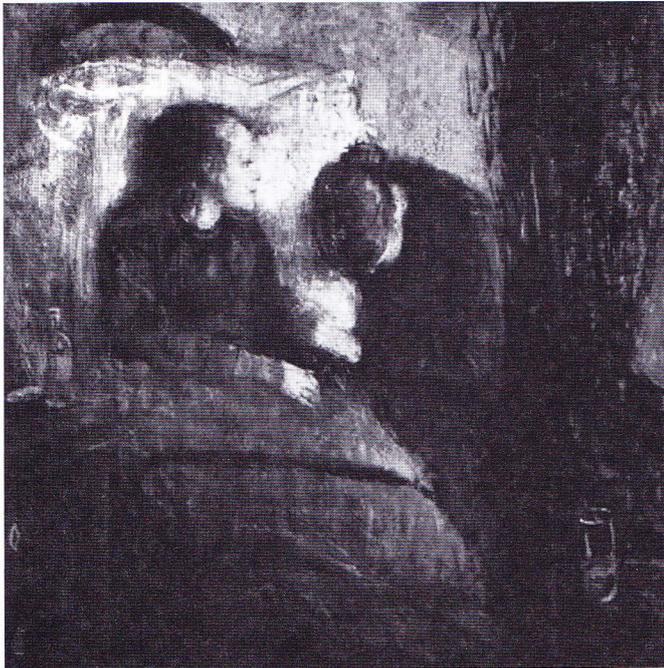


Figure 5.3 *The Sick Child*, by Edvard Munch (oil on canvas, 1885/86, National Gallery, Oslo). © Munch Museum/Munch - Ellingsen Group, BONO, Oslo/DACS, London 2011. See also Plate 3.



Figure 5.4 *The Sick Child*, by Edvard Munch (lithograph, 1896, p. 25, Sch 59, Munch Museum, Oslo). See also Plate 4.

a wicker chair (see Figure 5.5 and Plate 5). The focus is on the helplessness of the many relatives. The father is shown praying, a sister is bent in sorrow, and Munch himself (or his brother) is staring out of the window, further isolated from the family grouping. One sister, Inger, is standing, looking straight ahead, her weary eyes rimmed with red, drawing the viewer into the silent hopelessness of the scene. Interestingly, the family members are depicted as mature adults, and not at the much younger ages that they were (and Munch was) at the time of Sophie's death. Applicable to any family, not just that of Munch, is the aloneness of grief. No one is touching or facing anyone else. Each person is dealing with the grief within. The work depicts an often expressed insight—that even in the midst of family and friends, ultimately we grieve alone.

A major difference between Munch and Fildes is that Munch was far more innovative in his painting style, using flat planes, expressive colour, and simplified forms. Fildes was a deeply conservative, academic painter who expressed himself largely through the content of the scene, depicting the character of the intently caring doctor. Munch's more avant-garde expressionistic technique requires us to react to his (and our) own intense search for meaning. Despite the stylistic difference, each work compels us to experience the essence of our response to that powerful situation of the dying child.

Another artist imagines grief: the psychological probes of Kathe Kollwitz

We can conjecture that Edvard Munch was troubled by his own early experiences, and hoped to resolve these tragic memories through his art. Similarly, the German Expressionist artist, Kathe Kollwitz, often focused on the mother-child-death theme in her compelling works. At a young age she had experienced the death of her baby brother Benjamin, and perhaps with even more emotional impact, her mother's persistent grief for that loss.²¹ In various media, Kollwitz depicted both her personal loss and the universality of the subject. She continued to develop early studies of a *pietà*—Christ's mother mourning her son. She used her own young son Peter as a model for some of these studies, as well as for the dead child in *Woman with Dead Child* (see Figure 5.6).

Her close friend, Beate Bonus-Jeep, who had been temporarily out of touch with Kollwitz, was shocked when she saw *Woman with Dead Child* at an exhibition, and asked 'Can something have happened with little Peter that she could make something so dreadful?' Kollwitz's friend, Elizabeth Prelinger, in retrospect concluded that 'she is someone to whom it is given to reach beneath the ultimate veils.'^{22,23}

Kathe Kollwitz described her working method as follows:

When he [Peter] was seven years old, I made the etching 'Woman with Dead Child.' I drew myself in the mirror, holding him in my arm. That was very tiring, and I moaned. Then his little child's voice said comfortingly, 'Don't worry, Mother, it will be very beautiful.'

She developed the etching in eight stages, and took up the subject again in 1910, as *Death, Mother, and Child*, considered by Prelinger to be 'one of the most moving drawings Kollwitz ever made on the theme of death and leavetaking.'^{22,23} And again in 1910, she completed *Death and a Woman*, in which an agonized mother, her neck strained and wrenched, holds off the skeleton representing death.

Kollwitz's preoccupation with death and her depictions of raw, primal grief relate both to her personal loss and to her strong interest in social betterment of the world. She declared her desire to express—in her drawings, graphics, and sculpture—deep and extreme psychological empathy for human suffering. She wrote in her diary in April 1910 that 'Great piercing sorrows have not yet struck me.'²¹ Ironically they did strike eventually—her son Peter, who was the model for the dead boy, was killed in World War One at the age of 21 years, and her grandson, also called Peter, was killed in World War Two.

Picasso in his Blue Period

Pablo Picasso presents yet another instance of the artist forever affected by the illness and death of a sibling. When he was 13 years old, he and his family watched helplessly as diphtheria consumed the life of Conchita, his beloved younger sister.



Figure 5.5 *Death in the Sickroom*, by Edvard Munch (oil on canvas, 1895, National Gallery, Oslo). © Munch Museum/Munch - Ellingsen Group, BONO, Oslo/DACS, London 2011. See also Plate 5.

Deeply disturbed by the recent suicide of his close friend Carlos Casagemus, despairing of his own poverty and the poverty surrounding him, and haunted by his sister's death, Picasso created works in cold blue tones, tenderly depicting human suffering, pathos, and bleakness in a pervasive melancholy mood (see Figure 5.7).

Does *The Tragedy* refer to his own family without Conchita? Or does it hint at the death or impending death of someone who is not shown? Does the cloaked woman hold a sick infant in her arms? Or have any of the figures—presumably mother, father, and child—received a fatal diagnosis?²⁴ Is the child excluded from the grief of the parents?

This image distills other essences or truisms of bereavement and grief—anticipatory or after the fact.²⁵ In their suffering, the adults clutch their own bodies, turning within themselves, as in Munch's paintings. The 'contagion' of grief is clear, as one sees the youngest

touching his father's body, reaching out for support and assurance. If the dying (or dead) child who is not pictured was a sibling, the child's gesture might suggest his need for attention and inclusion. Siblings' grief needs to be acknowledged and validated. They need reassurance that nothing they did or thought caused the death. Perhaps the painting's title has less to do with the subject of a death than with the existential insight into the solitariness of grief, the tragedy being the unavailability of one to another.



Figure 5.6 *Woman with Dead Child*, by Kathe Kollwitz (etching, 1903, National Gallery of Art, Washington, DC © DACS 2011).

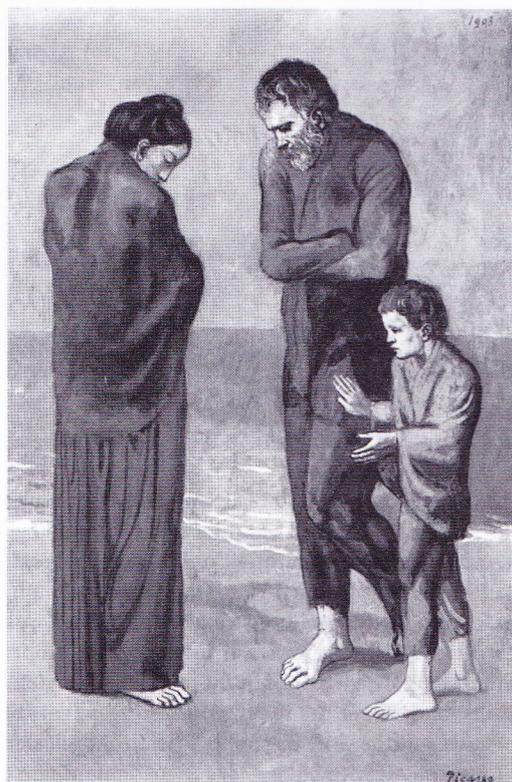


Figure 5.7 *The Tragedy*, by Pablo Picasso (oil on wood, 1903, National Gallery of Art, Washington, DC © Succession Picasso/DACS, London 2011).

The professional responds to the death of a child by making art

Telling it straight

In contrast to the painting by Fildes of the dedicated and heroic doctor, we shall now examine a poem written by a contemporary physician, John Graham-Pole, an American/British poet.²⁶ In 'Candor' (1997) he characterizes the doctor as a self-questioning, perplexed, and doubting professional, rescued only by the wit of a dying child.

In the poem, which is set not in the home as in Fildes' painting, but in the impersonal doctor's office, the mother wants the physician to 'square' with her 8-year-old child, to inform him that he is dying of his cancer. Graham-Pole is no neophyte physician. He is highly skilled in communication skills, and is a compassionate, authentic human being—he realizes that he can use himself as part of the medical treatment, and is willing to do so.

Candor

*At eight years old, the cancer running rampage,
Joe perches on my office sofa edge
thigh-to-thigh with mom
(who has enjoined me: Square with him).*

*But I beat around the bush a bit,
then come at last to it: Joey:
you're going to die, go to heaven—
words lost in his howl, like a wolf's*

*the hurling of his body into
the yellow print dress's recesses,
three minutes at least of this, this keening,
as we eye each other panicked:*

*Whatever else was right to do this wasn't it.
Then, as instantly, on a long-drawn-in
breath's end, he stops, swivels out, flicks a look,
spots tears on cheeks of mom, dad, nurse, me,*

*determines he's grieved enough: time to
lighten up, knowing me at other times a joker,
a wearer of odd socks, funny noses. He spies
memos, charts, photocopies, journals,*

*jetsam of an urgent life, bespattering my carpet,
and becomes the stand-up comic,
offers his own joke: Didn't your mom
teach you to pick up after yourself?*

First, we see the many points of view: the doctor, the child, and the mother are central figures, while the father and the nurse play lesser roles. Then the issue of candour is raised. Is it helpful for the doctor to address the child directly about his impending death? When the doctor 'squares' with Joey, the child's immediate response is to howl for three minutes, causing the adults inward panic and outward tears. Then we, the readers, experience sudden unexpected relief—the child makes a joke at the doctor's expense. The 'happy' ending that many of us long for materializes, as the child rescues the physician with his wit, thus making the scene more tolerable.

The complexity of the whole issue is brought up midway by the doctor's outright rejection of his own approach: 'Whatever else

was right to do this wasn't it.' The poem highlights not only the child's pain, but also the pain of the parents and the nurse: '[the child] spots tears on cheeks of mom, dad, nurse, me.' Told in the doctor's voice, however, it is his own doubts and suffering that are most apparent.

Perhaps the doctor in this poem should have prepared more carefully how he would approach telling the child. He seemingly came up with a plan on the spur of the moment to please the mother. He admits to beating around the bush and then announcing the unhappy truth in a blunt way that caught the child off balance and unprepared. However, in all fairness there is no template for handling this very difficult situation. One might even argue that the physician's fumbling attempt actually returned the control of the situation to the little boy, who in the end exhibits a sense of self-respect and self-worth that takes the reader by surprise. As a Dr Seuss character in *Horton Hears a Who!* tells us, 'a person is a person, no matter how small.'²⁷ The poem 'Candor' challenges us to become adept at ministering to the grief and stress of very ill children, their families, and the caregiving professionals involved.

There is no 'right' way to give a child news of this magnitude. In fact the notions of right and wrong in this case are irrelevant. What is important is to counteract the child's sense of isolation and fear that results from secrecy and what Glaser and Strauss have described as 'mutual pretence.'²⁸ Most contemporary studies posit that the psychologist, the parents, and the doctor should take time to determine what is the best, least stressful way to present the situation to the child in order to minimize the damage and allow opportunities for hope and healing. Of course, this telling has to be individualized to take into account not only the child's developmental stage but also their life experiences. Has the child seen other children as sick as they are in hospital who have died? Have they been aware of other children's illness trajectories? Often the child intuitively senses the situation. The results of Bluebond-Langner's research indicate that 'The issue is not "to tell or not to tell", but rather what to tell, when to tell, and who should do the telling.'²⁹

It is well accepted that children grow in spurts. The poem quoted previously is evidence that they also grieve in spurts, and when they cannot bear to grieve any longer, they distract and console themselves with other interests—in this case, the child focuses on the messiness of the doctor's office. One physician reading 'Candor' wondered if the child's remark at the end of the poem might be intended to symbolize the mess that the doctor had made of breaking the news.

It has been observed that children bring a sense of lightness and play to every aspect of their lives—even to dying. A very sick child may 'play dead' as a joke when a parent enters the sickroom, and wonder why it makes their mother cry rather than laugh. Children in a cancer ward have been known to act out funerals, taking turns at being the dead person. One nurse asked a child whether he wasn't uncomfortable keeping so still so that his tubes would stay in position, and he replied 'No, I'm practising for my coffin.'²⁹

Telling it slant

Having been criticized by other doctors for his bluntness as described in the poem 'Candor', Dr Graham-Pole replied to his colleagues in a later poem titled 'Slant.'³⁰ In this poem he tells in verse how one surgeon suggested that he (or the doctor in the poem) should be more 'soft-hearted' when telling a child bad news and 'tell the truth but tell it slant'—the surgeon echoing

a well-known line by Emily Dickinson. Dr Graham-Pole defends himself by pointing out that he had spoken to please the parents, so ‘there’d be no conspiracy of silence’, but instead there would be trust building. He also acknowledged in his first poem that he had compressed—that is, not told the whole story. In the later poem, he adds that he had recognized that the child already knew the essential truth. Finally, however, he asks himself in ‘Slant’ whether he had been too outspoken in his first poem:

*Was I too candid?
They’d thought so. For me, I knew he knew.
He knew I knew it: straight, no slant in that.³⁰*

He recognized that the child knew the situation, and he went for the truth—straight.

The situation described here is one that paediatric palliative caregivers continually confront in their practice. Some professionals would argue that the doctor in ‘Candor’ demonstrates the wrong approach, but others would defend his attempt to get at the greater good—trust building, truth, and ‘straight over slant.’

The poem that follows is by Richard Hain, another physician/poet.

Cancer Pain

*How many times
in a twelvemonth stalked and terrorised by a tumour,
did you ask ‘Will I die?’
And we, smiling into your eyes
with all the tyranny of tenderness,
tore up your question
and threw it away.*

*How often, when we spoke,
did we feed you hopes of immortality,
spoonful by narcotic spoonful,
to deaden the pain?*

*The pain we hoped to drug away was never yours.
Not the simple catch and scratch and smart of cancer
(we are used to that.
We have watched before,
while others did your dying).*

*The pain was ours.
It was the twist and ache of telling you
and seeing you know,
and watching you
while you watched yourself die
by the count
and the clock
and the calendar.*

*Our pain eats out our bones and bowels,
and long after the end of your immortality
when we have run out of smiles and other opiates,
our pain will go on.*

In this poem we are deliberately not told who, or how old, or even what sex the patient is. In contrast to Graham-Pole’s poem ‘Candor’, the narrator here chooses at first not to tell the patient the prognosis—that he or she is dying: ‘How many times... did you ask ‘Will I die?’ And we... tore up your question/and threw it away.’

The doctor is willing to absorb the distress of his choice, postponing until later any attempt to answer the patient’s question: ‘The pain was ours/It was the twist and ache of telling you.’

As in the poem by Graham-Pole, the patient eventually knows with certainty that the disease is fatal. The doctor is forced to watch the patient ‘while you watched yourself die.’ The doctor’s pain persists long after the patient—the child—has met death, and what the poet refers to as ‘hopes of immortality.’ The reader and the poet together confront the pangs and painfulness of the living who watch someone die, and of the dying passing to the total mystery.

These poems exemplify how the discipline of art is a resource for palliative caregivers, enabling them to reflect upon these basic questions vicariously and soulfully before, while, or after they face them, and to prepare for forthcoming situations. This brief sampling of three poems demonstrates how art depicts the human struggles of medicine, and serves as a form of catharsis for the physicians who are able to confront—if not resolve—some of their doubts and distress in the act of composing a poem.

Summary: art as a resource for caregivers and the bereaved

Paediatric palliative healthcare professionals can observe how individuals react to the death of children, and can look to art for many approaches, questions, reflections, suggestions, and insights with regard to how to attend to and relieve the suffering of patients and their families. During her most painful months, Lisa Schnell ‘leaned on’ other writers, who offered her their most intense impressions of life and grief. Art is a form of catharsis for artists, who are fortunate to have their medium as an expressive outlet as well as a lasting tribute and memorial to those whom they have lost. In turn, the artists’ transformation of grief and suffering into art helps those who are struggling to cope with, understand, or empathize with these emotions.

The bereaved, who often feel cut off from those who go about the routine of their everyday lives, can find suitable companionship with writers and artists who have shaped and ordered their own personal anguish. The bereaved can find a few ideas, or even one idea, that they can cling to, perhaps latching on to a simple statement such as Lisa Schnell’s ‘I am still Claire’s mom,’ rewriting it to fit their own situation.

The palliative caregiver can offer unobtrusively, or at least have available, poems, memoirs, biographies, photographs, paintings, photocopies, or even brief quotations, in the hope that a few of these might be exactly the right prescription for the pain. Paintings and poems console us by connecting us to others whose suffering reminds us of our own helplessness, our shared fears of death, and our common mortality. Reminding us that we are not alone, art offers us lifelines. It enables us to shift perspective, to borrow the lens of an artist, and to reflect anew. And so—back to newspapers, hard data, music, poetry, and paradox. In the words of the philosopher Friedrich Wilhelm Nietzsche, ‘We have art in order not to die of the truth.’

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