“I can’t tell my child they are dying”

Helping parents have conversations with their child

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***Abstract***

This paper explores the challenges of resolving conflicting feelings around talking with a child about their terminal prognosis. When children are left out such conversations it is usually done with good intent, with a parent wishing to protect their child from anxiety or loss of hope. There is however growing evidence that sensitive, timely, age appropriate information from those with whom children have a good relationship is helpful both for the child and their family. There is no evidence that involving children in sensitive and timely discussions creates significant problems, rather that withholding information may lead to confusion, frustration, distress and anger. The authors discuss ways in which families can be supported to have these significant conversations with their children.

*Author note*: Case examples are based on many years of clinical experience and have been modified to protect anonymity.

**Introduction**

When a parent is told that their child`s condition has no cure, or that treatment for a life-threatening illness has been unsuccessful, what should they do? Do they tell their child? What do they say? How do they say it? Should they share the whole story or an edited version? How is their decision influenced by the child`s age, personality or capacity? How is it affected by the parent`s fears? These questions are so far removed from most parents` experience that they do not know where or when to begin, or even whether to begin at all.

When children are not included in these conversations it is usually done with good intent. However there is growing evidence that sensitive, age and experience appropriate information is helpful both for the child and their family and that with-holding information may lead to confusion, frustration, distress and anger (1,2). Despite this some individuals involved in the child`s care may not want to talk openly with the child for a variety of reasons. They may then find themselves avoiding subtle hints or oblique questions from the child, side-stepping discussion and sometimes telling untruths. The adults may explicitly discuss and agree these responses between themselves or it may be unspoken. Sometimes the term ‘collusion’ is used to describe this process(3). The word itself is unlikely to be helpful to use with families since its pejorative nature may disable discussion. This well-meaning complicity may occur among colleagues, or between professionals and parents but prevents open discussion. Whatever the context, those involved can be left with a range of uncomfortable feelings, which have the potential to lead to longer-term psychological difficulties, including stress, anxiety and depression (1,2). Therefore it is important to acknowledge the challenge faced by everybody involved and to work sensitively with families to enable more openness in these situations. This is not easy and can take considerable expertise and sensitivity.

There are few studies which have assessed the proportion of parents or professionals who do talk to their child about their death. In a Swedish study 34% of parents reported having talked to their child about the child’s impending death ([4](#_ENREF_4)). None of these parents regretted doing so. 27% of those who had not talked with their child, however, regretted their decision, particularly those who had sensed that their child was aware of their prognosis. Earlier UK work ([5](#_ENREF_5)) found that only 19% of families of terminally ill children had acknowledged with the child their impending death. 29% felt the child was completely unaware and 23% said they did not know what their child knew.

For clinicians working outside palliative care, where the focus is predominantly on treatment and cure, conversations around end-of-life are not common and can present a daunting challenge. This paper explores some of the challenges of resolving conflicting feelings around talking openly with a child.

***The Child`s Perspective***

*Box 1*

*Clinical Example 1*

A newly-qualified staff nurse is asked by Tessa, a 15-year-old girl with a relapsed solid tumour, if she is dying. Tessa’s parents had been informed that there was no further treatment available and the nurse was aware that they were adamant that Tessa should not be told. The nurse had a good relationship with Tessa and she asked her what had prompted that question. Tessa told her she knew the tumour had come back in her lungs, she was not getting any better and she had not been offered any treatment. The nurse wondered if she wanted to talk to her parents about her concerns and offered to tell them what she had said. Tessa agreed and when the nurse told Tessa`s parents her concerns it made them rethink what they were doing. They asked if the doctor would come with them to talk to Tessa and explain what was happening.

Following the joint discussion Tessa was upset, tearful and angry with her parents for not telling her the truth earlier. She said she had thought she wasn’t going to get better and could tell something was wrong by the looks on her parents’ faces. However, later Tessa appeared much calmer. Her relationship with her parents was better than before and she talked to her mother about what she wanted to happen to her belongings after she died. She also talked about the music she wanted played at her funeral. Her father struggled to engage in these conversations. He found it too difficult, so he and Tessa avoided such discussions. They did however continue to enjoy each other`s company.

There are many reasons why parents do not want their child to know the truth about their prognosis, but the child often suspects that something is wrong (Box 1). Adults can argue that the child is too young and does not understand the concept of death and its relation to illness (Box 2).

Using developmental theories of children’s understanding of death to guide the decision to ‘tell’ or ‘not tell’ is problematic in that understanding varies depending upon many factors, including, most notably, the child’s experiences ([6](#_ENREF_6)). Traditional thinking on children’s developing understanding of death posits that children progress through different stages of cognitive maturation, with young children not understanding the irreversibility of death and the full implications of death only being understood in teenage years. However, this progression is not always so clear. Speece and Brent ([7](#_ENREF_7)) note that whilst a child`s understanding may broadly follow these stages, it is also heavily dependent upon experience as well as development and cognitive maturation. They argue that even young children can understand the irreversibility and universality of death if they have had experience of bereavement or terminal illness. Indeed, children as young as three can be aware of their terminal prognosis without having ever been told by an adult ([8](#_ENREF_8)).

It is important to recognise both the experience and developmental level of the child and to note the child`s cues as to whether they want to talk and how much they want to explore ([9](#_ENREF_9)). Children vary considerably and the same child can vary at different points in time. Some children will make it clear that they want the same information as their parents’, others will say that they do not want to hear everything and are happy for their parents to relay relevant details. Asking children what their wishes are about information exchange and routinely re-visiting this can sometimes be helpful. Certain time points can provide opportunities for discussions with the child, such as when the disease progresses, when a friend dies, or when the child is upset at the thought of treatment failure ([9](#_ENREF_9)).

***The Parent`s Perspective***

*Box 2:Clinical Example 2*

James was moving to senior school and asked his mother and father what to say if others asked him why he used a wheelchair sometimes. They realised he was becoming more curious about his condition and they decided that they wanted to be the ones who told him about what was happening to his body and that he had a neurodegenerative condition. However they were very anxious about it and thought he was still too young. They raised the issue with their son`s paediatrician. When the parents said that they wanted to talk to their son, but not yet as they thought he was still too young, the paediatrician gently asked them about their concerns. This opened up a discussion that eventually led to the parents deciding that maybe it was the right time to be more open with their son. They started to notice that James was more aware of his condition than they had thought and they decided to start to talk to him about it. They noticed that James started to sleep better after this and also that the family were more at ease with each other.

Talking with one’s child about them dying is an unimaginable task for most parents. Parents often have strong reasons for wanting to withhold a terminal prognosis from their child and these are sometimes borne out of very real fears about the consequences of doing so ([10](#_ENREF_10)). Parents may think that their child will simply ‘give-up’, either on an emotional level or literally by, for example, refusing treatment. As a consequence they may feel that not talking will protect the child from emotional pain. Fredman ([11](#_ENREF_11)) describes the belief held by some that “death talk kills hope ”, and many fear the consequences of potentially taking away hope from themselves and the child. However ‘false hope’, if it is perceived as such, can leave a young person feeling deceived, silenced and alone.

At either a conscious or unconscious level, a parent’s decision not to talk with their child may be serving a self-protective purpose in terms of avoiding the very real pain of discussing such matters with their child. Defense mechanisms such as denial, minimising and repression are not uncommon in this situation. When adults cite a need to avoid presenting their child with such potentially overwhelming information it may be that they are also protecting themselves from the anguish of managing such information or attempts to prevent decisional regret ([12](#_ENREF_12)).

Part of the role of a parent is to help resolve problems for their child and when they find themselves unable to resolve their child’s terminal prognosis the pain and sense of helplessness can be unbearable. As with James’ parents (Box 2), an open discussion with them about their own fears may be revealing and may free them up to alternative ways of coping and finding the resources within themselves to be more available to meet their child`s current needs.

***The Professionals` Perspective***

*Box 3 Clinical Example 3*

A GP asked the Consultant in Palliative Care for help with the symptom management of 14-year-old David, a boy with renal failure for whom dialysis was not possible. David was being cared for at home and there were discussions between his parents, the GP and the consultant about letting him know. The parents were struggling and did not want to say anything to him. His sister and brothers wanted to know what was happening but the parents were concerned that if they talked to them then this would let the ‘cat out of the bag’.

When the consultant was helping with the syringe driver David said, “I feel terrible. No-one is doing anything. Am I dying?” The consultant waited for his mother to say something but when she did not he started to talk to him about what was happening. His mother allowed the conversation to continue but afterwards was very angry with the consultant and ushered him out of the house. He was allowed no further involvement with David`s care, but learnt from the GP that his symptoms became much easier to manage after the visit and he died peacefully soon afterwards.

Upon reflection, the mother wondered if she might have talked more openly with her son. The doctors also wondered if they could have helped the parents with their own fears so they were better positioned to help their son.

With such strong emotions and arguments by some parents as to why their child should not be included, it is not surprising that professionals can find themselves reluctantly going along with the parents or using vague language to avoid upsetting them. It is difficult to question parents` wishes when they make it very clear, verbally or non-verbally, that they do not want their child to know what is happening. Also, the parent may believe that if the child does not ask then they do not wish to know. However, where information is only given when the child explicitly requests it there is a danger that children sense the unease and anxiety around certain topics and will therefore avoid asking, even when they want to know.

It is important to act in the child`s best interests. However professionals may fear an angry or ‘uncontained’ emotional reaction from the parents if they inform the child against their wishes (Box 3). They may also fear the reactions of colleagues who may be going along with the situation. This may be a particular concern for those in junior positions not wishing to undermine or contradict the wishes of more senior colleagues.Where several clinicians are involved there may be confusion about who is best to explore matters with the child, or a ‘diffusion of responsibility’, whereby individuals fail to have discussions because they assume that others have already done so (13). There may be occasions when professionals find discussing bad news difficult to tolerate, especially when they have been involved in vigorous curative treatment attempts.

The and colleagues ([3](#_ENREF_1)) examined factors contributing to false optimism in adult patients with lung cancer. They found doctors and patients collude in behaviour that fosters false optimism by focusing on the treatment plan and avoiding the issue of prognosis. With hindsight most patients regretted this approach. The work of The and colleagues ([3](#_ENREF_1)) illustrates the fact that health care professionals themselves are not immune to the emotional impact of ‘death talk’ and that avoidance is a strategy used to cope with anxiety by professionals as well as by family members.

***The Implications of not sharing information***

Reports suggest that mutual pretense in relation to a terminal prognosis is associated with poorer dying outcomes (i.e. a more painful or unhappy death ([11](#_ENREF_11))).When children are not included or questions actively blocked, younger children stop asking questions and older children become confused and cope less well ([14](#_ENREF_14)). Children receive cues from the behaviour of others that something is wrong and can be quick to sense that people are not being open with them (Box 1). They may realise that people do not wish to talk about certain topics because it upsets them. When children are not included in what is happening to them, they in turn may not feel able to raise their fears with others. This can leave them frightened and alone, with feelings of distrust and depression ([15](#_ENREF_15)).

When families cannot talk about the impending death of one of its members it means that relationships begin to exist in an unreal atmosphere and the healthy processing of emotions is stifled in a shared family context ([10](#_ENREF_10)). After the child’s death, the parents may be left with feelings of guilt and regret that they did not have more open conversations. In addition concealing the truth from the child can make it difficult to provide good palliative care, with its emphasis on growth in a most challenging situation.

Some parents may struggle to see why these conversations would ever be appropriate to have with their child. The role of professionals can be to explain why a shared knowing is often hugely beneficial to children and families ([16](#_ENREF_16)), playing a crucial role in supporting the child through their terminal illness ([10](#_ENREF_10)). Such conversations must be held in a respectful and sensitive manner, particularly if it is not clear what the parent’s own level of understanding is about their child’s prognosis. Parents’ intellectual understanding of their child’s impending death precedes their emotional understanding ([2](#_ENREF_3)) and less emotional awareness was, for fathers, the greatest predictor of depression. Therefore it is important that professionals try to support and enhance emotional awareness by providing opportunities for parents to talk and reflect on their understanding of the situation. In addition mothers and fathers may adopt different coping strategies and be in different places in terms of accepting, for example, that there are no other treatment options available.

Professionals need to have some rapport and a trusting relationship with the child prior to discussions about their illness and its implications ([17](#_ENREF_17)). The child, as the parents, is not only on a journey related to physical aspects of their illness, but also on an emotional journey.

***Benefits of openness***

*Box 4:Clinical Example 4*

Ellie, a 15-year old girl on the oncology ward, was referred to the Clinical Psychologist for help with pain management as medical staff were struggling to control her pain and distress. The girl’s prognosis was poor and both parents were aware of this, but they did not want her to know as they believed it would cause more harm than good. The mother told the psychologist that she was afraid her daughter would have a heart attack if she was told the truth.

The psychologist worked to encourage the parents to be more open, since she suspected that Ellie had already worked out from the behaviour of her family that she would not get better. The parents eventually decided to talk to their daughter about what was happening, but asked her to go with them to tell their daughter. The parents and psychologist went together to see Ellie. They began by saying that they thought she was probably wondering what was happening to her? Ellie was indeed eager to talk and soon asked if she was going to die. Gently facilitated by the psychologist, Ellie and her parents had a very moving conversation about what was happening, the joy of their lives together and the sadness at what was to come. Afterwards Ellie`s pain appeared to ease, her behaviour with her family was more relaxed and conversation became more open about her illness and prognosis. Everyone seemed to worry less about what to say or what might come up in conversation and Ellie`s parents were able to be openly supportive to her concerns.

Whilst there is good evidence that we frequently do not involve young people in discussions about their own death (18), there is no evidence in the literature to suggest a protective effect of withholding the truth about a prognosis from a child. Extensive clinical experience suggests that although some children may be upset when the topic is initially broached, others are relieved and most appear to appreciate it. Being open gives the child the opportunity to talk about what is happening and to share their concerns and fears. It may enhance the relationship between the child and family, particularly if the child suspects the truth has been previously avoided. It relieves the child of the burden of protecting their parents, help them connect authentically to family and friends and can help to relieve their own distress and pain (Box 4). When children are approaching the end of their life there may be critical opportunities for the child to leave behind a `legacy` (moments, connections, memories) which can help the parents adapt to life without their child (19). Legacies, whether intentionally or unintentionally occurring, provide inspiration and comfort to families. Such positive moments or thoughts about their child and their relationship with their child are helpful in the grieving process and can provide useful anchors to attach supportive and collaborative memories of the last few weeks or months of life.

**Conclusions**

**Two words of warning**

1.Having explored the value of appropriate openness in this paper it is relevant to end with words of caution before we rush in, `where angels fear to tread.` It is essential that the quality and quantity of conversations about death and dying are appropriate in intensity, timing, frequency , content and that they empower rather than undermine the family. Such discussions need to be carefully tailored to the individual child, to their desire for information, timed and gauged well and delivered with developmental appropriateness and sensitivity. Include the child, but as one mother said, ‘provide information not horror’. The paediatrician and psychoanalyst Winnicot wisely reminds us of, ‘`The importance for the child of the presentation of the world in small doses – the preservation of a certain amount of illusion –an avoidance of too sudden an insistence on the reality principle.`(20)

2.It is important to note that sensitive conversations with children about emotionally laden topics, whilst of much significance, can cause high levels of anxiety in those concerned. If these individuals have the opportunity to talk about and develop their work, with a person who is skilled and experienced in communication with children and their families, not only is their anxiety constructively managed but also their skills and ability in this area increased.

This paper has explored some of the potential difficulties arising when a child is not involved in conversations about what is happening to them. It is always appropriate to be thoughtful about the flow of information discussed with the child. Nevertheless both clinical experience and research teaches how valued it is by the child. Clinicians working with families need to be especially mindful of the potential adverse effects of excessively withholding information. They should aim to encourage appropriate openness to relieve individuals of the burden of secrecy, over protection or collusion. Specialist training and regular supervision can support the managing of these conversations.

*Box 5:Learning Points*

* Clinical experience and available literature suggest that sensitive, timely, age appropriate information helps the dying child.
* Parents should be supported to have open communication with their child.
* Palliative care teams and trained mental health professionals can provide helpful consultation and liaison in these situations.
* Regular training and clinical supervision is recommended.

**Further resources for parents and professionals**

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 Beale EA, Baile WF and Aaron J. 2005 Silence is not golden: communicating with children dying from cancer. Journal of Clinical Oncology, 23 (15) 3629-3631.

CCLG.org {Preparing your Child; Children’s Ideas and Understanding of Death}

Advice for parents on how to talk sensitively to their child about death.

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**Multiple Choice Questions:**

1. What, do the authors suggest, could be an effective way to approach conversations about prognosis with the child.
2. Ask the child directly if and how they would like to receive information about what is happening and revisit these conversations throughout their treatment.
3. Tell the child that it is important that they understand everything about their condition and that you will help to explain it in a way in which they can understand.
4. Keep asking the child if they have any questions during consultations, but do not initiate conversations about prognosis. If they do not ask, they probably do not wish to know.
5. There is no effective way to communicate about prognosis with young children.
6. When, do the authors suggest, might be the best time to approach conversations about prognosis.
7. At each consultation so that you are providing maximum opportunities for the child to talk.
8. At significant time points throughout treatment, such as when a friend dies or when the disease has progressed.
9. There may never be a good time to approach these conversations, so it is advised to wait for questions or cues from the child.
10. What method could you use to support parents to be more open with their child?
11. Talk about poorer dying outcomes in children who do not know.
12. Explain why openness can be beneficial
13. Suggest that it is unfair to exclude the child from such discussions
14. Point out that they are thinking more about their own needs rather than their child`s.
15. Give an example of another family who were not open with their child and regretted it.
16. Why is it important to include children in discussions about their terminal prognosis?
17. It is unethical not to
18. It can relieve the child of the burden of protecting their parents
19. There is no evidence to suggest it is protective to withhold the truth

Answers: 1. (a) 2. (b) 3. (b) 4. (b)