



A child has died in your office

Terry A. Purvis-Smith, PhD Michael W. Roberts, DDS, MScD

Potentially catastrophic events including death can occur casually or related directly to the delivery of dental care to children. Allergic reactions to medications, acute asthmatic attacks, severe seizures, and even cardiopulmonary collapse are all remote but possible sequelae.

While the incidence of serious complications and death associated with conscious sedation and general anesthesia is very low, it may increase as medicine sustains the lives of medically fragile children.^{1,2} These children constitute a new population requiring dental care. Their preexisting medical conditions together with the inherent risks associated with sedation and general anesthesia introduce the possibility of complications, and the death of children receiving dental care may increase.

Dental education and training do not prepare pediatric dentists to respond to the death of a child in their care. This essay provides direction in preparing for such an occurrence and for the challenging task of informing and caring for a child's parents. It addresses the dentist's personal preparation, and how to communicate with parents, tend to their feelings, and express your care. It does not review related issues such as the role of emergency medical personnel and police, or the immediate and ongoing care of office personnel or legal matters.

The first step — begin with yourself

An unlikely, but nonetheless possible, event is that a child will die while receiving dental treatment. If this happens, you will ask yourself, "What am I going to tell the parents?" "How will I tell them?" "How can I care for them?" "What is my role and what are my responsibilities?" The most effective way to address these questions is found in this paradigm: *begin with yourself*. This paradigm is based on the assumption that death touches us in a qualitatively different way than other challenges.

This difference can be explained by reference to a continuum. At one end of the continuum is "intellect" and at the other "feeling." As a pediatric dentist, you use your intellect more than your feelings to diagnose dental disease and to choose appropriate treatments.

Death, by contrast, moves us to the feeling end of the continuum no matter how mightily we struggle with it intellectually. We will die and the people we

love will die. This is what makes death qualitatively different from many other challenges in our professional lives. It is universal, and its universality is not first and foremost a matter of our professional role, but of our humanity. It challenges us personally.

Death exposes us to feelings in another way. In your role as a health care provider, you cannot avoid being exposed to and affected by the feelings of those around you at the time of death, especially the death of a child. You may see the horror on parents' faces when they hear the words, "I'm sorry. Ruth is dead." You may see the color wash from their faces, the welling up of tears in their eyes. You may hear a parent scream and look for someplace to run or something to hit. You may hear a parent's futile protest, "This can't be. I want to see my daughter and I want to see her now!" as if seeing her will prove that she is still alive. You may see a parent's entire body shake, or you may hear them ask, "How will we tell our other children?"

When the issue is death, you will be affected at a personal level. It is impossible to protect yourself from the intense feelings that will be expressed, although some of us steel ourselves in a way that makes it appear we are not moved. Nevertheless, how you respond to these strong feelings will permeate the way you, as a professional, relate to and care for the child's parents.

Begin with yourself at two specific times. The first is now, before a death occurs. Discuss death with colleagues, family, friends, clergy, or in continuing education situations. Talk about the deaths in your life—about parents, grandparents, siblings, friends, neighbors, or pets. Talk about the fact that you will die. Discuss how you feel in these conversations. Practice giving a voice to your own powerful feelings in the relatively safe context of trusting relationships with colleagues and family. Without these preliminary conversations, you leave yourself in the position of having your first awkward conversations about death at the time when a child has died, when you wish you had your very best "bedside manner."

Learning what others have found helpful, caring, or meaningful when a child dies is beneficial. You will hear statements like these: "I felt so empty, so hurt, that I didn't want anyone telling me things would be all right." "I think I would hit someone if they had told me 'God wanted another angel,' because I want my

child with me.” “Don’t tell me you know how I feel because you don’t. I’m the only one who has my pain. I’m the only one who knows how I feel.”

What we learn in these conversations can be integrated into our professional work. If your goals are to comfort parents and to communicate with them if their child dies, you will learn that trite sayings are not comforting to parents because the depth of their pain makes such comments sound glib and insensitive.

A second benefit of conversation about death is gaining an awareness of and articulating what you would value at the time of death. Indeed, one of your reactions may be to wish that you were informed that death was a possible, though remote, complication of a given situation. You may value having someone be with you, having someone listen when you want to talk, hold you when you want to be held, get you water if you are thirsty, help you think about next steps when you ask for help. What you value offers clues to what others may value at the time of death.

A third benefit of these conversations comes in response to feelings and questions you are apt to have when you first realize the child is dying. You may ask yourself if the death was due to something you did, failed to do, or could have done differently. Conversation with colleagues lets you learn how they have handled these feelings.

The second time to *begin with yourself* is after a child dies, but before going to tell the parents about the death of their child. This preparation consists of taking a moment to acknowledge what you are feeling and to review how you have prepared for communicating this reality to the parents.

An illustration will clarify the significance of this second, though brief, time of preparation. A young pediatrician told parents that their child was brain dead. She said, “I want you to know that you haven’t done anything wrong. You shouldn’t feel guilty. You did everything that you could have done. You are wonderful parents. There isn’t any need to feel guilty.” The parents had never mentioned guilt, and the physician’s emphasis on guilt might have carried an implicit message that the parents should think they had done something wrong.

Later, when she took time to attend to her *own* feelings about the death, the pediatrician indicated that she wondered if there was anything else *she* could have done to save the child’s life. She articulated feelings of guilt and wondered if she belonged in pediatrics. If this physician had begun with herself by acknowledging her own feelings when the child died, she could have refrained from imposing her own feelings of guilt on the parents. If she had begun with herself by having conversation with family and colleagues, she could have been prepared to elicit, hear, and respond to the parents and their needs.

When this pediatrician did seek out conversation with a senior colleague, she said with considerable relief, “I couldn’t believe that Dr. Alston also feels guilt

when a child dies. She’s an outstanding physician. I’d trust my own children in her care. She told me that some guilt is important because it means I have standards for myself and that I want to be the best possible pediatrician. I always knew the child’s death wasn’t my fault, but I felt terrible anyway.” The pediatrician discovered that she wasn’t alone in her feelings, that she wasn’t losing it altogether, or somehow less competent because she felt inadequate.

Beginning with yourself is quite different from other paradigms in health care. Health care professionals are expected to continue their work as if nothing has happened even though a child in their care has died. But if you begin with yourself, you will acknowledge your own strong feelings and recognize that your ability to function technically as a dentist and to communicate with children, their families, and staff may be impaired immediately after a child dies. You may find it necessary to cancel or delay appointments as you cope with what has occurred to *you*.

Remember these points.

1. You will be affected by the death of a child at a personal level, because death reaches beyond your professional role to your humanity.
2. You prepare yourself to handle the death of a child by beginning with yourself. Beginning with yourself means talking now with colleagues, family, friends, and clergy about death. It also means pausing after a child dies to acknowledge your feelings and to review your plan for attending to and comforting the parents.

The power of words

As you talk about death and think about the death of a child in your care, there are unique items to keep in mind—the power of words, trust, and anger. The power of words can be illustrated by the physician who said, “When I tell a family their child has died, it feels like I have killed that child because the death was not a reality for them until I have said the words ‘He’s dead.’” If you have similar feelings, remember, death has already taken place; that is the reality. You did not create it, even though you may feel as if you did when you speak the words and see the parents’ pained reactions.

Trust

If a child in your care dies, you may wonder whether the parents will trust you. Can they trust the care you provided? Can they trust the details you are now giving them? Parents do not have the expertise, to evaluate the care you gave their child. Absent this expertise, their trust rests on other factors, especially the quality of concern you express for them and for their child. Do you show care for them and what they are going through? Are you moved emotionally by what has happened? Or are you cold and distant? Do you give them the time and attention appropriate to what has just happened or do you only interact with them in a brief

manner and leave them with the impression that you have more important matters to attend to?

Other factors contribute to parents' trust in you. If you do not know the answer to one of their questions, admit you don't know. If you can find the answer, indicate you will find it and provide it for them. Be specific about when this will happen. Know the law in your state regarding postmortem examination of the body so that you will be able to properly inform the parents about what will be happening to their child's body. Know, too, what they must do to reclaim their child's body. Will they have the choice of picking it up from the medical examiner's office themselves or is their only choice to call on the services of a funeral home? If an autopsy is done, learn when the results will be available and how the parents can have a pediatrician review those results with them.

Anger

If a child dies in your care, both the parents and you may feel angry. Anger is a particularly challenging emotion when a child dies. It can appear in many forms. You may feel anger and express it indirectly by saying, "We didn't have any courses in dental school to prepare me for this." You may speak sharply, in a way that is out of character for you, to someone on your staff or to a colleague. You may feel irritated when the well-intentioned but not very helpful question is asked, "Are you okay?" When a child dies, you may become aware that you hold the assumption that what has happened is wrong because it is out of the natural order. Children are supposed to outlive their parents, and they are not supposed to die while receiving dental care. If you are not aware of your anger, you may become even more agitated or ineffective when the parents become angry themselves.

Your or the parents' anger may feel frightening. Handle anger with the same respect with which you respond to other feelings. That is, acknowledge feelings of anger. If someone is feeling joyful, you do not argue with them by saying, "Into each life a little rain must fall." You rejoice in that person's happiness with a comment like, "I'm glad you're feeling good." In the same way, when someone is feeling angry, do not argue with them or try to convince them to feel something else; acknowledge their feelings. You will need to discover in conversation with colleagues and family the best way for you to acknowledge anger. You may sit patiently and respectfully while allowing the person to talk about their anger. You might say, "I feel angry, too, that Sean is dead." Anger is a feeling and it does not simply dissipate over time as if it were excess energy.

A fundamental element within anger is helplessness. One person said to a pediatrician, "I'm so angry at you for not keeping her alive. That's what you're supposed to do. That's why you went to medical school and received all your specialized training." The pediatrician

was supposed to be in absolute control, but she was not. She was helpless to prevent the death. If you and the parents are angry after a child dies, this feeling may be a key to the more fundamental helplessness we all experience when confronted with the reality that we cannot control life and death.

How do you talk to parents?

Again, the basic paradigm for learning to talk with parents is to begin with yourself. When you begin with yourself, you learn that death has personal dimensions that permeate your professional role. In a similar manner, death permeates the entire life of the parents—their feelings, their thinking, their ability to function effectively. In addition, when you begin with yourself and become aware that powerful emotions are related inevitably to death, you already know that feelings will be the focus of interaction with the dead child's parents.

Keep in mind that all patients and families in your waiting and treatment rooms will become anxious before anyone has announced that there has been a medical emergency. They will have noticed the changed behavior of your staff or observed emergency medical personnel rushing into your office.

Have someone on your staff invite the child's parents to meet you in a private place. If you go personally to a public waiting area to take them to a more private setting, they are apt to read the expression on your face. "Is something wrong? Is my daughter all right? What's going on here?" The public announcement of this news will have already begun if you issue the invitation. The parents may refuse to follow you until their questions are answered.

Have a place for both the parents and you to sit. Look directly at them. Use brief descriptions in layman's language followed by periods of waiting to see what they need and want from you. "I'm so sorry. Something terrible happened in surgery. Sean has died." Then pause. The chances are very high that what you say after this will not be heard or understood. Use the word "dead" or "died" because the meaning of these words is clear. Phrases such as "passed" or "no longer with us" can be misinterpreted.

Wait for the parents to react and gauge your response by listening to their feelings and needs. Your task in speaking with parents of a child who has died is one of discovery: discover what they are feeling, how they express their feelings, how they cope in a crisis, and their view of death so that you can respond to them in terms that are meaningful to them. You may be inclined to react to their tears with tears of your own, to offer them a tissue, or gently touch a hand or offer a hug. You may decide that sitting quietly without saying or doing anything is most appropriate. When powerful feelings are being expressed it is tempting to want to do something. Instead of "doing," continue to "be" present with the parents.

You will need to make a careful assessment about when to leave the parents alone in the room. If you exit quickly and without discussion, they may feel abandoned at this time when they feel the greatest pain in their lives. On the other hand, the embrace of a husband and wife at a time like this or the tears a family shares may feel so intimate that you will feel like you are intruding where you do not belong. If you sense the family needs time alone, say "I am going to step outside the door. I will wait outside until you are ready for me to return." Then be sure to wait outside the door.

Some parents may cry and cry. Allow them the time and place to do so. Other parents hide their emotions. If their coping skills are built around hiding their feelings, respect this style. Some parents faint. Help them to fall gently to a chair or onto the floor. In most circumstances they will quickly regain their equilibrium.

Still other parents are so overwhelmed that they appear stunned or numb. Sometimes it takes these parents considerable time before they are ready to even acknowledge your presence or what you have told them much less think about viewing the body, leaving the office or hospital, how they are going to get home or who they want to contact. With these parents, it is often best to sit quietly, wait, and then ask if they are ready to learn what will happen next—such as viewing the body, contacting family or clergy, or calling a funeral home.

Some parents may say: "I am angry. I don't know why my daughter had to die. It just isn't right. It isn't fair." Parental anger may be expressed indirectly in the anguished question, "Why? I want to know why my daughter had to die." The question "why" may be the only safe way they know how to express anger. Still others will say they want an answer from God. This is a variation on the "why" question and implies anger toward God. A few will be overtly expressive by shouting, or blaming someone for the death of their child.

It is rare for a parent to attack someone verbally or physically; if this happens protect both the parent and the target by having the target leave the room. Since you are not in a position to fully assess whether this kind of behavior is a single isolated incident or may happen again, you have a responsibility to protect other patients, families, and staff from harm. Close the door to the room where the person is striking out and ask security personnel or police to be available in case the person is not able to quickly gain control of his or her behavior.

It is the exception for a parent to accuse the health care provider of killing their child or to hold the health care provider responsible for their child's death. If this should happen, it may be important to let them verbalize it. Most parents will apologize quickly and recognize that these accusations were an expression of anger, hurt, and helplessness. If the anger toward you persists, it may be wise to ask a colleague or another member of your staff to stay with the parents while you temporarily leave the room.

A few people may strike a table or punch the wall in response to the declaration that their child is dead. Do not restrain them. Recognize their anguish. This behavior is usually short-lived. Do not try to persuade them to feel or act differently. Sit quietly. Your presence will help them regain their composure.

When some people learn about their child's death, they feel confined in a conference room and dash for the door. Restraining them does not help. Let them go into the hallway or walk around the building. Those who need this outlet will return to the conference room and those who are waiting for them after they have exerted some physical energy. Accompany them for their protection, but at a distance. Other well-intentioned people may try to intervene by hugging them, by trying to force conversation, by offering prayer or a well-intentioned but misguided platitude. Thank them for their concern and explain that you are caring for this person.

The points to remember as a health care provider are these:

- 1). Meet with parents in a private place
- 2). Discover the parents' coping mechanisms
- 3). Remember that what is presented in the form of a question may actually be a statement about a feeling
- 4). Recognize that death will force you to relate to people in terms of feelings—acknowledge feelings, especially anger
- 5). Suggest conversation with their religious leader when spiritual or theological issues arise
- 6). Protect both parents and others from additional emotional or physical pain.

How you attend to the parents is what makes the difference between being perceived as sensitive and caring or as insensitive and uncaring.

Instruct someone on your staff to tend to the other patients and families. They can say, "You may have noticed that we have had a medical emergency. It does not involve your child. I will bring your child out to you." Because the medical emergency may disrupt your schedule, you may want to instruct your staff to add, "This emergency will be taking our attention. I'm sorry but we will have to reschedule your appointment. We can do that at the desk now or we can call you tomorrow for another appointment."

We have focused this essay on your preparation and the immediate issues of communicating with and caring for the parents. It is, nevertheless, important to indicate that a death or medically compromising response during dental care will create a maelstrom. You will be involved with emergency medical personnel, your staff, other patients and their families, colleagues, the physician who assumes the care of the child or who pronounces the child dead, police, perhaps even the media. Protect the parents' privacy and yours. You will feel overwhelmed. Ask others who are not immediately involved to help you think through your next steps and responsibilities. A colleague in a nearby office may be

willing to consult with you, because every health care provider knows that this could happen to them.

Viewing the body

A decision will need to be made about viewing the body. It is generally helpful for parents and siblings to see the body at the time of death. Seeing the body helps them realize that death has in fact taken place. This realization, as painful and devastating as it is, is also the first step on the road toward healing and learning to live with the new reality.

Offer parents the opportunity to see their child's body. You will be concerned with the way the body looks. Clean up excess blood, remove any apparatus that you can and wrap the body up to the neck with a sheet or blanket. These actions communicate your respect for their child's body and for the family's feelings. At the same time, death has taken place and no amount of cleaning will reverse that reality; do not prolong this process.

If the parents choose to view the body, tell them where it is, what they can expect, and that you will accompany them. An example dialogue is, "Sean's body is in room 3346, which is on this hallway. His body is on a table and is covered with a blanket. You will notice that his mouth is swollen and you may see blood stains on his chest and arms as a result of our efforts to revive him. I can answer any questions you have, and I will be with you when you view the body." Once you are in the room use your judgment about staying or asking if they would like to be left alone.

Brothers and sisters can be invited to see the body, too. In some families, mothers, fathers, brothers, sisters, and other extended family members go to view the body at the same time. What is crucial is to let the family use their own coping processes rather than imposing yours. Taking parents to view the body first can be beneficial as it gives them time to comfort each other. This gives the parents an opportunity to turn their attention to and care for their other children when they view the body.

Even though very young children cannot comprehend the finality of death, they cannot be neglected. Adults often forget that children of all ages have feelings and should not be left alone to contend with these feelings. Very young children will pick up the emotional tone from adults. Older children will both pick up the tone and have an idea, however immature it may be, about what death is. Children have imagination. When they are not participants in what is happening, they will listen to adult conversation and then create their own ideas about what has occurred. The danger here is that children do not have the ability to express in words what they imagine in their mind. If they are included, adults can help them understand what they have witnessed.

Children will have questions. They need to see their sibling. They will be affected by the powerful feelings of their parents and other adults. It is helpful for parents to explain they, themselves, need to cry now, that they will not always cry, that receiving a hug will be

very helpful, and that the child(ren) they are talking with did not do anything to make them cry.³ Let the surviving children act their age—come and go from the room where the body is at their own initiative with supervision, be inquisitive about what they see, get quickly bored with what is capturing adult attention, and say things that come spontaneously to them even though they may make adults feel uneasy.

Other questions

What happens if you cry? Parents will often express appreciation for your tears. A guideline is that you can cry as long as you are able to maintain your role as the person caring for the parents.

How do you say goodbye? Keep in mind that the parents came to the office or hospital with a child, but they're going home without that child. Express your sorrow. Take time to say goodbye when they leave your office. Do not delegate this task to someone else on your staff. You want the parents to know how important their child was and they are to you.

You will probably feel very helpless when you anticipate sending the grieving parents home from your office. You will wonder how they are going to cope with what has happened in their life. These feelings are clues to your added responsibility. Instead of sending them away by themselves, develop resources in your community. A nearby hospital chaplain or member of the clergy, someone from a mental health agency, a private practice psychotherapist, or bereavement counselor may be willing to come to your office to assist you. These are options you will need to plan for ahead of time. Offer the parents the use of your telephone to contact family, clergy, or anyone else they want to gather around them.

Should you contact the parents again later? Yes. Parents report a double hurt when a child dies. The first and biggest one is the death itself. The second one is being left alone. Parents report that people often act as if their child's death is contagious. Family, friends, and professional people avoid the parents because they are afraid of upsetting them. The upset has already happened; their child is dead. The upset can only be compounded by a sense of being abandoned when they have the biggest hurt in their life. Call the parents and say, "I wanted you to know I was thinking about Sean and about you." Parents who want to talk will often take it from there.

Conclusion

You can learn to talk with parents about the death of a child. Begin with yourself, because talking with parents involves more than theories about death and dying, crisis intervention, the grieving process, and communication skills.^{4,5} As important as these separate elements are, caring for the parents at this critical time calls for an integration of personal feelings and your professional role and responsibilities. The qual-

ity of your attending to the grieving parents will be the result of your own struggle with the reality of death.

Dr. Purvis-Smith was pediatric chaplain, University of North Carolina Hospitals, University of North Carolina—Chapel Hill and now writes from his home in Washington, DC. Dr. Roberts is associate professor and chair, Department of Pediatric Dentistry, School of Dentistry, University of North Carolina—Chapel Hill.

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