Supporting the Grieving Child and Family

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The death of someone close to a child often has a profound and lifelong effect on the child and results in a range of both short- and long-term reactions. Pediatricians, within a patient-centered medical home, are in an excellent position to provide anticipatory guidance to caregivers and to offer assistance and support to children and families who are grieving. This clinical report offers practical suggestions on how to talk with grieving children to help them better understand what has happened and its implications and to address any misinformation, misinterpretations, or misconceptions. An understanding of guilt, shame, and other common reactions, as well as an appreciation of the role of secondary losses and the unique challenges facing children in communities characterized by chronic trauma and cumulative loss, will help the pediatrician to address factors that may impair grieving and children's adjustment and to identify complicated mourning and situations when professional counseling is indicated. Advice on how to support children's participation in funerals and other memorial services and to anticipate and address grief triggers and anniversary reactions is provided so that pediatricians are in a better position to advise caregivers and to offer consultation to schools, early education and child care facilities, and other child congregate care sites. Pediatricians often enter their profession out of a profound desire to minimize the suffering of children and may find it personally challenging when they find themselves in situations in which they are asked to bear witness to the distress of children who are acutely grieving. The importance of professional preparation and self-care is therefore emphasized, and resources are recommended.

abstract

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children, many pediatricians are uncomfortable talking with and supporting grieving children.4

Bereavement is a normative experience that is universal in nature, but this does not minimize the impact of a loss. The death of someone close to a child often has a profound and lifelong effect on the child and may result in a range of both short- and long-term reactions. Pediatricians, within a patient-centered medical home, are in an excellent position to provide anticipatory guidance to caregivers before, during, and after a loss and can provide assistance and support in a number of areas, including the following:

- exploring and confirming that children understand what has occurred and what death means;
- helping to identify reactions such as guilt, fear, worry, or depressive symptoms that suggest the need for further discussion or services;
- providing reassurance to children who become concerned about their own health or those of family members;
- offering support to grieving children and their families to minimize their distress and accelerate their adjustment;
- informing families about local resources that can provide additional assistance; and
- offering advice on funeral attendance of children.

Pediatricians also can play an important role in supporting parents and other caregivers after the death of a child, even in the absence of surviving siblings.4–6 In addition, children may experience grief in response to a range of other losses, such as separation from parents because of deployment, incarceration, or divorce, which may be helped by similar caring strategies.

This clinical report is a revision of an earlier clinical report that introduced some of the key issues that pediatricians should consider in providing support to grieving children.7 Guidance is available elsewhere regarding how to support families faced with the impending or recent death of their child,4,8 including practical advice on how to approach notification of parents about the death of their child in a hospital setting8,9 or in the unique context of a disaster.10 Because traumatic events often involve loss, complementary information on providing psychosocial support in the aftermath of a crisis can be found in a recent clinical report,11 which may be particularly relevant to pediatricians providing care in emergency departments and intensive care settings.

IDENTIFYING CHILDREN’S LOSS EXPERIENCES

In a busy pediatric practice, it is likely that a pediatrician interacts with a child who is grieving a death virtually every week, if not every day. But many children who are grieving show few outward signs during an office visit. From an early age, children learn that questions or discussion about death make many adults uncomfortable; they learn not to talk about death in public. In the context of a recent death, children may also be reluctant to further burden grieving family members with their own concerns.

Children’s questions about the impact of a personal loss can be quite poignant and/or frame the experience in concrete and direct terms that underscore the immediacy and reality of the loss to adults (eg, “If Mommy died, does that mean that she won’t be here even for my birthday? How can I live the rest of my life without her?”). Adolescents who are in a better position to appreciate the secondary losses and other implications of a significant loss may raise concerns that surviving adults may not have yet appreciated (eg, “I don’t know if I ever will feel comfortable having my own children when I grow up, without Mom there to help me.”).

When children ask such questions or make similar comments, surviving family members may become tearful and/or obviously upset. Children may misinterpret these expressions of grief triggered by their questions as evidence that the questions themselves were hurtful or inappropriate. They subsequently may remain silent and grieve alone, without support. In addition, when children lose a parent or other close family member, they are often fearful that others they count on for support may also die and leave them all alone. Children may find it particularly unsettling to observe their surviving caregivers struggling and often respond to their surviving parent(s) demonstrations of grief by offering support or assistance (eg, “Don’t worry Daddy, I can help do many of the things Mommy used to do; we are going to be okay.”), rather than asking for help themselves, which may convince surviving caregiver(s) that the child is coping and has no need for assistance. For this reason, it is important for pediatricians to offer to speak with children privately after a family death to identify their understanding, concerns, and reactions without children feeling that they need to protect surviving caregivers.

Caregivers who are struggling with their own personal grief may be particularly reluctant, or even unable, to recognize or accept their children’s grief. The reality is that many children in this situation are grieving alone, postponing expressing their grief until a time when it feels safer, or seeking support elsewhere, such as at school or after-school programs where they can talk about their feelings and concerns with adults who have personal distance from the loss.
Young children, in particular, may not yet understand the implications the death may have for them or their family. Children and their families may wish to seek advice but view death as a normative experience that does not warrant professional assistance and may not realize that their pediatrician may be interested in helping and able to assist them. During an incidental pediatric office visit, children may be reluctant to raise the topic because they worry that they will start crying or otherwise embarrass themselves. They may be afraid to start a discussion in the pediatric office or at school because they worry that once they start to cry, they will be unable to compose themselves by the end of an office visit or a conversation at school. Children may also express their grief indirectly through their behavior or attempt to address their feelings through play. Grief is, in many ways, a private experience. Older children, especially, may elect to keep their feelings and concerns to themselves unless caring adults invite and facilitate discussion. These are among the many reasons why pediatricians may be unaware of a death involving a close family member or friend of one of their patients.

Pediatricians can increase the likelihood that children and families will bring significant losses to their attention by directly informing families, often during the initial visit and periodically thereafter, that they are interested in hearing about major changes in the lives of patients and their families, such as deaths of family members or friends, financial or marital concerns of the family, planned or recent moves, traumatic events in the local community or neighborhood, or problems or concerns at school or with peer relationships. At subsequent visits, pediatricians can ask whether any major changes or potential stressors at home, at school, or within the community have occurred or are anticipated. Practices that respond to these needs as they arise in families, by inviting conversations, expressing concern, and offering information and referral, create an atmosphere in which families are more likely to disclose their occurrence and actively seek assistance and support.

INITIATING THE CONVERSATION

Pediatricians and other caring adults often worry that asking children about the recent death of someone close to them may upset them. In the immediate aftermath of a major loss, the loss is almost always on survivors’ minds. Although a question about the death may lead to an expression of sadness, it is the death itself, and not the question, that is the cause of the distress. Inviting children to express their feelings allows them to express their sadness; it does not cause it. In contrast, avoiding the subject may create more problems. Children may interpret the silence as evidence that adults are unaware of their loss, feel that their loss is trivial and unworthy of comment, are disinterested in their grief, are unwilling or unable to assist, or view the child as unable to cope even with support. Instead, the following steps can be used to initiate the conversation:

- Express your concern. It is okay to be tearful or simply to let them know you feel sorry someone they care about has died.
- Be genuine; children can tell when adults are authentic. Do not tell the child you will miss her grandfather if you have never met him; instead, let the child know that you appreciate that he was important to her and you feel sorry she had to experience such a loss.
- Listen and observe; talk less. Simply being present while the child is expressing grief and tolerating the unpleasant affect can be very helpful.
- Invite discussion using open-ended questions such as “How are you doing since your mother died?” or “How is your family coping?”
- Limit the sharing of your personal experiences. Keep the focus on the child’s loss and feelings.
- Offer practical advice, such as suggestions about how to answer questions that might be posed by peers or how to talk with teachers about learning challenges.
- Communicate your availability to provide support over time. Do not require children or families to reach out to you for such support, but rather, make the effort to schedule follow-up appointments and reach out by phone or e-mail periodically.

Adults are often worried that they will say the wrong thing and make matters worse. In the context of talking with a patient who has recently experienced a death, caregivers may wish to consider the following suggestions:

- Although well intentioned, attempts to "cheer up" individuals who are grieving are usually neither effective nor appreciated. Anything that begins with “at least” should be reconsidered (eg, “at least he isn’t in pain anymore,” “at least you have another brother”). Such comments may minimize professionals’ discomfort in being with a child who is grieving but do not help children express and cope with their feelings.
- Do not instruct children to hide their emotions (eg, “You need to be strong; you are the man of the
house now that your father has died.”

- Avoid communicating that you know how they feel (eg, “I know exactly what you are going through.”). Instead, ask them to share their feelings.

- Do not tell them how they ought to feel (“You must feel angry.”).

- Avoid comparisons with your own experiences. When adults share their own experiences in the context of recent loss, it shifts the focus away from the child. If your loss is perceived by the child as less important, the comparison can be insulting (eg, “I know what you are going through after the death of your father. My cat died this week.”). If your experience appears worse (eg, “I understand your grandfather died. When I was your age, both my mother and father died in a car accident.”), the child may feel compelled to comfort you and be reluctant to ask for help.

The use of expressive techniques, such as picture drawing or engaging children in an activity while talking with them, may be helpful in some situations in which children appear reluctant to address the topic in direct conversation. Pediatricians can also provide written information to families about how to support grieving children (eg, After a Loved One Dies: How Children Grieve and How Parents and Other Adults Can Support Them), which is freely available and can be accessed through the coping and adjustment Web page of the American Academy of Pediatrics at https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Children-and-Disasters/Pages/Promoting-Adjustment-and-Helping-Children-Cope.aspx.14 Books written specifically for younger children that help them develop a better understanding of death or that help children and adolescents cope and adjust with a personal loss (eg, Guiding Your Child Through Grief is one such resource for older children15) can be found through recommendations of a children’s librarian or at bookstores. Pediatricians can identify a few books to recommend and, ideally, may even choose to stock their offices with a couple of copies to lend to families.

### CHILDREN’S DEVELOPMENTAL UNDERSTANDING OF DEATH

Before the development of object permanence, something out of view is felt to be literally “out of mind.” Therefore, it is unlikely that infants in their first 6 months of life can truly grieve. But as children develop object permanence during the second half of the first year of life, they begin to acquire the ability to appreciate the possibility of true loss. It is therefore not coincidental that peek-a-boo emerges during this time period as a game played by children in all cultures, wherein the child shows heightened concern at separation and joy at reunion, as if “playing” with the idea of loss. Infants and toddlers play this game repeatedly as they try to understand and deal with the potentiality of loss. It has been suggested that peek-a-boo is one of many games that children play that might allude to loss or death. In fact, “peek-a-boo” is translated literally from Old English as “alive-or-dead.” Parents who worry that it is too early to raise the topic of death with their preschool- or even school-aged children likely do not realize that they began communicating with their children about loss at an early age.

Research has shown that there are 4 concepts that children come to understand, or that help them make sense of, and ultimately cope with, death: irreversibility, finality (nonfunctionality), causality, and universality (inevitability).14-19 On average, most children will develop an understanding of these concepts, outlined in Table 1, by 5 to 7 years of age. Personal loss or a terminal illness before this age has been associated with a precocious understanding of these concepts, education has been shown to accelerate children’s understanding as well.20 The death of a pet in early childhood can be used as an opportunity to help young children both understand death and learn to express and cope with loss.

Understanding the concepts of death can be viewed as a necessary precondition, but not necessarily sufficient, for acceptance and adjustment. Children at a very young age can understand that death is irreversible; indeed, even toddlers come to learn “all-gone.” But accepting that someone about whom you care deeply will never return is difficult even for adults. Pediatricians can counsel parents to help children understand these concepts and assess children’s comprehension directly through simple questions. Parents can be encouraged to be patient with children’s repetitive questions after a loss, which may occur over an extended period of time. For young children, such questions may reflect attempts to develop a more complete understanding over time as cognitive development progresses.

Misinformation or misconceptions can impair children’s adjustment to loss. Literal misinterpretations are common among young children. For example, children may become resistant to attending a wake after being told that their parent’s body will be placed in the casket; adults often assume this is because of a fear of dead bodies. But some children, when told that the “body” is placed in 1 location, may conclude that the head is placed elsewhere; their reluctance to attend the wake may be attributable to a fear of viewing their parent decapitated. It is best not to assume the reasons for children’s worries or hesitation but instead ask what they are thinking about. Young
children also may have difficulty understanding why families would choose to cremate a loved one after death. Providing developmentally appropriate explanations for parents and other caregivers to use to address common questions can be helpful and reassuring (eg, explaining to preschool-aged children that once people die, their body stops working permanently and they no longer are able to move, think, or feel pain, which is why it is okay to cremate the body, or use high temperatures to turn the body into ashes).

To minimize misinterpretations, it is best to avoid euphemisms; especially with younger children, it is important to use the word “dead” or “died.” For example, a young child told that a family member is in eternal sleep may become afraid of going to sleep himself. Religious explanations can be shared with children of any age according to the wishes of their caregivers. But because religious concepts tend to be abstract and therefore more likely to be misunderstood by young children, it is important to also share with children factual information based on the physical reality. For example, a young child told only that a brother died “because he was such a good baby God wanted him back at his side” may begin to fear attending church (if this is viewed as “God’s home”) and misbehave whenever brought to religious services.

Children with intellectual disabilities will generally benefit from explanations geared toward their level of cognitive functioning, followed by questions to assess the degree of comprehension and to probe for any misunderstandings. Children with neurodevelopmental disorders, such as autism spectrum disorder, may benefit from practical suggestions about communicating their feelings and needs, as well as additional support to promote coping. Children unable to communicate verbally may show their grief through nonspecific signs or behaviors, such as weight loss or head banging. To provide support after a death, parents and other caregivers can draw on the strategies and approaches that have worked with their children in the past to provide comfort when faced with other stressors and to explain challenging concepts.

**ADOLESCENTS**

Adolescents may have a mature conceptual understanding of death, but they still experience challenges adjusting to the death of a close family member or friend. Although they are capable of rational thinking, adolescents, like adults, nonetheless benefit from additional explanation and discussion in addition to emotional support. Although they often turn to peers for support and assistance in many situations, after the death of a close family member or friend, they can benefit from the additional physical and emotional presence of adults. Unfortunately, many adolescents receive limited explanation or support after a death. Often, surviving caregivers rely on them to take on more adult responsibilities, such as contributing to the care of younger siblings and performing more chores within the home, and may count on them to serve the role of a confidante and source of emotional support for the caregivers themselves. Pediatricians may be able to assist in such cases by encouraging adult caregivers to identify their own support, such as through faith-based organizations, community-based support groups, or professional counseling.

Juniors or seniors in high school are at a point in their development when they may be particularly vulnerable to difficulties in coping with the death of a close family member or friend. This is a time of heightened academic demands, and the common short-term negative effect on academic productivity may be compounded by the high level of academic scrutiny characteristic of applying to college. Completing high school and leaving family to
Guilt and Shame

Because of the egocentrism and magical thinking that are characteristic of young children’s understanding of causality, children will often assume that there was something they did, did not do, or should have done that would have prevented the death of someone close to them and develop guilt over a death. Even older children, and indeed adults, often feel guilty when there is no logical, objective reason for them to feel responsible for a death. People may assume some responsibility because it helps them believe that, by taking actions they failed to take before, they can prevent the future deaths of others about whom they care deeply and feel more in control. For example, if a child assumes that the reason his father died was because he attended a friend’s party rather than staying home to monitor his father, he can reassure himself that his mother will be okay as long as he never leaves the home at night again. The alternative to this kind of thinking is accepting that we have limited influence over tragic events, but that reality leaves many feeling helpless. It is frightening to realize someone else we care about could die at any time, no matter what we do. But assuming fault for a death in this manner does not prevent future loss, and the resulting guilt contributes to further distress. In situations in which children’s actions clearly contributed to the cause of death (e.g., a child who accidentally discharges a firearm that results in the death of someone) or when children persist in feeling responsible (whether such guilt is logical), pediatricians should consider referral for counseling. In the context of ongoing support, children can be helped to either dismiss illogical guilt or come to forgive themselves for unintended actions they believe have contributed in some way to the death.

Children are also more likely to feel guilty about a death when the preexisting relationship with the deceased was ambivalent or conflicted. The relationship between adolescents and their parents often has some element of such ambivalence or conflict as the adolescent strives for independence, and conflict is more likely to be present if the deceased had a chronic mental or physical illness or problem with substance abuse or had been abusive, neglectful, or absent (e.g., incarcerated or deployed). Guilt of other family members may also lead to difficulties: for example, it can distort the relationships between parents and surviving children after the death of a sibling.²²

It is helpful for pediatricians to approach children who have lost a loved one to presume that guilt may be present, even when there is no logical reason for it. Pediatricians can explain that they know there is nothing that the child did, failed to do, or could have done to change the outcome but wonder if the child ever believes that he or she somehow contributed to the death as many children do in similar situations. They can explain that feeling bad does not mean you did anything bad and feeling guilty does not mean you are guilty. When pediatricians help children express their guilt associated with a death, it allows children to begin to challenge their faulty assumptions about personal responsibility and promotes a refocusing on the child’s feelings about the loss.

Children also may experience guilt over surviving after a sibling died or feeling relief after a death that followed a lengthy illness. In the setting of a protracted illness, family members and friends often experience anticipatory grieving. They can imagine the death and experience graduated feelings of loss, but when it becomes overwhelming they can reassure themselves that their loved one is still alive. Anticipating the death allows them to accomplish some of the “work” of grief before the death actually occurs. But this is a painful process, and at some point, many individuals in this situation will wish for the death to occur. Although they may couch this in terms of hoping for the person who is dying to be able to end his or her suffering, the death would also end some of their own emotional suffering as they anticipate the death of a loved one and free them of their responsibility to focus much of their time and efforts on the needs of the person who is critically ill. This situation can result in further guilt and complicate the grieving process.⁸

When children assume that the cause of the death was the result of the actions, inactions, or thoughts of the person who died, they may feel ashamed of the person who

...
died and/or the death and reluctant to talk with others about their loss. Shame is also likely to complicate bereavement when the death is somehow stigmatized, such as death from suicide or resulting from criminal activity or substance abuse. This shame further isolates grieving children from the support and assistance of concerned peers and adults.

Suicide is often complicated by both guilt and shame among survivors. As a result, discussion about the cause of death is often limited, and children may struggle to understand the cause or circumstances of the death. Open communication helps prevent suicide from becoming a "family secret," which may further disrupt the grieving process. If the explanations are too simplistic, concerns may be increased. For example, if children are told only, "Your uncle killed himself because he was very, very sad," they will likely notice that extended family members and friends, who are overwhelmed with grief, may look "very, very sad" and worry that they, too, will kill themselves. A preferable explanation might aim to convey that suicide is usually the result of underlying depression or other mental health problems; it may also be related to alcohol or other substance abuse. It is important to emphasize that suicide is not generally a logical "choice" made by someone who is thinking clearly and able to consider a range of solutions to problems. In addition, children should be encouraged to communicate when they are distressed or feeling depressed, informed about where they can go for advice and assistance, and instructed not to keep in confidence when peers or others communicate to them that they are considering self-harm. Sample scripts and language for discussing suicide with children at different developmental levels, prepared by the National Center for School Crisis and Bereavement, can be used by schools to respond to a death by suicide of a student or member of the school staff (freely available at www.schoolcrisiscenter.org).

**SECONDARY AND CUMULATIVE LOSSES**

Although children generally show a remarkable resiliency and ability to adjust to the death of someone close to them, nonetheless, they do not "get over" a death in 6 months or a year. Rather, they spend the rest of their life accommodating the absence. In fact, many find the second year more difficult than the first. The first year after the death is filled with many anticipated challenges: the first holiday or birthday without a loved one or the first father-daughter dance after the father's death. Expectations typically are reduced (ie, the child expects to feel sad at the first special holiday without a loved one), and multiple supports are usually in place. But when these special occasions are still not joyful in the second year, children may wonder if they will ever be able to experience joy again. Unfortunately, by this point in time, the support they may have received from extended family, teachers, coaches, and others at school and in the community has probably already ended. However, the sense of loss is persistent, and without proper support it may be perceived as overwhelming. Maintaining support for children and families is important well beyond the initial period of grief.

When children experience a death of someone close to them, they lose not only the person who died (ie, the primary loss) but also everything that person had contributed or would have contributed to their life (ie, secondary losses). Common secondary losses include the following:

- change in lifestyle (eg, altered financial status of the family after the death of a parent);
- relocation resulting in a change in school and peer group;
- less interaction with friends or relatives of the person who died (eg, friends of a child's sister no longer visit after the sister dies);
- loss of shared memories;
- decreased special attention (eg, a child may no longer value participating in sports activities without his parent there to cheer for him);
- decreased availability of the surviving parent (who may need to work more hours or who becomes less available emotionally because of depression); and
- a decreased sense of safety and trust in the world.

Relationships that seemed incidental may take on new meaning after they are no longer available. For example, after the death of his sister, a younger brother may now miss the advice and guidance provided by his sister's boyfriend, who no longer visits. Other losses may not become apparent until years later. A 5-year-old girl experiencing the death of her grandmother who was her primary caregiver may not realize until many years later that she has lost her grandmother's advice and support as she faces puberty or her first date, or on the first night her newborn infant cries inconsolably. At each new milestone, the loss of someone for whom we care deeply is redefined and grief is revisited.

When children experience a death at a young age, they may also not fully understand the death or its implications. Each new developmental stage, as cognitive development advances and experience widens, may prompt a resurfacing of their grief and be accompanied by questions that permit the child to come to a more mature understanding of the death and its implications.
Subsequent losses and stressors also add to the challenge of adaptation. Children who have experienced traumatic events or significant losses in the context of insufficient support and internal capacity to cope may experience posttraumatic growth and emerge with increased resiliency and new skills to cope with future adversity. These children may shift their life goals to align more with public service; place a higher priority on family, friends, spirituality, and helping others; or become more empathic. But in communities that are characterized by high rates of violence, poverty, and frequent deaths of peers and young family members, such supports are generally not present or are insufficient to meet the heightened need. Children in such environments do not somehow “get used to death” or become desensitized. Rather, these losses make them progressively more vulnerable to future stresses and loss. Children in these circumstances often come to appreciate that adults in their communities are unable to provide for their safety and are unwilling or unable to provide support and learn not to seek assistance from these adults because they know it is unlikely to be offered. One reason children and adolescents in these environments may instead turn to peers (and gangs) is to seek such support, which may contribute to high-risk behaviors that jeopardize their safety. They may engage in risky behaviors out of fear for their own mortality and the need to challenge these fears by engaging in the same behaviors they know to be dangerous. Only by surviving these risks can children and adolescents reassure themselves that they are safe, at least for the moment. In this context, it becomes critical that adults in our society take responsibility for ensuring that the environment is safe for children and adolescents, especially in communities characterized by violence, poverty, and frequent loss, and that we provide them with the support and assistance they need to cope with loss and crisis.

GRIEF TRIGGERS AND ANNIVERSARY REACTIONS

Grief triggers evoke sudden reminders of the person who died that can cause powerful emotional responses in children who are grieving. Although they are most common in the first few months after the death, they may happen months or years later, although the strength of the emotions generally lessens with time. Some triggers, such as a Mother’s Day activity in class or a father-daughter dance at school, are easier to identify, but grief triggers can be ubiquitous and often difficult to anticipate. A child may pass by a stranger wearing the same perfume as her aunt or hear a song that her grandfather used to sing and be reminded of the loss. Parents can work with teachers to both minimize likely triggers in school settings and create a “safety” plan wherein students know they can leave the classroom if necessary. If children know that they can leave if they need to, they are less likely to feel overwhelmed or afraid they will cry in class. As a result, they will rarely need to exit and are more able to remain within the classroom and engaged in the coursework.

Anniversaries of the death, birthdays of the deceased, holidays, special events, and major transitions (eg, changing schools, graduating high school, moving homes) are also times when a loved one’s absence will be acutely felt. Pediatricians can help the family find ways to meaningfully honor these events. The medical home is uniquely well suited to provide ongoing periodic bereavement support. Pediatricians should invite children and their families to reach out for assistance and advice as children adjust to the loss over time. However, many individuals who are grieving may not anticipate the challenges posed by anniversaries or events or may feel uncomfortable imposing on the physician for advice for what they believe to be a normative and universal experience. Pediatricians can, instead, schedule follow-up appointments to coincide with such timed events (eg, just before the start of a new school year; just before the first-year anniversary of the death), when modest changes in the timing make it practical, or can call, write, or e-mail a patient/family periodically to check in and let the child and family know of their continued availability and interest. Pediatricians interested in providing significant direct bereavement support for children and families within their practice can explore coding by time for counseling and coordination of care to maximize reimbursement for these services. When the pediatrician lets the family know he or she is still concerned and available, it increases the chances that the child or family will seek advice and assistance when needed.

FUNERAL ATTENDANCE

Children, like adults, often benefit from participating in funerals, wakes, and other memorial or commemorative activities after the death of a close family member or friend. It provides them with an opportunity to grieve in the presence of family and friends while receiving their support and, as appropriate to the family, solace from their spiritual beliefs. Parents and other caregivers sometimes exclude children from funerals and wakes for fear that the experience may be upsetting or because they, themselves, are grieving and unsure whether they can provide appropriate support. Children who are excluded from memorial or funeral services often resent not being able to participate in a meaningful activity involving
someone they care deeply about and may wonder what is so terrible that is being done to the loved one that it is not suitable for them to view. What they imagine is likely to be far worse than the reality.

It is best to invite children to participate in wakes, funerals, or memorial services, to the extent they wish. Begin by providing basic information in simple terms about what children can expect from the experience. For example, include information about whether there will be an open casket and anticipated cultural and religious rituals (eg, guests may be invited to place some dirt on the coffin at the gravesite), as well as how people may be expected to behave (eg, some people may be crying and very upset; humorous stories and memories may be shared). Ask children what additional information they would like and what questions they might have. Children should not be forced or coerced to participate in particular rituals or to attend the funeral or wake. If older children who had a very close relationship with the deceased (eg, teenagers whose parent has died) indicate they do not want to attend the funeral, it is helpful to explore the reason for their not wishing to attend and ask them to describe what accommodations might be made in the plans to meet their needs (eg, they prefer not to attend the wake but will attend the funeral service). But, as with all true invitations, the decision is ultimately left to the child. Families can work with children to identify alternate ways for them to recognize the death, such as a private visit to the funeral home once the casket has been closed or a visit to the gravesite after the burial. All children can be invited to make meaningful but developmentally appropriate decisions about the service of an immediate family member; they may be permitted to select a flower arrangement or a picture of the parent to be displayed at the wake.

It can be helpful to assign an adult whom the child knows well but who is not personally grieving (eg, a teacher, babysitter, or relative who is close to the child but less familiar with the deceased) to accompany and monitor the child throughout the services. If the child is fidgeting or appears distressed, the adult can suggest they go for a walk and inquire about how the child is coping with the experience. If the child prefers to stand outside of the room and hand out prayer cards, that level of participation can be accommodated without disrupting the experience for other grieving family members (ie, the child would be less able to stay outside of the room if being watched by the mother who feels it important to stand by her husband’s coffin throughout the wake). Older children and adolescents may wish to invite a close friend to sit with them during the service or assist with greeting guests as they approach the room. Suggestions on how to address the needs of children related to commemoration and memorialization involving a crisis, especially in a school setting, can be found elsewhere.11,13

CULTURAL SENSITIVITY

Different cultures have a range of traditional practices and rituals as well as expectations around how members of their culture typically mourn the death of a family member or close friend. Although it is helpful for pediatricians to know something about these cultural differences, it is important to remember that the fundamental experience of grief is universal.

Knowledge of the common practices of a particular culture may not accurately predict how a family or individual from that culture will behave. Many families have mixed backgrounds and/or have been exposed to different cultures through their communities or schools. Parents sometimes have different beliefs or practices from their children. Families or individuals may choose to follow practices of a different culture if they seem to align better with their current preferences. Assumptions about how someone ought to mourn in a particular culture may result in a stereotype that could cloud our perceptions and make us miss opportunities to be helpful. Pediatricians should therefore ask families what they feel would be most helpful for their family or for individuals within the family.

The best approach is to be present, authentic, and honest. Approach children and their families with an open mind and heart and be guided by what you see, hear, and feel. The following are questions that may assist in this process:

- “Can you tell me how your family and your culture recognize and cope with the death of a family member?”
- “How does this fit with your own preferences at this time?”
- “Can you help me understand how I can best be of help to you and your family?”

WORKING WITH SCHOOLS

Children typically experience at least temporary academic challenges after the death of a close friend or family member. The effect the loss has on learning may first appear weeks or even months later. Some children may even respond to a death by overachieving in school. Children with learning problems that predated the loss may experience a marked worsening.

In general, it is best for the family to anticipate at least brief difficulties in learning and concentration and to establish a proactive relationship with the school to coordinate...
supports at school with those within the home. If schools wait for academic failure to become apparent, then school becomes a source of additional distress rather than a potential support. Instead, academic expectations should be modified as needed and supports put into place in anticipation of a possible need.

Caregivers and educators can work together to identify the level of academic work that feels appropriate and achievable at a particular point of time in the recovery process after a major loss. Some modifications that may be considered include the following:

- adapting assignments (eg, allow a student to prepare a written presentation if he feels uncomfortable with an oral presentation; substitute smaller projects for a large project that may feel overwhelming in scope);
- changing the focus or timing of a lesson (eg, excuse the student from a lesson on substance abuse if her sister recently died of a drug overdose or consider postponing it to later in the semester);
- reducing and coordinating homework and extracurricular activities so that the student is able to meet expectations for what is being required; or
- modifying or excusing the student from tests or placing more weight on grades achieved before the death.

The goal is to maintain reasonable expectations while providing the support and accommodations so that the student can achieve at that level and be prepared for successful advancement to the next grade level.13

Pediatricians can help provide training to schools about how best to support grieving students and provide consultation after a death has occurred involving a member of the school community.11,13,25–27

The Coalition to Support Grieving Students was formed to develop a set of resources broadly approved by 10 of the leading professional organizations of school professionals to guide educators and other school personnel in supporting and caring for their grieving students. The resources are available at no charge to the public at www.grievingstudents.org. The video-training modules feature expert commentary, school professionals who share their observations and advice, and bereaved children and family members who offer their own perspective on living with loss. Handouts and reference materials oriented for classroom educators, principals/administrators, and student support personnel that summarize the training videos, as well as a range of additional resources, can be downloaded from the Web site. Although developed for use by educators, the materials are applicable for the professional development of pediatric health care providers as well. Many are also appropriate for other sites where child congregate care is provided, including early learning centers, preschools, and in-home day care settings. Those caring for children younger than school age similarly benefit from the support and training that can be provided by pediatricians.

**COMPLICATED MOURNING AND INDICATIONS FOR REFERRAL**

In the immediate aftermath of a death, the reactions of children and adults can be quite extreme and varied. It is best to avoid the tendency to judge or try to categorize such acute reactions as either “normal” or “abnormal.” If children or adults appear to be at risk of harming themselves or others, action should be immediately taken to preserve safety. Pediatricians should be aware of community resources for bereavement support. These resources may include the following:

- bereavement support groups and camps (a listing of national and regional services and resources for grieving children can be found at http://www.newyorklife.com/nyl/v/index.jsp?contentId=143564&vgnextoid=755540bf8c442310VgnVCM100000ac841cacRCRD);
- school-based programs and services;
- counselors who are interested and qualified in counseling children who are grieving; and
- other mental health professionals trained to counsel grieving children who are also experiencing depression, anxiety, or trauma symptoms.

As noted previously, adults in the family may benefit from their own support so that they do not depend unduly on their children for emotional support and so they are better able to discern and address the needs of their grieving children.

Grief from the death of a close family member or friend can dominate children’s lives in the immediate aftermath of the loss, causing disinterest in engaging in previously enjoyed activities, compromising peer relationships, interfering with the ability to concentrate and learn, causing regressive or risk-taking behavior, or creating a challenge to healthy social and emotional development. But with time and adequate support, grieving children learn that their lives in the absence of the deceased, although permanently altered, nonetheless can be meaningful and increasingly characterized by moments of satisfaction and joy. Children who instead experience complicated mourning may fail to show such adjustment over time.28 They may experience difficulty with daily functioning at school or at home that persists months after the death. They may become preoccupied with thoughts about the deceased or develop nonadaptive
behaviors, such as tobacco, alcohol, or other substance use; promiscuous sexual behavior; or delinquent or other risky behaviors. Referral for counseling is particularly important in this context. More immediate or urgent referral is indicated if children show deep or sustained sadness or depression, especially if they are perceived to be at risk of suicidal behavior.

**PROFESSIONAL PREPARATION AND SELF-CARE**

Pediatricians often enter the profession because of a desire to help children grow, develop, and be healthy and happy. Understandably, pediatricians can find it difficult to witness children's distress as they grieve the death of someone about whom they care deeply. Many pediatricians have received limited training about how to support grieving children. It is difficult to believe you are helping people when they remain in such distress. You want to help people feel "better," but when they freely express their sorrow in the immediate aftermath of a death, it is difficult to know that you are helping them ultimately adjust and cope. Following up with children and their families over time and actively inquiring about how they are continuing to adjust will help the pediatrician support and observe the course of recovery and understand his or her role in that process. Professional preparation and education are helpful; resources are available on various professional Web sites (eg, the American Academy of Pediatrics at www.aap.org/disasters/adjustment; the Coalition to Support Grieving Students at www.grievingstudents.org; or the National Center for School Crisis and Bereavement at www.schoolcrisiscenter.org). Pediatricians can also seek out and request professional development training through professional meetings, through grand rounds, from other continuing medical education venues, and via retreats and psychosocial rounds in hospital settings.

Children's grief may also trigger reminders of loss and other reactions in pediatricians. It may remind adults of their own losses or raise thoughts or concerns about the well-being of those they love. Children's grief is often unfiltered and pure; their questions are direct and poignant. It is difficult to witness a child's grief and not feel an effect personally. In fact, not being affected should not even be an expectation or a goal. Nonetheless, pediatricians should monitor their reactions and feelings and limit their support to what they feel ready and able to provide to any particular family at that point in time. If the family is in need of additional supportive services, the pediatrician can seek the assistance of a professional colleague in the office or through referral to someone in the community.

It is important for pediatricians to examine and understand their personal feelings about death to be effective in providing support to children who have experienced a personal loss or who are faced with their own impending death. Often, this understanding will involve an awareness of the effects of deaths of patients on pediatricians' professional and personal lives. The culture in medicine needs to acknowledge that it is understandable to feel upset when bearing witness to something that is upsetting. As professionals, pediatricians should offer support to our colleagues and seek out and accept support for ourselves.

Pediatricians who do provide support to grieving children and families often have a meaningful and lasting impact. A relatively modest effort to provide compassion and support can have a dramatic effect. It can help reduce the amount of time grieving children feel confused, isolated, and overwhelmed. Pediatricians will not be able to take away the pain and sorrow (and should not see that as their goal), but they can significantly reduce the suffering and minimize the negative effects of loss on children's lives and developmental courses.

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ASPECTS OF CHILD AND FAMILY HEALTH, DISASTER PREPAREDNESS
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