

For Pediatricians and Pediatric Nurses

Childhood Traumatic Grief Educational Materials

From the National Child Traumatic Stress Network Childhood Traumatic Grief Task Force Educational Materials Subcommittee

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Information for Pediatricians and Pediatric Nurses on Childhood Traumatic Grief

Introduction

This guide to childhood traumatic grief for pediatricians and pediatric nurses builds on the "In-Depth General Information Guide to Childhood Traumatic Grief" and "Brief Information on Childhood Traumatic Grief" and should be read in conjunction with them. Those guides provide essential material for understanding uncomplicated bereavement following a death, further background on childhood traumatic grief, and other reactions to trauma, and can be found at www.NCTSNet.org.

Medical professionals must work with a wide range of patients, many of whom have experienced traumatic loss. It is estimated that 25 percent of all children will face a significant traumatic event before the age of 16, many of which can involve the death of a person who was significant to them. The experience of a death from natural causes, such as cancer, can also prove to be traumatic for a child. Therefore, it is important to be able to recognize the signs of traumatic grief in children and know how to facilitate services for children and families in need.

Many patients are willing to seek help for physical complaints but reluctant to ask for psychological or emotional help. Pediatricians are in a unique position to discern the hidden need behind a child's presenting problem. This guide does not call on pediatricians or pediatric nurses to take on the responsibility of conducting therapy with children who have childhood traumatic grief, rather it is offered to help medical professionals who are often the first professionals to see a child in need of psychological help, and therefore in the best position to make referrals.

When working with children who have experienced traumatic losses, it is natural to experience strong personal reactions and feelings related to the child's loss. Medical personnel should monitor their own thoughts and feelings about the death and the child and family's experience and seek support or input from other staff when needed.

Not every child who experiences a loss will experience childhood traumatic grief. Many children will experience an appropriate grieving response and in time, with adequate support, will adjust to the loss of the loved one. In some cases however, children may experience enduring difficulties that interfere with their ability to function. Every child is different.

What Is Childhood Traumatic Grief?

Childhood traumatic grief is a condition that some children develop after the death of a close friend or family member. Children with childhood traumatic grief experience the cause of that death as horrifying or terrifying, whether the death was sudden and unexpected (for example, due to homicide, suicide, motor vehicle accident, drug overdose, natural disaster, war, terrorism, and so on) or due to natural causes (cancer, heart attack, and so forth). Even if the manner of death does not appear to others to be sudden, shocking, or frightening, children who perceive the death in this way may develop childhood traumatic grief.

In this condition, even happy thoughts and memories of the deceased person remind children of the traumatic way in which the deceased died. A younger child may be afraid to sleep alone at night because of nightmares about a shooting that she witnessed, while an older child may avoid playing on the school baseball team his father used to coach because it brings up painful thoughts about how his father died in a terrible car accident. These children get "stuck" on the traumatic aspects of the death, and cannot proceed through the normal

bereavement process. It is important to note that not all children who lose a loved one in traumatic circumstances develop childhood traumatic grief. Many experience normal grief reactions. Additional research is needed to identify risk factors for developing childhood traumatic grief.

Symptoms of Childhood Traumatic Grief that Impact Physical Health

Childhood traumatic grief can have a significant impact on children's physical health as well as on their psychological and emotional functioning. Medical professionals may encounter children who have a variety of physical symptoms. Children with this condition are at risk for and may exhibit the following complaints:

- Somatic symptoms severe enough to warrant sick-child pediatric visits
- Presentation of new somatic symptoms with no clear underlying medical cause
- Presentation of symptoms that mimic the deceased person's cause of death
- Significant worsening of existing chronic medical conditions (diabetes, asthma, and so forth)
- Noncompliance or decreased compliance with usual medication regimens
- Depressed affect, changes in behavior, and other psychiatric symptoms
- Self-injurious or suicidal behaviors

Guidance for Assessing Children with Childhood Traumatic Grief

Children with childhood traumatic grief often avoid talking about death or the person who died. In order to determine if traumatic grief underlies or is contributing to a child's presenting complaints, pediatric providers should consider the following:

- Routinely asking parents and caregivers if their children have experienced any deaths or traumatic
 events since their last visit
- Checking in with children directly about how they have been doing and if anything unusual has happened since their last visit
- Following-up with children and families known to have experienced a death in their recent experience, or with children who are approaching an anniversary or reminder of that loss
- Paying particular attention to children who have experienced other traumas in addition to the loss of a loved one, because exposure to other trauma (violence, abuse, accidents, disasters, terrorism, war, or others) may worsen traumatic grief symptoms
- Inquiring about adjustment to deaths that are seemingly long past, because grief reactions sometimes surface at later points in life

Do not hesitate to ask children directly about their experiences with trauma or the death of a loved one. Not asking may inadvertently communicate to the child that it is unacceptable to discuss these things with adults. If your questions make the child's symptoms worse, this may be a sign that professional help is warranted. Pediatric providers are often in the best position to ask children about trauma and death because your patients already have a trusting relationship with you.

In some cases, it may be helpful to ask the parent to step out of the room during these conversations, because children with traumatic grief are often overly concerned with not causing their parents any additional emotional distress and may deny symptoms in a parent's presence to avoid worrying them.

What to Do if You Think Your Patient Is Experiencing Childhood Traumatic Grief

For children

- Ask the child about the symptoms noted above in a sympathetic, nonjudgmental way.
- Assure the child that many children experience similar reactions following the traumatic death of a loved one.
- Use the above guidelines to assess the symptoms of childhood traumatic grief and provide appropriate support and referral if warranted.
- Be sensitive, when treating the child for other conditions, when doing invasive medical procedures or examinations that may somehow remind the child of previous traumatic experiences.
- Adjust medical appointments, procedures, and treatment recommendations in consideration of the way childhood traumatic grief impacts physical illness and treatment compliance.
- For children that are demonstrating treatment compliance issues, it is best to address these issues
 directly with the child and parent. If barriers to compliance persist, it is likely that a mental health
 consultation is warranted to provide support to the child and family.

For parents

- Keep materials on hand to educate parents about childhood traumatic grief. Parents rely on pediatric providers for accurate information about childhood disorders, and you may be the first person to recognize that the child has this condition.
- Try to reassure parents that reactions to a traumatic loss are normal, but when these reactions begin to interfere with a child's ability to function on a day-to-day basis, it is time to seek help.
- Explain that it is often best for parents to be involved in treatment to address their own reactions as well as learn how best to help their child.

For both child and parent

- Discuss making a referral for specialized treatment with both the child and parent.
- Refer the child to a mental health professional, ideally one who has experience in treating
 - o children with emotional difficulties
 - o childhood traumatic stress, and
 - o childhood grief and loss.
- Encourage parents of these children to call you if additional symptoms or other concerns arise, or if they have difficulty in arranging mental health follow-up.
- Reassure children and parents that these problems can be successfully treated and children can recover with appropriate help.

Where to Go for Additional Information and Help

Effective treatments are available for childhood traumatic grief, and children can return to their normal functioning. Additional information for parents and professionals about this condition and where to turn for help is available from the National Child Traumatic Stress Network at (310) 235-2633 and (919) 682-1552 or www.NCTSNet.org.



In-Depth General Information Guide to Childhood Traumatic Grief

Introduction

This guide presents an overview of childhood traumatic grief, a condition that can affect children's development, relationships, achievement, and later effectiveness in life if not treated or otherwise resolved. We begin by describing normal grief and the grieving process and then define psychological trauma and describe how traumatic experiences can affect children. We explain the differences between normal or uncomplicated grief and childhood traumatic grief. Finally, we present an understanding of what happens when a child experiences the death of another and reacts in ways that interfere with the intense normal course of grieving and present ongoing difficulties. The information will be useful for medical and psychological professionals, parents, caregivers, educators, and others working with children who are experiencing intense grief responses.

The child's perception, rather than the cause of death, plays the key role in determining the development of symptoms following the death of a significant person. Not every child develops traumatic grief after a death that happened in a particularly dramatic or threatening manner. On the other hand, some children may experience what most of us would consider an expected and normal death of another person as a traumatic event.

Because research and information about this special condition is still evolving, we do not yet know which children are most at risk for developing childhood traumatic grief. Signs that a child or adolescent is having difficulty coping with the death may be noticeable in the first few months, or may not be apparent until one or more years later. What we do know is that there are effective treatments for children experiencing childhood traumatic grief and that it is most important to recognize its signs and symptoms.

What Do We Mean by Grief?

Grief describes the intense emotional distress we have following a death. *Bereavement* refers to the state or fact of being bereaved, or having lost a loved one by death. *Mourning* refers to the encompassing family, social, and cultural rituals associated with bereavement. Thus, when you are bereaved, you feel grief, and mourn in special ways.

What Is the Typical Grieving Process?

There is no right or wrong way to grieve or "appropriate" length of time to experience grief following the death of a loved one. The process can vary from child to child and may change as the child grows older. Issues and questions may arise as children have new experiences and face new challenges that may remind them of an earlier loss. A toddler may have new questions about how his brother died when he reaches school age, a teenage son may miss his father when he learns how to drive, or a daughter may feel a new sense of longing on her wedding day for a mother who died when she was a preteen. With each new developmental challenge,

children are likely to experience their loss in new ways. Throughout their life, children continue to adjust to the loss and develop new ways of coping. Over time, it is helpful if children can relate to their loss in the following ways:

- Accept the reality and permanence of the death.
- Experience and cope with the painful emotional reactions to the death, such as sadness, anger, resentment, confusion, and guilt.
- Adjust to changes in their lives and identity that result from the death.
- Develop new relationships or deepen existing relationships to help them cope with the difficulties and loneliness that may have resulted from the death.
- Maintain a continuing, healthy attachment to the person by reminiscing, remembering, modeling behaviors, and maintaining a memorial.
- Make meaning of the death, a process that can include beginning to understand why the person died and what significance the loss has for the living.
- Continue through the normal developmental stages of childhood and adolescence.

What Is Common Following a Death?

Any death can be difficult for a child, and certain reactions are common. Children's difficulties with grief vary according to a child's age, developmental level, previous life experiences, emotional health before the death, and family and social environment. An uncomplicated bereavement response may include the following:

- Emotional reactions: feeling sad, angry, anxious, numb, lonely, guilty, powerless, ashamed, insecure, and remorseful
- Changes in behaviors: lack of interest and participation in usual activities, diminished self-care, unpredictable or odd behaviors, angry or aggressive behaviors, irritability and conflict with others, impulsivity, regression to more childlike or infantile behaviors, changes in sleeping patterns (such as increased sleep), difficulty sleeping or not being able to sleep alone, changes in appetite resulting in weight gain or loss, and changes in overall physical health
- Interpersonal interactions: withdrawal, social isolation, peer difficulties, clinging, irritability, difficulty sharing memories, difficultly participating in group or athletic activities, and general lack of interest in others
- Changes in thinking: constant thoughts and memories about the loved one, persistent thoughts about the death, disbelief about the death and the finality of death, constant or intrusive thoughts about death, preoccupation with one's own or another loved one's physical health, difficulty making decisions, confusion, impaired memory and concentration, lowered self-esteem and self-confidence, disillusionment, thinking that the death was one's fault, and survivor guilt
- Altered perceptions: believing the deceased is still present, feeling the person's presence nearby or
 watching over the living, seeing the person's face in a crowd, smelling the person's perfume, hearing
 the person's voice, and experiencing vivid dreams about the person

- Physical reactions: susceptibility to illness, loss of energy, fatigue, difficulty or changes in eating, physical complaints, and changes in physiological arousal (for example, increased heart rate, respiration, and startle response)
- Changes in academic functioning: poor school performance, difficulty studying or concentrating, and
 potential school failure

What Is Trauma, and How Do Children and Adolescents Respond to It?

Traumatic events can involve an actual death, other loss, serious injury, or threat to the child's well-being. These events could include natural or man-made disasters, interpersonal violence, car accidents, war, or terrorist acts, among many other possibilities. A child may be traumatized by directly experiencing or witnessing a traumatic event or by hearing about another person's experience with such an event. Children respond to trauma in different ways, and their responses can change over time. In the immediate aftermath of a traumatic event, children may experience feelings of terror, intense fear, horror, helplessness, lack of control, and physical stress reactions such as a rapidly beating heart or shakiness. Intense feelings such as fear and helplessness are likely to be experienced in the first weeks following a traumatic event or after repeated exposure, such as in child abuse. These acute responses can be disruptive to the child's functioning but may go away naturally over time.

For some children and adolescents, responses to traumatic events can have a profound effect on the way they see themselves and their world. These children may experience important and long-lasting changes in their ability to trust others, their sense of personal safety, their effectiveness in navigating life challenges, and their belief that there is justice or fairness in life. Traumatized children may develop changes in behavior that are often referred to as externalizing problems or acting out. They may become involved in fights or other conflicts with peers, have difficulty interacting with authority figures, become socially isolated or withdrawn, develop poor school attendance, and begin using illicit substances. They may also experience changes in their emotional and psychological functioning, referred to as internalizing problems, such as depression or anxiety. These internal changes may be more difficult for others to detect than external changes but can still cause significant impairment in functioning.

What Is Posttraumatic Stress Disorder?

In some cases, the difficulties resulting from exposure to trauma persist over time and can result in what is called Posttraumatic Stress Disorder (PTSD). PTSD is diagnosed when the child has specific symptoms that continue for a month or more following exposure to a traumatic event. Not all children exposed to a trauma will develop PTSD, and for some children PTSD symptoms will lessen naturally over time. However, children who experience the disorder often have a variety of symptoms that can significantly impact their day-to-day functioning. These symptoms fall into the following general categories:

- Re-experiencing: recurrent upsetting thoughts about the event, repeated distressing nightmares, or repetitive play in young children
- Hyperarousal: nervous, jumpy, or agitated behavior, irritability or anger, and hypervigilance or increased startle reaction
- Avoidance: avoiding thoughts, feelings, or places that remind the child of the trauma, withdrawing, becoming disinterested in activities, or developing emotional distance

If left untreated, PTSD can lead to more serious difficulties over time. PTSD has been linked to adult depression, substance abuse, eating disorders, and other psychiatric difficulties. If a child shows symptoms of PTSD, it is important that he or she be evaluated, and consultation with a qualified mental health professional is encouraged.

What Is Childhood Traumatic Grief?

Childhood traumatic grief may occur following the death of a loved one when the child perceives the experience as traumatic. The death may have been sudden and unexpected, or it may have been an anticipated death due to illness or other natural causes. Childhood traumatic grief is distinct from the normal bereavement process and PTSD, but it shares features of both. The distinguishing feature of childhood traumatic grief is that trauma symptoms interfere with the child's ability to navigate the typical bereavement process. A mental health professional with experience in childhood traumatic grief may be needed to distinguish between the sometimes overlapping symptoms of uncomplicated bereavement and traumatic grief. Children may show different signs of childhood traumatic grief at different ages. However, difficulties specific to childhood traumatic grief that commonly occur across developmental stages include the following:

- *Intrusive memories about the death*: These can appear through nightmares, guilt, or self-blame about how the person died or recurrent or intrusive thoughts about the horrifying manner of death.
- **Avoidance and numbing:** These can be expressed by withdrawal, the child acting as if not upset, or the child avoiding reminders of the person, the way she or he died, or the event that led to the death.
- Physical or emotional symptoms of increased arousal: These can include irritability, anger, trouble sleeping, decreased concentration, drop in grades, stomachaches, headaches, increased vigilance, and fears about safety for oneself or others.

In childhood traumatic grief, the interaction of traumatic and grief symptoms is such that any thoughts or reminders, even happy ones, about the person who died can lead to frightening thoughts, images, or memories of how the person died. Three types of reminders may trigger them:

- **Trauma reminders:** places, situations, people, sights, smells, or sounds reminiscent of the death. These may include the street corner where a fatal accident occurred, the bedroom where a parent died, or the sound of an airplane reminding a child of a mother who died in a crash.
- Loss reminders: people, places, objects, situations, thoughts, or memories that are reminders of the
 person who died—for example, photo albums or a new coach who has replaced a parent who
 previously headed a child's sports team.
- **Change reminders:** situations, people, places, or things reminding the child of changes in his or her life resulting from the death—for example, moving to a new house or having to walk home with a babysitter rather than with an older sibling who died.

These reminders may lead to the child re-experiencing the traumatic events that led to the death. The terror associated with these memories results in hyperarousal symptoms. The child then attempts to handle the distressing re-experiencing and hyperarousal symptoms through the use of avoidance or emotional numbing. Because traumatic aspects of the death are so upsetting, the child tries to avoid all reminders of the trauma, loss, or resulting changes so as not to stir up unpleasant thoughts or feelings.

For example, a younger child may be afraid to sleep alone at night because of nightmares about a tragic shooting, whereas an older child may avoid flying in a plane because it brings up painful memories about a father who died in a plane crash. Hence, the traumatic reactions make it difficult for children to:

- remember or enjoy positive memories of the deceased person,
- cope with the many life changes that occur as a result of the death, and
- continue with normal development.

What Additional Challenges Increase the Risk of Childhood Traumatic Grief? (Secondary Adversities)

Secondary adversities refer to related challenges, difficulties, and stressors that follow from the death or traumatic experience. Although the study of childhood traumatic grief is in its infancy, some evidence suggests that bereaved children who experience additional life adversities that result from the death, or who are already facing difficult life circumstances, are especially at risk for experiencing traumatic grief reactions. For example, following their father's fatal heart attack, children who must move due to changed financial resources are forced to contend not only with the ongoing absence of their father but also with disruptions and changes in their home environment and social network. A child who witnessed her mother's murder by her father may face a spectrum of severe secondary adversities, such as participation in legal proceedings, intrusive questions by peers, or placement in the home of relatives.

Example of a Child with Traumatic Grief

Five months after a ten-year-old boy's father was killed in a car accident, he began waking up in the middle of the night in fright and spending the remainder of the night in his mother's bed. He was difficult to arouse in the morning and had trouble leaving the house for school. His grades began to slip, and he was uncooperative with the tutor his mother had obtained. He also refused to drive with anyone except his mother, creating a burden for her and making it difficult for him to go on outings with friends. He refused to allow his mother to display pictures of his father in the house. In this example, the boy would at first glance be fearful of separation from his mother. However, on further assessment it became clear that he was having nightmares in which he saw speeding cars and heard cars screeching. He also experienced panic in any car other than his mother's. Before his father's death, he and his father had begun working together on his science homework, creating various experiments and projects. This was the last thing they did together before his father left the house the night of the accident. Thus the boy became upset whenever he had to do his schoolwork with someone other than his father, as it led to reminders of the last time he saw his father before the crash. His functioning at home, at school, and with friends was suffering from the intrusion of such traumatic symptoms, and he was unable to have happy memories of his father without thinking about the night of his death.

This boy is displaying several classic features of childhood traumatic grief. Rather than finding comfort from memories of his father, he is avoiding such memories because for him they trigger memories of the traumatic way his father died. He also avoids activities that are important to his ongoing development—such as doing homework and riding in friends' cars—because these also trigger traumatic memories. He is unable to work through the loss of his father and the pain associated with missing him, because he cannot tolerate any reminders of him, even seeing his picture. Thus, this boy is "stuck" due to the impingement of trauma symptoms on his ability to tolerate memories of his father and accomplish the tasks of normal grieving.

How Is Childhood Traumatic Grief Treated?

Fortunately, children experiencing childhood traumatic grief recover with appropriate help. Consultation with a qualified mental health professional is encouraged. Ideally, this professional should have experience working with children and adolescents and specifically with issues of grief and trauma. Treatment itself should address both the trauma and grief symptoms. In learning how to manage the trauma-related reactions, a child becomes better able to reminisce productively about the person.

Several treatment manuals have been developed by the NCTSN Childhood Traumatic Grief Task Force for treating this condition at different developmental stages. In general, all of these treatments incorporate components of evidence based treatments for trauma symptoms. These include affective regulation, stress management, and cognitive reprocessing skills, as well as encouraging the child to tolerate increasingly more detailed memories of the traumatic event that led to the death through the creation of a trauma narrative. These interventions also include grief-focused treatment components, such as acknowledging what has been lost in the relationship, exploring "unfinished business" with the deceased, memorializing the person who has died, and committing to other relationships in the present. Treatments for children and younger adolescents

include parents in treatment, while adolescent treatment is often provided in a group format. It is important for the caregiver to process and work on personal trauma and grief issues in order to best help a child. More information about these treatment models is available at NCTSNnet.org.

Further information about these topics, additional fact sheets, resources, and assistance in locating appropriate treatment is available from the National Child Traumatic Stress Network (NCTSN) at (310) 235-2633 and (919) 682-1552 and at the National Child Traumatic Stress Network Web site, www.NCTSNet.org.

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Brief Information on Childhood Traumatic Grief

What Is Childhood Traumatic Grief?

This brief information guide to Childhood Traumatic Grief summarizes some of the material from the "In-Depth General Information Guide to Childhood Traumatic Grief," which can be found at www.NCTSNet.org.

- Childhood traumatic grief is a condition that some children develop after the death of a close friend or family member.
- Children with childhood traumatic grief experience the cause of that death as horrifying or terrifying, whether the death was sudden and unexpected or due to natural causes.
- The distinguishing feature of childhood traumatic grief is that trauma symptoms interfere with the child's ability to work through the typical bereavement process.
- In this condition, even happy thoughts and memories of the deceased person remind children of the traumatic way in which they perceive the death of the person close to them.
- The child may have intrusive memories about the death that are shown by nightmares, feeling guilty, self-blame, or thoughts about the horrible way the person died.
- These children may show signs of avoidance and numbing such as withdrawal, acting as if not upset, and avoiding reminders of the person, the way the person died, or the event that led to the death.
- They may show physical or emotional symptoms of increased arousal such as irritability, anger, trouble sleeping, decreased concentration, drop in grades, stomachaches, headaches, increased vigilance, and fears about safety for oneself or others.
- These symptoms may be more or less common at different developmental stages.
- Left unresolved, this condition could lead to more serious difficulties over time.
- Not all children who lose a loved one in traumatic circumstances develop childhood traumatic grief;
 many experience normal grief reactions.

What Is Normal Grief?

In both normal childhood grief (also called *uncomplicated bereavement*) and childhood traumatic grief, children typically feel very sad and may have sleep problems, loss of appetite, and decreased interest in family and friends.

In both normal and traumatic grief, they may develop temporary physical complaints or they may regress, returning to behaviors they had previously outgrown, like bed wetting, thumb sucking, or clinging to parents.

Both groups of children may be irritable or withdrawn, have trouble concentrating, and be preoccupied with death.

Children experiencing normal grief reactions engage in activities that help them adapt to life. Through the normal grief process children are typically able to:

- Accept the reality and permanence of the death
- Experience and cope with painful reactions to the death, such as sadness, anger, resentment, confusion, and guilt
- Adjust to changes in their lives and identity that result from the death
- Develop new relationships or deepen existing relationships to help them cope with the difficulties and loneliness that may have resulted from the death
- Invest in new relationships and life-affirming activities as a means of moving forward without the person being physically present
- Maintain a continuing, appropriate attachment to the person who died through such activities as reminiscing, remembering, and memorializing
- Make meaning of the death, a process that can include coming to an understanding of why the person died
- Continue through the normal developmental stages of childhood and adolescence

What Additional Challenges Increase the Risk of Childhood Traumatic Grief? (Secondary Adversities)

Some evidence suggests that bereaved children who experience additional challenges related to the death—called secondary adversities—or who are already facing difficult life circumstances are at risk for experiencing traumatic grief. For example, a child who must move after the death of a father must contend with both the absence of a parent and disruption of a social network. A child who witnessed the murder of her mother may face an array of severe additional adversities, such as participation in legal proceedings and facing intrusive questions from peers. Children whose lives are already very complicated and filled with challenges and adversities may be particularly susceptible to developing traumatic grief reactions.

What to Do for Childhood Traumatic Grief

Children with childhood traumatic grief often try to avoid talking about the deceased person or their feelings about the death, but talking about it may be important for resolving trauma symptoms that are interfering with the child's ability to grieve. If symptoms similar to those listed on this sheet persist, professional help may be needed. The professional should have experience working with children and adolescents and specifically with issues of grief and trauma. Treatment itself should address both the trauma of the death and grief symptoms. Effective treatments *are* available, and children can return to their normal functioning. If you do not know where to turn, talking to your child's pediatrician or a mental health professional may be an important first step. They should be able to provide you with a referral to a mental health professional who specializes in working with children and adolescents experiencing traumatic grief reactions.

Additional information is available from the National Child Traumatic Stress Network at (310) 235-2633 and (919) 682-1552 or www.NCTSNet.org.