Pediatricians can play important role after a child's sudden unexplained death
by Erin Bowen M.D., FAAP

When my 17-month-old son, Conor, woke up with a fever of 102, I was not concerned. As a pediatrician, I had counseled countless parents about fever as the body's healthy response to illness.

Conor was well-appearing and within two hours of receiving ibuprofen, he was afebrile and happily playing with his older sister. He went down for a nap, and less than an hour later, my husband found him unresponsive. When Conor died, we were left with endless questions, and there was nothing in my medical education that prepared me for answering those questions.

After a thorough investigation, Conor's cause of death could not be determined. In our search for answers, we learned about SUDC, sudden unexplained death in childhood, which is the sudden and unexpected death of a child 12 months of age or older that remains unexplained after a thorough investigation including autopsy.

SUDC affects approximately 400 children annually, according to the Centers for Disease Control and Prevention. It is the fifth leading category of death in children ages 1-4, yet there is limited medical awareness of it and no targeted federal funding to support research. The SUDC Foundation is the only organization worldwide whose purpose is to promote awareness, advocate for research and support those affected.

As we connected with other families through the SUDC Foundation, we realized we were not alone. There were striking similarities in our stories. However, we were struck by the variability in how our children's deaths were investigated and the care we received afterward.

Recognizing the need for consistency in approaching sudden unexplained pediatric deaths, the SUDC Foundation funded a grant for a collaboration between the National Association of Medical Examiners and the AAP. An expert panel of more than 30 multidisciplinary contributors published the first national consensus guidelines for the investigation, death certification and care of families following sudden pediatric deaths (see resources). Following are some of the recommendations applicable to pediatricians:

- After the sudden, unexpected death of a child, numerous professionals enter families' lives, including first responders, law enforcement, emergency department physicians and nurses, social workers and child protection agencies. Pediatricians can serve as a liaison between professionals during this overwhelming time.
- Professionals should maintain a non-accusatory approach to prevent further trauma.
- Hospitals should establish trauma-informed protocols in conjunction with their medicolegal death investigator and establish a single point of contact for families.
- Families should have the opportunity to see and hold the child in supervised conditions. Memorial keepsakes should be offered (e.g., handprints, footprints, lock of hair).
- Offer a face-to-face meeting with the family within two weeks to assess for grief response and address mental health and medical screening and/or referrals.
- Maintain communication, recognizing that grief is not linear and the family's needs may change over time.
- Refer families to the SUDC Foundation early. Even if the cause of death is explained later, the SUDC...
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Foundation can provide resources.

- Be aware of the local medicolegal death investigation system and provide the family with a realistic timeline and contact information.
- Act as a liaison between the medical examiner's office and family. If desired by the family, help set up a conference after the autopsy is complete.
- Ensure adequate support of siblings, who often are "forgotten mourners" as they grieve the loss of their sibling and the loss of their parent to the grieving process. Screen at annual physicals and around possible trigger times, such as anniversary of the death or their sibling's birthday. Provide age-appropriate resources, including recommendations for books, strategies for parents on how to discuss death with their children and referrals for sibling support groups and mental health specialists.
- Approach the care of siblings with sensitivity for the family's unique needs, recognizing the parents may fear that their surviving and subsequent children will die. Balance the need for providing compassionate care with not overmedicalizing these children. Medical referrals for siblings will vary but may include cardiology, genetics and neurology.
- Refer families for research opportunities such as the SUDC Registry and Research Collaborative, which provides a case review by a multidisciplinary team, including neuroimaging, neuropathology and whole exome sequencing of both biologic parents and the deceased child, at no charge to families.

The national consensus guidelines represent an important step toward understanding sudden unexplained pediatric deaths. A standardized approach to death certification and investigation will lead to better surveillance, more accurate data and hopefully, prevention strategies.

March is SUDC Awareness Month. While SUDC is unpredictable and unpreventable, we can ensure that we adequately support families after these tragedies. Educate yourself and fellow medical professionals about SUDC. Increased awareness can foster future research and ultimately may lead to prevention of these deaths.

*Dr. Bowen is a pediatrician in private practice in Connecticut. She is vice president of the SUDC Foundation and a member of the Panel on Sudden Unexpected Death in Pediatrics, which authored the consensus guidelines. She also is a member of the AAP Section on Child Death Review and Prevention.*

**Resources**

- [SUDC Foundation](#)
- Learn more about the national consensus guidelines published in *Unexplained Pediatric Deaths: Investigation, Certification and Family Needs.*