

SUMMARY OF NEW NATIONAL CONSENSUS GUIDELINES APPLICABLE TO PEDIATRICIANS

- ✦ After the sudden and unexpected death of a child, there are a multitude of medical professionals who enter the families' lives, including first responders, law enforcement, emergency department physicians, nurses, social workers, child protection agencies, and pediatricians. The family's pediatrician is often the one professional who has a pre-existing relationship and who should serve as a liaison between professionals during this overwhelming time.
- ✦ Professionals should maintain unbiased nonaccusatory communication to prevent further trauma.
- ✦ Hospitals should establish trauma-informed protocols in conjunction with their local medicolegal death investigator.
- ✦ When permitted by death investigation officials, families should have the opportunity to see and hold the child in supervised conditions. There have been studies showing that in situations wherein parents were unable to hold their child, there were heightened grief and trauma responses, with effects lasting for years afterward.²
- ✦ Memorial keepsakes should be offered to families (handprints/footprints/lock of hair).
- ✦ Open and timely communication with a single point of contact is recommended to foster positive long-term bereavement outcomes.
- ✦ Offer a face-to-face meeting with the family within 2 weeks to assess for grief response and to address necessary mental health and medical screening and/or referrals. Maintain ongoing communication, recognizing that grief is not linear and the families' needs may change over time.
- ✦ Refer families to the SUDC Foundation early if there has been a sudden and unexpected death of a child. Even if the cause of death later becomes explained, the SUDC Foundation provides services to all families of unexpected deaths in childhood.
- ✦ Be aware of the local medicolegal death investigation system and be prepared to provide the family with a realistic timeline and contact information.
- ✦ Act as a liaison between the medicolegal death investigator and the family, providing updates and establishing a conference once the investigation is complete to assist with communication of the results.
- ✦ Ensure adequate screening and support of siblings, who often are referred to as the "forgotten mourners" as they grieve the direct loss of their sibling and the indirect emotional loss of their parents to the grieving process. Screen siblings at annual physicals, as well as around possible trigger times, such as the 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 surviving child or children, referrals for sibling support groups, and, when necessary, mental health referrals.
- ✦ Approach the care of siblings with sensitivity for the families' unique needs, recognizing that parents may fear for the health of their surviving and subsequent children. Balance the need for providing compassionate care with not overmedicalizing these children.
- ✦ Medical referrals for the siblings will vary, but may include cardiology, genetics, neurology, and others as clinically indicated. Cardiac referral is recommended for all first-degree relatives of sudden unexpected death, regardless of age. Genetic testing may be complicated by financial limitations of the medicolegal death investigation system and/or the family. In these circumstances, research opportunities may be beneficial for families to seek further answers.
- ✦ Refer families for research opportunities such as the SUDC Registry and Research Collaborative (SUDCRRC), which provides a thorough 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: sudc.org/research-medical-info/sudc-registry-research-collaborative
- ✦ Multidisciplinary case reviews of child fatalities should be utilized for public health research and advocacy.
- ✦ Home visits should be considered to assess families' needs and to facilitate support and provide them with resources.
- ✦ Medical professionals should seek appropriate self-care.
- ✦ Education of medical professionals should provide specific training around death communication.