

Guidelines for Interacting with Families

(highlighted areas indicate professionals involved)

Best Practices and Applicable Guidelines	EMS	LE	MDI	ED	PC	CPS	FH	OPO	PH	OB/ GYN	Genetics	72h	After 72h
No two individuals grieve alike. Sensitivity and respect for cultural, religious, and individual preferences should be pursued and accommodated to the extent that the investigation allows (1-13).												X	X
The healthcare team provides personal, compassionate, and individualized support to families while respecting social, spiritual, and cultural diversity (1-9, 11-13).												X	X
Refer to the child by their name (6, 10, 11).												X	X
Extend condolences (14).												X	X
Explain your role and that your goal is to help in this tragic situation. Provide contact information in writing. Explain the policies in the local jurisdiction that justify your role. Explain that this role is mandatory for all child deaths and that questions and procedures are not meant to be accusatory but rather to assist in determining how and why the child died (10, 11, 14-16).												X	X
Provide information in multiple formats (i.e., verbally, brochure, and website) on the basic death investigation process, including why it is necessary and required. Keep the language as simple as possible. Anticipate questions in advance. If a significant segment of your population is non-English speaking, offering similar brochures in commonly spoken languages for your area is appropriate. Access to non-family translators, including sign language for deaf families, should be available (1-13, 17-19).												X	X
Provide next of kin with reasonable expectations. Convey what is known and not known, including time frames (if known), what may occur, how they will find out the cause of death, and who they can contact if they have questions (6, 10, 11, 17-19).												X	X
Provide information on resources available to the next of kin to assist them in their grief early in investigation. Provide care for the bereaved members of the patient's family that may include information and arrangements for bereavement care services, and follow-up with family to address any concerns or questions (1-3, 6, 11-13, 20).												X	X
Provide information on choosing a funeral home, burial options, and financial assistance if appropriate. Provide written resources for bereavement, burial services and assistance, as well as any local support services available after death of an infant/child. Recognize that if the family does not have a medical home, the emergency department may need to assume the role of assessment and referrals for ongoing needs.												X	X
Maintain an unbiased, nonaccusatory sensitive approach to parents during the investigation. Irrespective of whether there are concerns about criminal intent, there should be a respect for privacy, dignity, and comfort for families of deceased infants and children.												X	X

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Do not speculate on the cause of death. This biases the investigation and can undermine the medical examiner/coroner's relationship with the family once the final cause of death is determined.												X	X
Observe the surroundings of the scene where the infant/child was found unresponsive and communicate findings to investigators. (See Chapter 4 for more information).												X	
Explain parental rights after sudden child death.												X	X
Ensure safety of other children in the home while avoiding adding additional trauma to the event. Dedicate an officer, chaplain, or victim advocate to sit and play with surviving children away from the active investigation and out of sight of their deceased sibling.												X	
If desired by families, allow families to observe resuscitative efforts and when discontinued, explain rationale in clear and simple terms. Have a single staff member available to be present with family members during resuscitation to answer questions and provide support (6; 21).												X	
When permissible to medical death investigators: allow the next of kin, when they desire it, to be with the child's body for even a short time, with supervision, for goodbye rituals that contribute to a healthy grieving process. Families should be aware and counseled on the need/rationale for investigation protocols (6, 10, 11, 22, 22-24).												X	
The health care team clarifies with the family the child's medical home and promptly notifies the child's primary care provider and appropriate subspecialty providers of the death and, as appropriate, coordinates with the medical home and primary care provider in follow-up of any postmortem examination (4, 6, 9, 11, 15).												X	
Identification and notification of medical examiner/coroner regarding all deaths, as directed by applicable law. Routinely offer postmortem autopsy to families for all nonmedical examiner/coroner cases (6, 11).												X	
The ED health care team uses a patient-centered, family-focused, and team-oriented approach when a child dies in the prehospital or ED setting (6, 11, 14, 25, 26).												X	X
Offer to contact additional family members to be present with family for support.												X	
Hospitals and MDI agencies should establish a single point of contact – for example, a “Decedent Affairs Officer” or, where resources allow, an “Office of Decedent Affairs” – to coordinate communication between hospital personnel with an interest in the case (attending physicians, hospital pathologists, hospital quality committees, risk managers, etc.) and the medical examiner. The same point of contact should coordinate communication between hospital personnel and next of kin. The hospital's point of contact should be identified in all communications sent to the medical examiner and next of kin (25, 27, 27-29).												X	X

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EMS personnel, attending physicians, and other hospital personnel with knowledge of the circumstances surrounding the death should make reasonable efforts to make themselves available to the medical examiner for consultation throughout the investigation. The referring hospital should expeditiously fulfill requests from the medical examiner for medical records, specimens, etc., that may be necessary in determining the cause and manner of death (25).												X	X
The hospital should make the conduct of an autopsy a priority when an unexplained or unexpected death is not investigated by the medical examiner. The hospital should convey to next of kin the value of an autopsy, emphasizing the potential benefits to the family of the deceased, such as discovering hereditary illness, and the important contributions of postmortem examinations to hospital quality assurance, medical education and medical research (25).												X	
When the medical examiner declines jurisdiction, and the hospital declines to conduct an autopsy, the hospital should provide information to next of kin regarding options for obtaining an autopsy elsewhere (25).												X	
MDI staff who have the potential to interact with next of kin should receive training appropriate to their duties. This training should include but not be limited to: death notification, interacting with people in crisis and trauma, grief education, and the management and return of personal effects (6, 10, 11).												X	X
Coordinate interviews with MDI in safe home environment or other neutral environment. If parents are separated for interviews, this will likely increase stress and anger, impacting the success of a thorough interview. Explain to parents why this is occurring and if standard for all child death investigations. This will alleviate an accusatory tone. When possible, do not separate parents from deceased child for purpose of interviews.												X	
MDI provides information about the death investigation process to next of kin, the referring hospital and other parties with a legally-defined interest in the case. This verbal and written information, should include, at a minimum, an overview of the death investigation process, an estimate of the time frame within which preliminary and final autopsy results will be available, any rights the parties may have to access medical examiner reports and related records, and the process to request such reports and records.												X	X
Provide information and reassurance in how the investigation process will/will not impede the family's ability to plan funeral/open casket/burial/cremation, etc. Provide information on choosing a funeral home and burial options.												X	
The medical examiner's decision to accept or decline jurisdiction of a case referred for review should be communicated to the referring hospital within a reasonable time frame (6, 11).												X	X

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MDI should establish a single point of contact, which could be accomplished by maintaining a central telephone number, to coordinate communication between MDI and parties with an interest in the case (next of kin, the referring hospital, etc.). State and local governments should provide adequate funding to facilitate effective communication between the medical examiner and parties with an interest in the case (6, 10, 11, 25, 26).												X	X
With MDI approval before or at autopsy, offer to provide memorial keepsakes (photos, lock of hair, hand prints, foot prints, etc.) or offer keepsake collection at funeral home if post autopsy and release from MDI (10, 23).												X	
Unless the case is the subject of an ongoing criminal investigation and release of information would compromise the investigation or the prosecution of a criminal case, the medical examiner should, upon request, share preliminary autopsy findings with next of kin, the referring hospital, and other parties with a legally-defined interest in the case. Final autopsy results should be shared promptly with requesting parties when they become available (6, 11).												X	
Prepare next of kin for the condition of the remains (6, 10, 11).												X	
Ensure that families understand their rights to access the final autopsy report, that they understand how to obtain the autopsy report, and that the reports are provided in the most meaningful and compassionate manner (6, 10, 11).												X	X
Inform next of kin regarding issues related to public information and the media (6, 10, 11).												X	X
Ensure that families receive personal effects in a sensitive and timely manner (6, 10, 11).												X	X
Recognize and respect the family's right and need to understand how and why their loved one died. The worst news can be delivered with sensitivity and compassion. The method of communicating the final cause of death to the next of kin should be mentioned early on in the investigation. If the next of kin have a preference for a specific method (i.e., scheduled call vs. unanticipated call, letter, or meeting etc.), considerations should be given to attempt to comply with their wishes (6, 10, 11, 23, 25, 30).												X	X
The medical examiner should make himself or herself available to participate in a post-autopsy conference with the next of kin and other parties of the next of kin's choosing, such as the deceased's attending and/or personal physician(s). The medical examiner should also make a reasonable effort to make himself or herself available to hospital personnel to discuss the final autopsy report (6, 10, 11, 23, 25, 30).													X
Upon request, the medical examiner should provide information to next of kin regarding options for obtaining an independent autopsy or a review of the medical examiner's findings and conclusions (6, 25).													X

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With approval of medical examiner/coroner, convey known and available research opportunities (31, 32).												X	X
Facilitate DNA banking and appropriate medical referrals for families when cause of death has medical implications for relatives. Hospitals should retain all biospecimens obtained until they are provided to the MDI (31, 32).												X	X
Pediatrician/primary care should attain/maintain open and ongoing communication with the medical examiner/coroner to assist in investigation and provide optimal care of family (14, 25, 26, 33-38).												X	X
Offer a face to face meeting with the family with surviving siblings within two weeks of the death of the child to assess for grief response, address necessary mental health and medical screening and/or referrals (14, 15, 17, 39).													X
Maintain ongoing follow-up with the family: send a condolence card; schedule clinic visits and phone follow-ups to reassess medical and mental health needs over time (14, 25, 26).													X
Assess for crisis and pursue any immediate applicable medical screening for families based on circumstances of deaths, investigation concerns of medical examiner/coroner and family history (14, 15, 17, 18, 40-48).												X	X
Funeral homes: ensure next of kin understand death certificate process for pending versus final certificate, how they will receive the certificate/s, and how the certificate affects death benefits.												X	X
Organ procurement agencies: local statutes will apply. With approval of medical examiner/coroner, communicate organ versus tissue donation opportunities. Tissue donation is more common in sudden unexpected death in pediatrics due to death often preceding discovery.												X	X
Public health agency: local policies will dictate if/when public health officials are in contact with families. If contacted, ensure the family has full knowledge of available and accessible services and applicable research opportunities in writing.												X	X

EMS – Emergency medical services; LE – Law enforcement; MDI – Medicolegal death investigator; ED – Emergency department;
 PC – Primary care; CPS – Child protective services; OPO – Organ procurement agencies; FH – Funeral home;
 PH – Public health; OB/GYN – Obstetrician-gynecologist

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