

SUDDEN UNEXPECTED INFANT AND CHILD DEATH

**A GUIDE FOR EMERGENCY
DEPARTMENT PERSONNEL**

Massachusetts Center for Sudden Infant Death Syndrome
Massachusetts Infant and Child Death Bereavement Program

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INTRODUCTION

Infant and child deaths

Every year in Massachusetts, approximately 400 children die in the first year of life. In the first year, the leading causes of death are disorders related to short gestation and low birth weight, congenital anomalies and sudden infant death syndrome (SIDS). Other causes include medical conditions, such as infection, cancer, disorders of the circulatory and nervous systems, and accidental injuries, suffocation and homicide. Another 60 children die between 1 and 4 years of age to sudden unexpected death in childhood (SUDC), medical conditions, injuries and homicide.

Sudden unexpected infant and child death

Infants and young children die suddenly and unexpectedly due to many of the causes listed above. The leading cause of sudden unexpected infant death is sudden infant death syndrome (SIDS). Approximately 25 to 30 infants in Massachusetts die each year of sudden infant death syndrome (SIDS); The definition of SIDS is currently characterized as one of exclusion: the sudden and unexpected death of an apparently healthy infant under one year of age whose death remains unexplained after the performance of an autopsy, a death scene investigation and a review of the infant's medical history. (National Institute of Child Health and Human Development 1990). SIDS is the leading cause of death among infants between one month and one year of age. SUDC occurs throughout childhood (<18 years of age) but most commonly in toddlers between 1 and 4 years of age. The definition of SUDC differs from SIDS only by the age criteria, i.e., SIDS occurs in infants <1 year of age. SIDS, the leading cause of postneonatal infant mortality in the United States, is 37 times more common than SUDC, with an overall rate of 56/100,000 deaths per year. The defined age criteria for SIDS and SUDC are operational so that there is a question of whether SUDC in toddlers is the same entity as SIDS, but occurring after the first year of life, or is, alternatively, a completely separate entity.

SIDS was recognized as a public health problem with the enactment of the SIDS Act of 1974. This legislation provided for case identification; confirmation of the cause of death by means of death investigation, including autopsy; the appropriate use of SIDS on the death certificate; prompt and accurate notification of families concerning the cause of death; and prompt and continuous counseling for family survivors. In addition, the legislation provided for the development and distribution of informational material as well as for the provision of educational programs to health professionals who may be involved in a sudden unexpected infant death event. Finally, the collection of data is required for purposes of assisting with research efforts.

BASIC FACTS ABOUT Sudden Unexpected Infant and Child Death

Approximately 4,500 infants die suddenly and unexpectedly each year in the U.S.

Approximately half of these infant deaths are due to sudden infant death syndrome

SIDS is the leading cause of death among infants between the ages of one month and one year.

Babies between 2 and 4 months of age are most often the victims of SIDS, but older and younger babies also die of SIDS.

Death occurs within seconds, usually during sleep, and the baby does not suffer.

Cases of SIDS have been reported throughout history, as far back as the time of the Old Testament.

Suffocation or aspiration does not cause SIDS, but is a cause of death in and of itself.

Most SIDS victims appear to be healthy before death.

SIDS is not caused by child abuse.

SIDS is not caused by immunizations.

SIDS is not contagious.

SIDS is not hereditary.

SIDS occurs in families of all social and economic backgrounds.

Researchers believe that SIDS probably has more than one cause although the final process appears to be similar in most cases.

Since the cause(s) or mechanism of death in SIDS is not yet fully known, there is no guarantee of prevention.

Services of the Massachusetts SIDS Center and Massachusetts Infant and Child Death Bereavement Support Program

The Massachusetts Center for Sudden Infant Death Syndrome, established in 1975, has expanded its bereavement support services by establishing the Massachusetts Infant and Child Death Bereavement Support Program. The purpose of the program is to provide

culturally competent bereavement support and educational services to families and caregivers of infants and young children who die of all causes of death (0-3 years) throughout Massachusetts.

The Center, supported by the Massachusetts Department of Public Health, is funded to ensure that throughout Massachusetts the response to families bereaved by the death of a child is both skillful and sensitive.

The Center is located at Boston Medical Center. You can reach the Center directly between 9:00 a.m. and 5:00 p.m. by calling 617-414 -7437 or 800- 641-7437.

If no one is in the office a voice message answering machine will take your message. Center staff will return the call as soon as possible.

Services

Support for the bereaved

- bereavement counseling and information
- home visits by specially trained bereavement counselors
- parent support group meetings
- peer support contacts

Research

- case identification system for all infant deaths
- database for infant deaths

Education and training

- emergency responders, hospital providers, law enforcement
- community health nurses, social workers, and community outreach workers
- clergy and funeral directors
- licensed and informal child care providers
- literature for families, health professionals and child care providers

Advocacy for infant mortality issues

- consultation with professionals locally, regionally and nationally on infant mortality, risk reduction and grief and loss
- public awareness
- membership on fetal and infant mortality review (FIMR) and child fatality review (CFR) teams

GUIDELINES FOR EMERGENCY DEPARTMENT INTERVENTION

FOR UNEXPECTED INFANT AND CHILD DEATH

These guidelines are intended for staff members of the Emergency Department who come in contact with the family at the time of initial crisis. Emergency health care personnel should be responsive to the family's emotional needs and aware of possible causes of death including sudden infant death syndrome (SIDS) and sudden unexplained death in childhood (SUDC). Sudden infant and child death can trigger emotional reactions, which may result in serious psychological problems for parents, surviving siblings, other family members and caretakers.

Through a sensitive approach, emergency staff can support family members as they begin to grieve the death of their child.

A Initial Care

When an infant or young child presents in the emergency department of the hospital in a lifeless or near lifeless condition, the child is evaluated and emergency resuscitative measures instituted if necessary and appropriate. It is very reassuring for parents to know that everything possible is being done for their child.

B Medical Evaluation and Diagnosis

Before speaking with the family, the emergency personnel team should review information provided by parents, caretakers, police and ambulance personnel. This review will assist the health team in determining an appropriate and sensitive approach to discuss the child's death with family members.

In cases of sudden and unexpected infant or child death, causes which should be considered, are:

- 1) Infections: sepsis, meningitis, encephalitis, pneumonia, and botulism
- 2) Cardiac disease: myocarditis, congenital heart disease, and sudden arrhythmia
- 3) Aspiration or airway obstruction
- 4) Injury
- 5) Congenital anomalies
- 6) Genetic disorders

7) Seizure disorders

8) Sudden infant death syndrome or sudden unexpected death in childhood

Any diagnosis made in the emergency department is tentative pending an autopsy and death investigation unless there is a documented disease or obvious severe injury.

The medical examiner, who must be notified regarding the infant's death, makes the final decision concerning the performance of the autopsy and determination of final cause of death.

SIDS is diagnosed on the basis of the absence of diagnostic conditions plus autopsy findings consistent with the typical findings of SIDS (intrathoracic petechiae, mild pulmonary edema, and minor inflammatory changes in the airway.) SIDS is the final diagnosis in about 85% of sudden and unexplained infant deaths.

Additional pertinent information, which may be helpful in assisting the pathologist as well as those providing counseling, may be documented on the emergency room form. (See Appendix B)

C Informing the Parents

It is desirable that the doctor in charge of the resuscitative effort or the primary care physician (if present in the emergency department), and the emergency team member who has been assigned to the family be present when the family is informed of the child's death.

The physician may tell the family: "We know your child died suddenly and unexpectedly, an autopsy must be performed to establish the cause of death."

If the family is resistant to the idea of autopsy, the physician or nurse may be able to alleviate anxiety associated with this procedure. First, it is helpful to explain to parents that an autopsy is a medical procedure similar to surgery or an "operation". A specialized physician or pathologist performs this operation in a respectful manner. Second, besides ruling out injury, an autopsy will eliminate or confirm any unsuspected illness or congenital anomaly as the cause of death. Third, in almost all cases in which autopsies are NOT performed, the family may have lingering doubts as to the cause of death.

It may be difficult or impossible for parents to assimilate information during the state of shock usually experienced at this time of crisis. It is important to provide adequate information to families, but only as much as they can handle at this time. Information about the cause of death will be repeated and discussed more thoroughly through counseling provided by the Massachusetts Center for Infant and Child Death.

D Parent Support

Each person reacts differently to the sudden unexpected death of a child. It is important for emergency personnel to respond to the needs of family members, keeping in mind individual differences and cultural patterns. A member of the emergency team should stay with the parents as much as possible to provide support and answer questions. In the event of complicated grief reactions, a social worker, psychiatric nurse or chaplain may be contacted for immediate crisis intervention.

Be prepared for difficult situations, including extremes in behavior such as screaming, collapsing, or even expressing no emotion. Encourage the parents to talk about the child; use the child's name. Give permission for next of kin to grieve. Appropriate support during this time may set the tone for the entire process of grieving.

Parents should be encouraged to see and hold their child. Spending time with the child assists parents in focusing on the reality of the death while providing an opportunity to say goodbye. Resuscitative equipment may be removed after discussion with the medical examiner. If equipment removal is not possible, it should be made as unobtrusive as possible. An emergency staff member can accompany the parents and support them as they touch and hold their child.

Efforts should be made to contact absent family members or any individual whose presence is important to the family. The presence of a member of the clergy and/or performance of family rituals such as baptism should be discussed. A keepsake certificate can be prepared for the family. The certificate includes the child's full name, date and time of birth, date and time of death, weight and length, a Polaroid picture, a lock of hair if possible, a footprint and a bracelet. These physical reminders give the parents something to look at, hold and touch.

Since many parents are unfamiliar with funeral arrangements, it may be helpful to inform the family of the necessity of contacting a funeral director and/or a member of the clergy for assistance. The funeral director will assume the responsibility for the infant's body after its release from the medical examiner or hospital.

Listen.

Ask open-ended questions.

Develop a rapport with the family that will allow free expression and facilitate a healthy grieving process.

E Follow-Up

Before the family leaves the emergency room inform them when and by whom they will be told of the autopsy results. Find out where they can be reached - frequently families

do not return to their own homes.

Call the Massachusetts Center for Infant and Child Death at 617-414-7437 or 800-641-7437. A staff person is available to provide crisis counseling for families and consultation for hospital personnel. Center staff contacts families within 24-48 hours of the death and informs parents of preliminary autopsy findings.

Bereavement counseling will be arranged through the Center's nurse coordinator. The purpose of follow-up is to:

1. Give the family further information about the cause of death.
2. Review the autopsy findings.
3. Provide anticipatory guidance through the grief process.
4. Assess the family for any pre-existing problems or potential problems initiated by the death.
5. Respond to questions.
6. Make available information about counseling, home visits, parent support groups, and parent to parent contacts and referral for mental health counseling.

Fill out the emergency room form. Maintain one for hospital records. Send a copy to the Massachusetts Center for SIDS, Boston Medical Center, One Boston Medical Center Place, Boston, MA 02118.

If appropriate, give the family the enclosed fact sheet and a copy of the Center's brochure or 24-hour telephone number.

F Emergency Team Conference

It may be helpful for the emergency room staff to meet for support to discuss feelings and concerns regarding unsuccessful resuscitation and the family's anguish. The emotional drain on the emergency room staff needs to be taken into account and addressed. It is also helpful to evaluate intervention strategies with families in order to gain a sense of competency. Was the family supported at the time of crisis and was provision made for follow-up care? Appropriate intervention in the emergency room sets the tone for how parents begin to cope with the impact of their child's death. Supportive care in the immediate crisis period in conjunction with long-term follow-up promotes mental health and reduces the incidence of psychiatric morbidity.

APPENDICES

Appendix A

**EMERGENCY DEPARTMENT CHECKLIST FOR SUDDEN INFANT
AND CHILD DEATH**

- ___ Resuscitation
- ___ Staff person assigned to family members
- ___ Primary care physician notified
- ___ Medical Examiner notified
- ___ Clergy called (hospital chaplain and/or family clergy) if parents desire
- ___ Family notification of death and medical examiner request for autopsy
- ___ Family encouraged to see and hold infant (further suggestions, see Guidelines page 5, Section D)
- ___ Performance of cultural or religious rituals
- ___ Family given keepsakes such as lock of hair, footprints, Polaroid picture
- ___ Family allowed to express grief; staff responds to individual needs
- ___ Family understands they will be contacted regarding autopsy findings
- ___ Funeral and burial choices discussed
- ___ Family informed of follow-up services by the Massachusetts Center
- ___ Emergency Department Chart completed (including emergency room form)
- ___ Emergency Department Staff conference

Patient's Name: _____

Staff Member: _____ Date: _____

Appendix B

MASSACHUSETTS CENTER FOR SUDDEN INFANT AND CHILD DEATH
EMERGENCY ROOM FORM

Patient Information

Name: _____ Age: _____ Sex: M ___ F ___

Birthdate: _____

Last seen alive: Date _____ Time _____

Found dead: Date _____ Time _____

By whom: _____

Place: Crib, Parent's bed, Other _____

Position: _____

Appearance of Infant: Body Temperature _____

Color of Skin _____

Nasopharyngeal discharge: Yes _____ No _____

Resuscitative Efforts CPR: Yes _____ No _____

Intracardiac medication: Yes _____ No _____

Other medication (Please specify) _____

Birth and Medical History

Birthweight: _____ Gestational Age: _____ Birthplace: _____

Source of medical care:

Well baby or child visits: Yes _____ No _____ Unknown _____

Most recent visit _____

Most recent weight _____

Immunizations: Yes _____ No _____ Date _____

Type of feeding: Breast _____ Bottle _____ Both _____

Illness in last two weeks: Yes _____ No _____

Cold, sniffles, stuffy nose _____

GI Symptoms _____

Other minor/major _____

Describe _____

Medical Examiner

Name: _____

Autopsy: Yes _____ No _____ By whom: _____

Parental Data:

Mother: _____ Age: _____ Father: _____ Age: _____

Address: _____

Telephone: _____ Emergency phone: _____

Pregnancy Complications: _____

Type of delivery: _____ Anesthesia: _____

Complications during labor, delivery or neonatal period: _____

Previous infant deaths: Yes _____ No _____ Cause _____

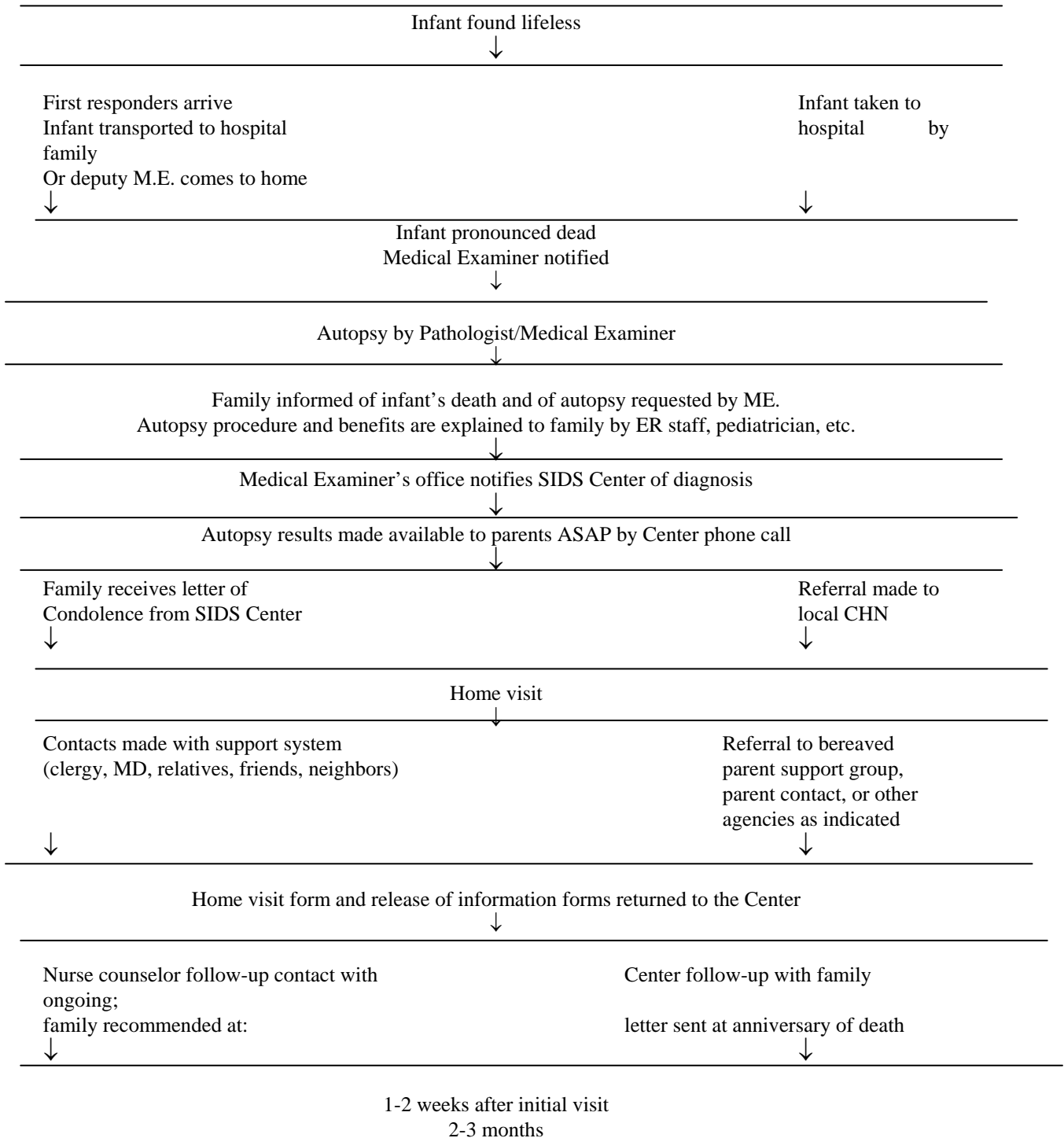
Number of Siblings: _____

Report filed by: _____

Date: _____

APPENDIX C
MASSACHUSETTS CENTER FOR SUDDEN INFANT DEATH SYNDROME
MASSACHUSETTS INFANT AND CHILD DEATH BEREAVEMENT PROGRAM

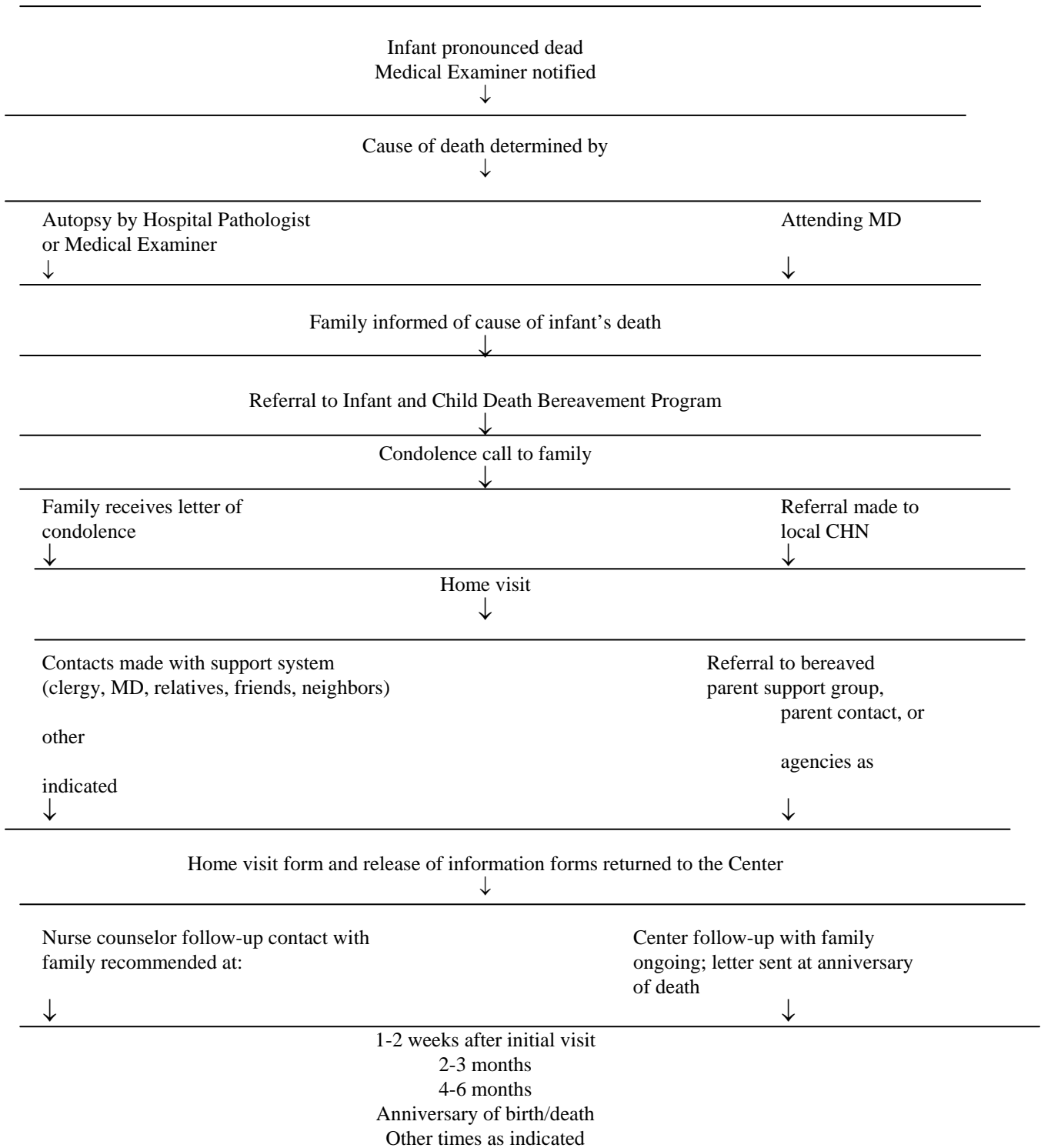
CASE MANAGEMENT FLOW CHART
UNEXPECTED INFANT AND CHILD DEATH



APPENDIX C
4-6 months
Anniversary of birth/death
Other times as indicate

MASSACHUSETTS CENTER FOR SUDDEN INFANT DEATH SYNDROME
MASSACHUSETTS INFANT AND CHILD DEATH BEREAVEMENT PROGRAM

CASE MANAGEMENT FLOW CHART
FETAL DEMISE, STILLBIRTH, NEONATAL AND OTHER INFANT AND CHILD DEATHS



Appendix D

Case Management of Infant and Child Deaths: A Profile Revisited

The Massachusetts Center for Sudden Infant Death Syndrome (SIDS) is responsible for coordinating services to families whose children die of sudden infant death syndrome and other causes of infant and child mortality (0-3 years). Funded originally by the SIDS Act of 1974 and subsequently through block grants and private fund raising, the Center has pursued its primary mission of ascertaining the cause of death in sudden infant and child mortality, notifying parents of the medical findings, and offering support to family members during their bereavement.

The Center's statewide services include: crisis contact within 24 - 48 hours of referral, counseling by medical doctors and the SIDS nurse coordinator, regular follow up by community health nurses, support group meetings, and parent to parent contact. Other services include the provision of educational materials and seminars, as well as compilation of epidemiological data for the Massachusetts Department of Public Health.

Initial Care and Follow-up

When an unresponsive child is brought to the emergency room of the hospital, a set of guidelines is recommended by the Center to all emergency staff. The child is examined and resuscitation attempted while the parents are provided a private space. An attending nurse or social worker informs the parents about their child's condition. When the mother and father are informed of their child's death, emergency staff offers immediate emotional support and encourages parents to see and hold their child. Before parents leave the hospital, staff ascertains where and how they can be contacted in the immediate future.

The Center receives notification of the child's death from the medical examiner, hospital, pediatrician, family member and parents themselves. Telephone contact is made by the Center staff with the family within 24-48 hours to provide crisis counseling, preliminary autopsy information, and notification that a bereavement counselor will call to schedule a home visit. A condolence letter is sent to the family with brochures and other information about the cause of death and the grieving process. All families are informed of parent support group meetings and the availability of a parent contact. Support groups are emphasized because they provide a nurturing environment in which parents can express their feelings, meet other grieving parents, receive reliable information and ultimately help others.

The Center notifies the child's pediatrician of the death, informs him/her that the Center will be providing services to the family, describes what those services include, and often provides updated information on SIDS and professional support as well.

Continuing Care

The professional nurse counselor or social worker is responsible for providing care to the bereaved family. The overall goal of counseling is to mobilize the strengths of the family to

assimilate the loss of the baby in a way that allows family members to continue to function and to recognize that life is worth living and happiness is possible.

More than 40 agencies and 100 community health nurses and social workers contract with the Massachusetts Center to provide follow-up to the families during the first year of bereavement. Through the counseling process-assessment, intervention, and evaluation - the professional designs a plan of care with each family. During family meetings, the counselor presents accurate information about the cause of death; provides anticipatory guidance regarding the grieving process; evaluates each family member's response to the death; assesses social support systems; informs the family of available resources; obtains medical information for the Center's statistical data base; and reviews written autopsy reports. The nurse provides continued care through home visiting and telephone contact during the first year of bereavement and beyond.

Culturally Competent Services

Community health nurses who provide bereavement counseling come from various racial and ethnic backgrounds including African-American, Haitian, Latino, Portuguese, West Indian and Cape Verdean. Center staff train nurses, who are fluent in Spanish, Haitian, French Creole, Portuguese and French. These training programs include information on cultural awareness and sensitivity as well as cultural beliefs regarding death, dying and bereavement. Appropriate bereavement follow-up is enhanced with the assistance of qualified interpreters.

Professional Education and Training

Education prepares professionals and community members to respond appropriately when an infant or child dies suddenly and unexpectedly. Educational programs conducted by the Center provide physicians and nurses, emergency responders, police officers, hospital emergency department personnel, child care providers, funeral directors, medical examiners, clergy, social workers, students and lay persons with information to assist them in supporting families who have experienced the tragedy of infant or child death. The Center provides training, consultation, and professional support for the nurses who provide home visiting and bereavement support for affected families.

The Center publishes an annual newsletter, guidelines for hospital emergency department personnel, and a bereavement counselor training manual and several brochures.

Data Management and Reporting

The Center has a computer based database management system and data collection forms that are utilized to compile data and perform statistical analyses. The Center collects medical and demographic data for the population served, as well as data, which summarizes the services provided by the Center. This data management system enables the Center to provide timely reports of its activities and to maintain a database of potential value for SIDS research.

Parent Support Groups

Center staff facilitates support groups for bereaved parents, which meet monthly in three locations. Support groups aid in the resolution of the early trauma of grief experienced by parents following the sudden unexpected death of their infant or young child. Parents need to talk about their own grieving, reactions of other children, and concerns about subsequent children.

The Support Group provides:

- A safe environment for parents to express their feelings.
- Contact with others who share their grief and are at various stages of resolution.
- A reliable source of information about SIDS and other causes of infant and child death.
- The opportunity to help others.

Any parent experiencing the death of a child is welcomed, as are grandparents, siblings, extended family members, friends and caretakers. No registration is required, and there is no fee.

Parent-to-Parent Contact

Upon request the Center matches newly bereaved families with a parent contact. Center staff train and supervise parent contacts that are at least one year removed from their child's death. Parent contacts are parents, grandparents and child care providers who provide a network of support to bereaved families. When possible contacts are matched with families according to demographic characteristics and circumstance of death. Parent contacts are accountable to the Center regarding their intervention with families.

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