

RESPONDING TO SUDDEN UNEXPECTED INFANT AND CHILD DEATH: **STRATEGIES FOR THE PROFESSIONAL**

The Massachusetts Center for Unexpected Infant and Child Death

2021

Disclosure

- Boston Medical Center grants nursing and social work contact hours to those who complete this program. You must stay for the entire program, participate in the activity, and complete the evaluation form.
- This program has no commercial support. Faculty and planners have no vested interests, and there are no conflicts of interest. There will be no discussion of off label uses of drugs.
- Boston Medical Center is an approved provider of continuing nursing education by American Nurses Association, Massachusetts, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.
- Professional Education Program at Boston University School of Social Work is authorized through the MA state board of Social Work to provide CE Credit Hours.



***The Massachusetts Center for
Unexpected Infant and Child Death
supports families, communities, and
professionals after an unexpected
death during pregnancy, infancy, or
early childhood.***



Our Center Aims to...

- Provide an individualized, continuous, and compassionate response to bereaved families
- Offer integrated, meaningful, and professional resources
- Help affected families and their communities grieve



Whom We Serve

Families of children under 3 who die suddenly and unexpectedly of:

- SIDS/SUID
- Accidents
- Unknown cause, unknown manner
- Perinatal and stillborn



Center Activities

- Family Support
- Advisory Board
- Community Events
- Child Fatality Review Team Participation
- Policy Work



Referral Pathways



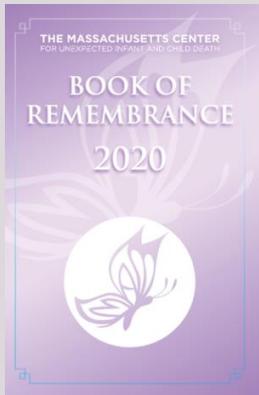
Family Support

- Upon referral, connection with bereavement specialist for continuous, tailored resources
 - Remote contacts (phone, e-mail, etc.) – anticipatory guidance, mobilization, assessment of needs
- Resources may include:
 - Connections to support groups
 - Linkages to individual therapists
 - Supports for surviving siblings
 - Peer-to-peer connections
 - Free literature
 - Inclusion in commemorative opportunities
 - Ongoing bereavement support as needed

Walk to Remember



Book of Remembrance



Daniel Rivlin

Remembering my beloved brother, Daniel

The morning glory blooms but for an hour
and yet it differs not at heart from the giant pine
that lives for a thousand years

-Teitoku Matsunaga, Japanese Poet

Diego Fox Román
January 11, 2019 - June 11, 2019

La mariposa voló
Una hermosa mariposa
voló, sus alas voló,
sabió, sus alas voló,
que lo voló voló,
y antes las puestas del cielo
responsable se acordó.
Puedo en Baitan a la puerta
pero me quedé de día,
(¿ si él me hubiera volado
se preguntó con temor,
¿ si él que se comen
me más fue un rano?
¿ si él me más se comen
y no voló voló?
¡Maldita de dios!
Pero si esto todo un día
se preguntó voló
y siempre voló en la tierra
y en puestas voló.
Lo que más le gustó de ella
fue en la tierra voló,
por me voló la guerra
y la mariposa voló,
y cuando más me más
mucho más voló,
- María Alonso Sarmiento

Alexander Shaw
5 years after saying goodbye (4/2/15-5/16/15)

It is hard to believe that only 5 years have passed since we last held you, and you
no longer are little brother... 5 years since we held hands and our souls kept us
close. When you left us, we always looked to see again. We still find the large hole
that your absence has left in our family, but slowly over the last 5 years, we have
learned to live with that empty space, because how do children leave
people. Today we write to do good and help others in your memory, especially
through our work in the NICU and in building the Little Angels school.
We do it for you because you can't show the world the strong influence you
would have had on it, but we feel your powerful strength and do our best to
share it with the world for you. We have all grown and changed so much of the
last 5 years (especially your siblings), and love that you left us with your generous
gift - to pass on your love, brother. Don, who has helped us lead from being your
and pass on the blessings of your love into what you might be like today. Do let
prepare to lead off to school, we find ourselves wondering what it would be like
to see both of our baby boys off to kindergarten together. How would certainly
be more confident with you by his side and would surely find a path to find
and pleasure. Would you be the same child? Would you be more
curious? What activities you would enjoy? Would you be creative and artistic
like Ethan, or love to run around and play games like Alex, Dylan and Brad?
Would you be quiet and thoughtful like Matt and Dylan or more outgoing like
Eve and Ethan? We will never get answers to our curious questions, so instead
we do our best to keep your memory alive in our family, as long as we can have
always, and to continue to pass on to you as best as we can through our involvement
in the NICU and our good deeds in the in your memory - you are and always
will be our little angel in heaven. Please continue to watch over all of us, especially
your siblings! They have been lucky that we do have them very very generous
angel in heaven and wish you were still here.

SIDS vs. SUID



SUID and SIDS

- **Sudden Unexpected Infant Death (SUID)** is a term used to describe the sudden and unexpected death of a baby less than 1 year old in which the cause was not obvious before investigation. These deaths often happen during sleep or in the baby's sleep area.
- **Sudden Infant Death Syndrome (SIDS)** refers to death in a seemingly healthy infant younger than 1 year of age whose death remains *unexplained* after a thorough case investigation including a complete autopsy, review of medical and clinical history, and death scene investigation.



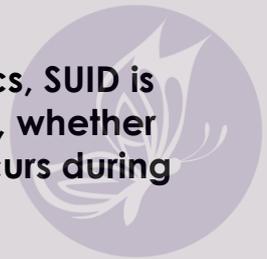
What is Sudden Unexpected Infant Death (SUID)?

Accidental suffocation in bed (ASSB)

Undetermined Causes

Sudden infant death syndrome (SIDS)

“According to the American Academy of Pediatrics, SUID is described as “any sudden and unexpected death, whether explained or unexplained (including SIDS), that occurs during infancy.”



Facts

SIDS remains the leading cause of death among US infants under 1 year of age.

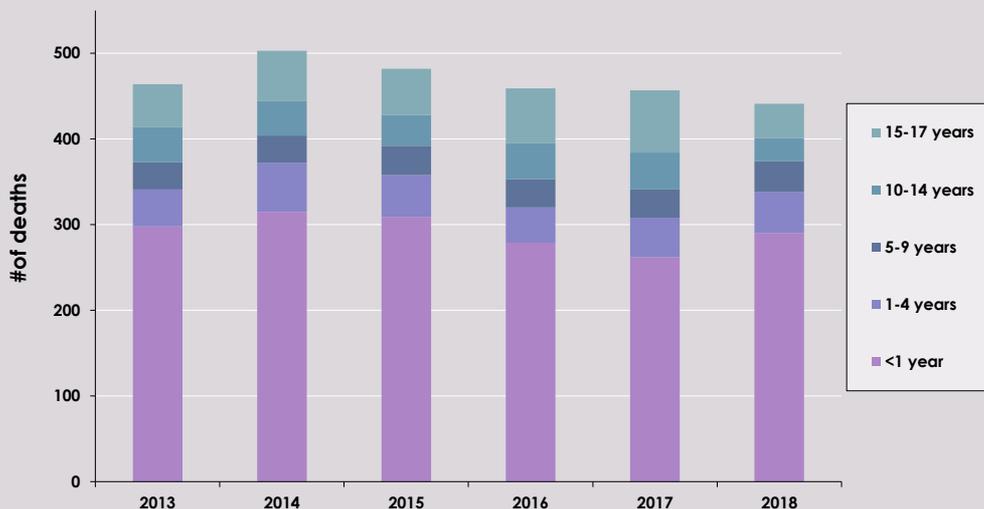
SUID remains the leading cause of death among MA infants under 1 year of age.

Each year there are approximately 3,500 SUID deaths in the US, and 44% of them (1,500 deaths) are attributed to SIDs.

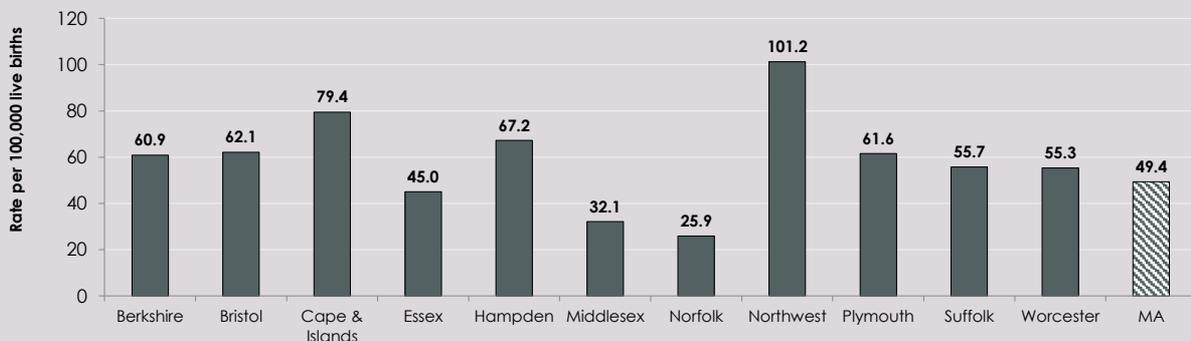


Sources: Registry of Vital Records and Statistics, MDPH, 2014
Kawai O Tanabe, MPH and Fern R Hauck, MD, MS., 2018

Magnitude and Trends in Deaths by Age Group, MA Residents 0-17 Years, 2013-2018



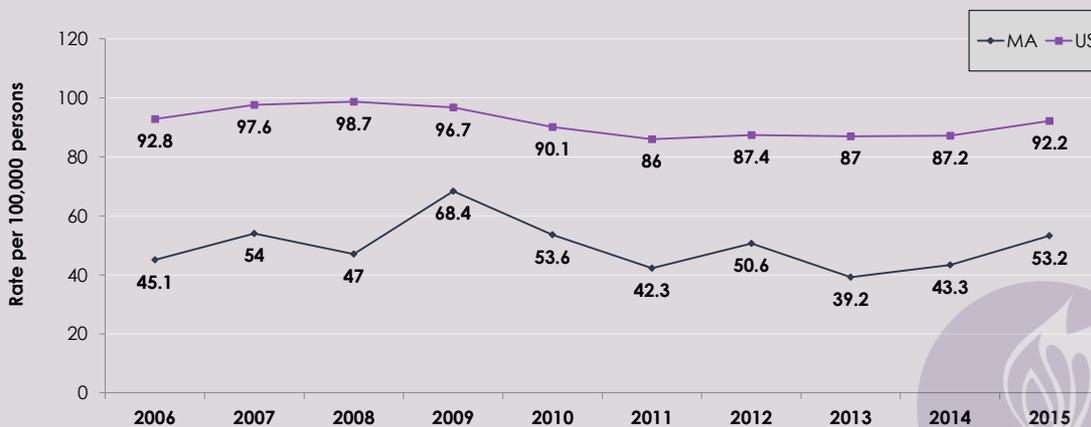
Average Annual Rate of Sudden Unexpected Infant Death by District of Residence, MA Residents <1 Year, 2006–2015 (n=366)



SUID includes: SIDS, accidental suffocation & strangulation in bed, and undetermined cause
 Cape & Islands includes Barnstable, Dukes, and Nantucket counties. Northwest includes Franklin and Hampshire counties.

Source: MA linked infant birth-death files, Registry of Vital Records & Statistics, MA Department of Public Health. File dates are: 2006-2011: 7/12/2018; 2012: 7/3/2018; 2013-2015: 6/29/2018. All linked infant birth-death files use the open MA birth and death files at the time of file linkage.

SUID Rate, MA and US Residents <1 year, 2006-2015



Source: Registry of Vital Records and Statistics, MA Department of Public Health and United States Department of Health and Human Services (US DHHS),

Following a Death: General Process



Investigations & Autopsies

- Many entities become involved upon the death of a child:
 - The Department of Children and Families (DCF)
 - Law Enforcement (State or Local Police, driven by DA Offices)
 - Office of the Chief Medical Examiner (OCME)
- The Autopsy:
 - Required by law in most cases
 - Can typically take many months to complete, often times over a year
 - Can be highly technical – includes written description of the autopsy findings, laboratory and imaging results, and details about the clinical setting
 - Unless otherwise specified, will arrive in the mail, oftentimes unexpectedly
 - Religious considerations can be very challenging to access



Challenges for the Investigator

- Mandates provide strict parameters to the work
- Systematic challenges between agencies mean that decisions need to be made before all data is available
- Investigators may have received little or no training related to SUID/SIDS and grief
- We're all human
- What else?



TODAY

- 9:30 – 10:30 AM: *Supporting Families: Interdisciplinary Principles of Intervention*
Dr. Maxine Weinreb, Ed.D.
- 10:30 – 11:30 AM: *Working with Grieving Children & Families: Key Skills for Navigating Difficult Conversations*
Kathleen McAleer, MSW LICSW
- 11:30 – 12:00 PM: **Break**
- 12:00 – 12:45 PM: *Reducing Disparities in Sudden Unexpected Infant Death*
Boston Medical Center Pediatric Resident Team
- 12:45 – 1:45 PM: *Advisory Panel: Perspectives and Experiences*
- 1:45 – 2:15 PM: *How to Support Grief Occupational Stress Injuries (OSI's)*
Beth Milaszewski, LICSW
- 2:15 PM: *Closing*

