



# SIDS Counselor Update

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SERVICES**

**JANUARY 23, 2019**



NCDHHS, Division of Public Health | SIDS Annual Update | January 23, 2019

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## Training Objectives

Upon completion of this training activity, participants will be able to:

- Define Sudden Unexpected Infant Death (SUID) and Sudden Infant Death Syndrome (SIDS) and other sleep-related causes of infant death;
- Describe state trends regarding sleep-related deaths;
- Identify local and national resources available for patient and provider support;
- Discuss the protocol for serving as a SIDS Counselor;
- Enhance the support offered to families who have experienced the death of an infant;
- Describe strategies to practice self-care.





## Facts About Sudden Unexpected Infant Death (SUID)

**Sudden Unexpected Infant Death (SUID)** is the death of an infant younger than 1 year of age that occurs suddenly and unexpectedly.

After a full investigation, SUIDs that occur during an unobserved sleep period may be diagnosed as one of the three types of SUID:

1. Sudden Infant Death Syndrome (SIDS)
2. Accidental suffocation and strangulation in bed (ASSB)
3. Undetermined/Unknown

These investigations are often very complicated and this makes it difficult to make a diagnosis. This is why so many deaths are classified as undetermined and unknown.



**Sudden Infant Death Syndrome (SIDS)** is the sudden death of an infant younger than 1 year of age that cannot be explained even after a full investigation that includes a complete autopsy, examination of the death scene, and review of the clinical history.

Important to note:

- In North Carolina, if a sleep-related infant death was associated with an unsafe sleep environment, including bed sharing it would not be classified as SIDS.
- **Bed sharing** is when an infant sleeps on the same surface (bed, couch, chair, etc.) as another person (parent, sibling, caregiver, etc.).



**Accidental Suffocation and Strangulation in Bed (ASSB)** is a cause-of-death code used for vital statistics purposes. This code is used to identify infant deaths caused by suffocation or asphyxia (blockage of the infant's airway) in a sleeping environment.

For example:

- Suffocation by soft bedding
- Overlay
- Wedging or entrapment
- Strangulation

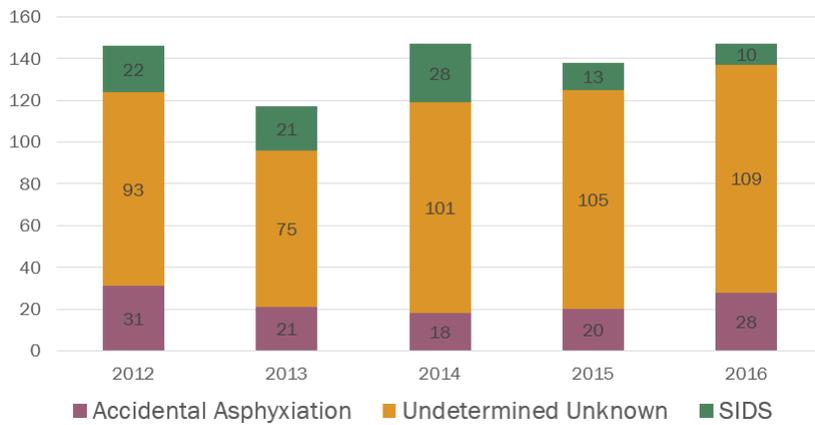




## NC Infant Death in Sleep Environments 2012-2016

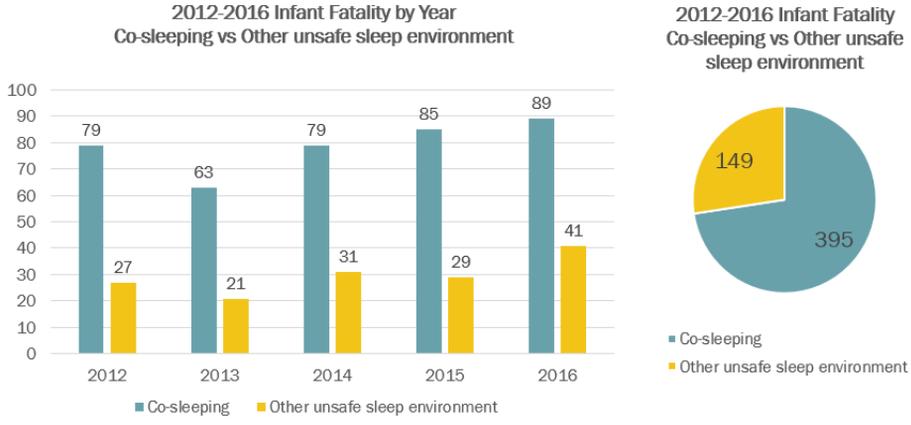
### Infant Fatality 2012-2016

#### Accidental Asphyxiation---Undetermined Unknown--SIDS



Source: Office of the Chief Medical Examiner-Division of Public Health North Carolina Department of Health and Human Services, 2018. Sleep-Related Death Infant Investigations 2012-2016

## Infant Fatality Trends 2012-2016



Source: Office of the Chief Medical Examiner-Division of Public Health North Carolina Department of Health and Human Services, 2018. Sleep-Related Death Infant Investigations 2012-2016



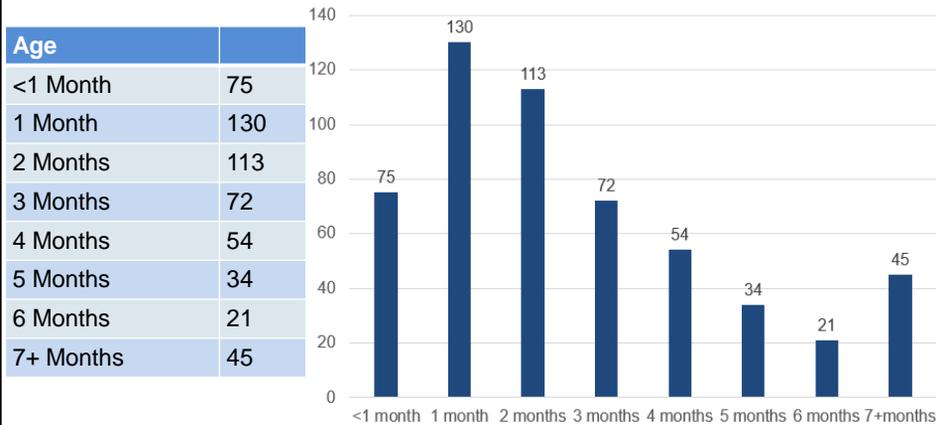
## Infant Fatality by Location 2012-2016

Adult bed Total	330	<p>Alone On Adult Bed: 37 With Other Adults: 219 With Other Adult(s) and child(ren): 64</p>
Couch Total	62	
Recliner	8	
Crib/Bassinet	73	
Car seat	9	
Other	49	
Unknown with adult(s)	13	

Source: Office of the Chief Medical Examiner-Division of Public Health North Carolina Department of Health and Human Services, 2018. Sleep-Related Death Infant Investigations 2012-2016



## Number of Sleep-Related Infant Fatalities by Age, 2012-2016



## Summary NC Infant Death Investigations 2012-2016

Total of 969 deaths of children under the age of 1 year

Of those 969 children: 544 (56%) were related to some kind of unsafe sleep environment, 94 were SIDS (9%)

Of the 544,  
 -395 In a sleep environment involving co-sleeping  
 -149 In a sleep environment that did not involve co-sleeping but was unsafe

Majority (52%) of infant deaths in sleep environments occurred in an adult bed (330 infants) with the presence of an adult(s) (283 infants)

Source: Office of the Chief Medical Examiner-Division of Public Health North Carolina Department of Health and Human Services, 2018. Sleep-Related Death Infant Investigations 2012-2016





**Safe Sleep NC  
Champions**

## Goal of Safe Sleep NC Champions



To emphasize the importance of safe sleep education and to disseminate it effectively throughout all 100 counties

Please note:

- Participation is voluntary
- Current SIDS Counselors do not have to serve as a Safe Sleep NC Champion

## Help Promote Infant Safe Sleep



- Take the Safe Sleep NC Champion online training
- Utilize and tell others in your organization about Safe Sleep NC resources
- Promote Safe Sleep NC messages by using the E-Toolkit

 SafeSleepNC.org



**Resources for Providers,  
Clinics, &  
Parents/Caregivers**

## Bereavement Resources



Click [HERE](#) for a list of support groups for parents and families who have experienced the death of an infant



## Healthcare Provider Safe Sleep Training



- 60 minute online training
- Free 1.5 Nursing Contact Hours approved by the North Carolina Nurses Association.
- Access it here: [bit.ly/safesleepnc](https://bit.ly/safesleepnc)



# Available North Carolina Resources Handout (English and Spanish)



**Does Your Baby Sleep Safe?**

Reduce the risk of Sudden Infant Death Syndrome (SIDS) and other sleep related causes of death by creating a **safe sleep space for your baby.**

**Safe Sleep** Learn more at [SafeSleepNC.org](http://SafeSleepNC.org)

**How to make a Safe Sleep Space for Baby**

- Share your room, not the bed.** Have baby's crib, bassinet, or pack n play in the same room. Baby should not sleep in car seats, strollers, or on a couch, alone, with you or with anyone else.
- Put baby to bed on their back for every sleep.** This is the safest sleep position for babies.
- A bare sleeping space is best.** Baby's sleeping place should not include blankets, pillows, stuffed toys, or crib bumpers. Just a tight-fitting sheet on a firm mattress.
- Use a firm sleep surface in a safety-approved crib, bassinet, or pack n play.** All new cribs sold after June 20, 2011 meet current safety standards.
- Don't let baby get too hot during sleep.** At most, a baby should wear only one layer more of clothing than an adult would wear to be comfortable.
- Keep your home and car smoke and carbon free.** Keeping baby free of second-hand smoke and carbon monoxide reduces the risk of death. Head help [www.1-800-QUIT-NOW.com](http://www.1-800-QUIT-NOW.com).

**Common Safe Sleep Questions**

**What if my baby chokes on her back?** No infants are actually less likely to choke when placed on their backs. When your baby is on their stomach, anything left up can block the windpipe and cause choking or breathing problems.

**My mother tells me that my baby should sleep on his stomach or side, should I still put my baby on his back to sleep?** No. We have learned over the years that babies are less likely to die from SIDS if they are placed on their back to every sleep.

**How can I go to bed if my baby doesn't sleep with me?** Put your baby to bed in your bed so that you can easily pick her up for feedings during the night and ensure when her to her crib for sleeping.

**How will I bond with my baby if he doesn't sleep with me?** There are plenty of other times for bonding with your infant, but when your baby is sleeping it is safest for them to be in their own space. You might sleep better too.

**I have a lot of people who sleep with their babies, how can I not be like that?** The truth is babies are more likely to suffocate when they sleep with an adult or another child.

**What if I fall asleep with my baby?** Ask others to move the baby back to her crib or set an alarm for yourself to wake up and move her. You can remove all babies' bedding from your bed to reduce the risk of suffocation. However, there is no 100% safe way to bed-share with baby.

**Safe Sleep** Learn more at [SafeSleepNC.org](http://SafeSleepNC.org)

 [SafeSleepNC.org](http://SafeSleepNC.org)

# Available North Carolina Resources Posters (English and Spanish)



**Does Your Baby Sleep Safe?**

**Share the Room, Not the Bed.**

Your baby sleeps safest on their back and in a crib or pack n play.

Over 130 babies in NC die each year of sleep-related causes. Many of these deaths could be prevented.

**Safe Sleep** Learn more at [SafeSleepNC.org](http://SafeSleepNC.org)



**Does Your Baby Sleep Safe?**

We now know babies sleep safest alone, on their backs, and in a crib or pack n play.

Over 130 babies in NC die each year of sleep-related causes. Many of these deaths could be prevented.

**Safe Sleep** Learn more at [SafeSleepNC.org](http://SafeSleepNC.org)



**¿Duerme seguro tu bebé?**

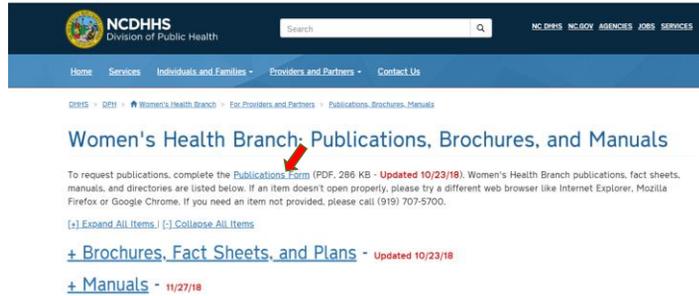
Ahora sabemos que los bebés duermen más seguros solos, sobre su espalda y en una cuna o corral.

Más de 130 bebés en Carolina del Norte mueren cada año por causas relacionadas al sueño. Muchas de estas muertes pueden ser prevenidas.

**Safe Sleep** Aprende más en [SafeSleepNC.org](http://SafeSleepNC.org)

 [SafeSleepNC.org](http://SafeSleepNC.org)

## Available North Carolina Resources



**NCDHHS**  
Division of Public Health

Search

NC DHS NC GOV AGENCIES JOBS SERVICES

Home Services Individuals and Families Providers and Partners Contact Us

DHS > DDI > Women's Health Branch > For Providers and Partners > Publications, Brochures, Manuals

### Women's Health Branch Publications, Brochures, and Manuals

To request publications, complete the [Publications Form](#) (PDF, 286 KB - Updated 10/23/18). Women's Health Branch publications, fact sheets, manuals, and directories are listed below. If an item doesn't open properly, please try a different web browser like Internet Explorer, Mozilla Firefox or Google Chrome. If you need an item not provided, please call (919) 707-5700.

[\[+\] Expand All Items](#) | [\[-\] Collapse All Items](#)

[+ Brochures, Fact Sheets, and Plans](#) - Updated 10/23/18

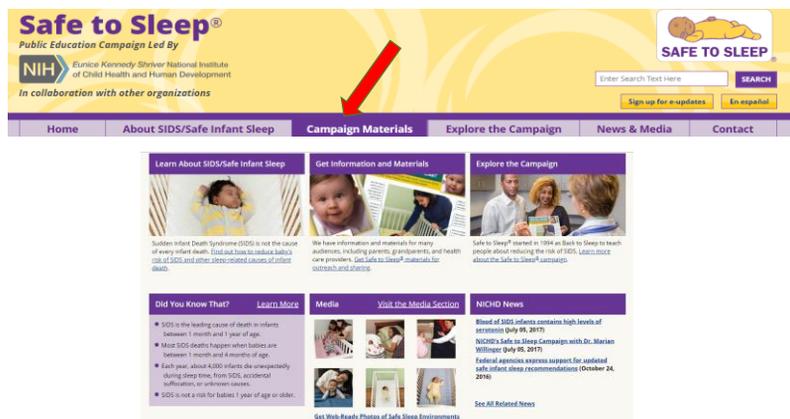
[+ Manuals](#) - 11/27/18

- Order these FREE resources by going to this link <https://whb.ncpublichealth.com/provpart/pubmanbro.htm>
- Click "Publications Form"
- See page 3 under "Parenting & Baby"
- Fax your order to **919-870-4827**



## Available National Resources

<https://www1.nichd.nih.gov/sts/materials/Pages/default.aspx>



**Safe to Sleep®**  
Public Education Campaign Led By  
**NIH** Eunice Kennedy Shriver National Institute of Child Health and Human Development  
In collaboration with other organizations

Enter Search Text Here  **SEARCH**

[Sign up for e-updates](#) [Español](#)

Home About SIDS/Safe Infant Sleep **Campaign Materials** Explore the Campaign News & Media Contact

**Learn About SIDS/Safe Infant Sleep**  
Sudden Infant Death Syndrome (SIDS) is not the cause of every infant death. Find out how to reduce a baby's risk of SIDS and other sleep-related causes of infant death.

**Get Information and Materials**  
We have information and materials for many audiences, including parents, grandparents, and health care providers. Get Safe to Sleep® materials for outreach and online.

**Explore the Campaign**  
Safe to Sleep® started in 1994 as Back to Sleep to teach people about reducing the risk of SIDS. Learn more about the Safe to Sleep® campaign.

**Did You Know That?** [Learn More](#)

- SIDS is the leading cause of death in infants between 1 month and 1 year of age.
- Most SIDS deaths happen when babies are between 1 month and 4 months of age.
- Each year, about 4000 infants die unexpectedly during sleep time, from SIDS, accidental suffocation, or other causes.
- SIDS is not a risk for babies 1 year of age or older.

**Media** [Visit the Media Section](#)

**NICHD News**

Blood of SIDS infants contains high levels of serotonin. [See It.](#)

NICHD's Safe to Sleep Campaign with Dr. Marian Williams. [Q&A 05.2017](#)

Federal agencies express support for updated safe infant sleep recommendations. [October 24, 2016](#)

[See All Related News](#)

Get Web Ready Photos of Safe Sleep Environments



## Available National Resources



**United States  
CONSUMER PRODUCT SAFETY COMMISSION**

Safe to Sleep® - Crib Information Center

**Videos**



**Posters**



### Recalls and Crib Standards



**6 New Federal Requirements:**  
 ☑ Traditional drop sides often cannot be made or sold, dismantled and repair kits not allowed  
 ☑ Head ends must be made of stronger woods to prevent breakage  
 ☑ Crib hardware must have anti-loosening devices to keep it from coming loose or falling off  
 ☑ Mattress supports must be more durable  
 ☑ Safety testing must be more rigorous

Beginning June 20, 2011 all cribs sold in the United States must meet new federal requirements for overall crib safety.

www.cpsc.gov  
 NCPSC  
 MDA 11.2  
 Issued by a Campaign of the U.S. Consumer Product Safety Commission

cpsc.gov/cribs



SafeSleepNC.org

## North Carolina Safe Sleep Campaign Contact Information



Home About Us Key Services Patient Education Materials Resources for Practice  
 Search MomBar

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megancanady@med.unc.edu

919-843-7865



SafeSleepNC.org

NC Department of Health and Human Services  
2019 SIDS Annual Update  
January 23, 2019



## Serving as a SIDS Counselor

### Notification of an Infant Death

- **Primarily:**
  - Received from the Office of the Chief Medical Examiner.
  - This information is sparse, only including the infant name, county, pathologist name and sometimes the date of birth and date of death.
  - This information is then shared with the counselors at the Local Health Department (LHD) using a Single Point of Contact (SPOC).

## Notification of an Infant Death

**“A new child case has been entered into the body tracking system for autopsy facility Body number: B2019XXXXX**

**Decedent: Baby S. Infant**

**County: Wake**

**Age: 8 mos.**

**Pathologist: John Smith”**

## Notification of an Infant Death

- **Secondarily:**
  - **Locally through communication with community partners.**
    - **This requires immediate communication with the Women’s Health Branch (WHB).**
    - **Prompts timely service provision to grieving families.**

## Following Notification

### • Discovery

- The counselor has the responsibility to use agency and local resources to determine more information on the deceased infant and their family.
  - Vital Statistics
  - CC4C
  - Child Health Clinics
  - First Responders- EMS, Law Enforcement
  - Obituary section of the newspaper
  - Local funeral home websites

## Following Notification

### • Sharing

- Once the counselor obtains the name and address of the grieving family, share it with the PM at WHB.
- A letter/resources is sent to the family
- A letter/ resources is sent to the counselor

### • Outreach and Service provision

- What does this look like?
  - Home Visits
  - Documentation
  - But what else...





## Supporting Bereaved Families

### Talking with Families in the Midst of Grief

- **SIDS Counselors are in a sensitive position**
  - This may make you feel unsure of what to say, how to say it and what to do.
  - Bearing witness to the grief of another person can be overwhelming and stressful
- **PRAM**
  - **P**ause
  - **R**eflect
  - **A**cknowledge
  - Be **M**indful

## Talking with Families in the Midst of Grief

### Outreach

#### Phone communication:

- **Avoid referring to self as “SIDS Counselor”**
- **Speak clearly and succinctly**
- **“My name is \_\_\_\_\_ from \_\_\_\_\_ I provide support to families whose babies have died. I want to know if I can provide that support to you and your family.”**
- **Indecisive-** reassure the caregiver that no decision is needed at this time. Ask them to think about it and that you will call them back in a (#) days. BE sure to keep your word.
- **Refusal-** leave an open door should their mind change. Ensure that no pressure is applied in any way to the family.

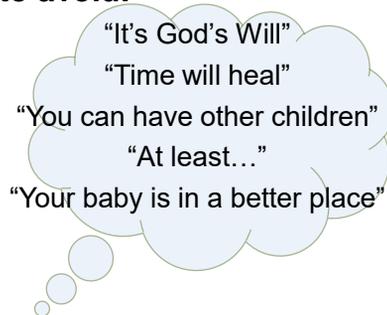
## Talking with Families in the Midst of Grief

### Initial Home Visit

- **Know and use baby’s name**
- **Open ended questions**
  - “Tell me about your baby”
  - “What’s your understanding of what happened?”
- **Avoid providing a premature cause of death**
- **Avoid saying, “I understand what you are going through” unless you have firsthand experience with grieving an infant loss**
- **Utilize active listening**
- **Silence is a tool**
- **Remember: Parents in crisis hear only 10% of what is shared**

## Talking with Families in the Midst of Grief

- **Other phrases to avoid:**



- **Do not complete the contact form in the presence of the family**
- **Be mindful of body language**
- **Mirror the position of the bereaved**

## Talking with Families in the Midst of Grief

### Follow-Up Home Visit

- **Prep caregiver for the wait**
- **Autopsy reports**
  - Preliminary findings
- **Be prepared for unknown/ undetermined findings**



## Safety and Self-Care

### Safety is a Priority

#### Practice sound home visitor safety

- Someone from your office should be aware
- Park your car where you cannot easily be blocked in
- It is ok to ask if anyone else is home
- Know where the exits are and never have your back to a door
- [Home Visiting Safety: Staying Safe & Aware on the Job](#)

## Self-Care is a Priority

- Debrief with your supervisor
- Maintain boundaries
- Engage with your own spiritual/ religious activities
- Adopt healthy outlets

Please feel free to direct all questions about the NC  
SIDS Grief Counseling Program to:



**Rebecca Severin, MPH, CPH**

**Maternal Health Program Manager  
Women's Health Branch**

**(919) 707-5680**

[rebecca.severin@dhhs.nc.gov](mailto:rebecca.severin@dhhs.nc.gov)

Thank you for participating in the 2019 SIDS Counselor Update.

Please follow the link to complete the evaluation

[https://unc.az1.qualtrics.com/jfe/form/SV\\_9ukk9KZoFUYjpkx](https://unc.az1.qualtrics.com/jfe/form/SV_9ukk9KZoFUYjpkx)

