



HOME MONITORING FOR SUDC SIBLINGS

Key points:

- **To help reduce the risks of death or illness in any baby or young child attend well child care visits, obtain healthcare when clinically indicated, maintain current vaccinations and follow the *Back to Sleep* and AAP recommendations to reduce the risk of Sudden Infant Death Syndrome (SIDS) and provide a safe sleep environment.**
 - **There are many options for monitoring- discuss them with your Pediatrician.**
 - **There is no scientific evidence that home apnea-bradycardia monitoring prevents infant deaths.**
 - **There has been no research on monitor use for SUDC siblings**
 - **Most SUDC parents choose some form of monitoring for their children into the toddler years. Unless abnormalities are found, there is no need to use home apnea-bradycardia monitors for SUDC newborn siblings after 3-6 months of age.**
 - **Monitors such as video, motion, sound and temperature are available through most baby product stores. These are not medical devices and do not require medical assistance to obtain them. There are no studies on their ability to prevent death.**
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How can you best protect your new baby or other children from dying, when you do not know what caused your previous child's death? This is a difficult question to answer. Clearly, if we knew the cause of SUDC, we could determine whether it was likely to happen again in your family, and we may be able to make interventions to prevent your other children from dying. However, since we do not know the cause of SUDC, and we do not know which children are particularly vulnerable, we do not have specific scientific information that assures us of preventing SUDC in any given child.

However, there are general things that every parent should do to reduce the risks of death or illness in any baby or young child. These include attending well child care visits, obtaining healthcare when clinically indicated, maintaining current vaccinations and the *Back to Sleep* recommendations to reduce the risk of Sudden Infant Death Syndrome (SIDS) and provide a safe sleep environment. The current recommendations (2005) of the American Academy of Pediatrics are listed below.

- Be sure to get good prenatal care and start it early in pregnancy. Do not smoke cigarettes during pregnancy. Do not drink alcohol or use any drugs or medications (including street drugs), which are not prescribed by and discussed with your physician.
- Once your baby is born, be sure that your baby sleeps flat on his/her back for their first year of life. Although sleeping on the stomach is the highest risk for SIDS, side sleeping also has an increased risk. Do not use propping devices to keep your baby on the side. Sleeping on the back is the safest position. Back sleeping has not been associated with an increased risk of aspiration (inhaled material that was spit up). This practice is not necessary after age one-year.
- Reduce the chance that flat spots will develop on your baby's head. Provide "Tummy Time" when your baby is awake and someone is watching them. Avoid too much time in car seats, carriers and bouncy seats.
- Do not smoke cigarettes around your baby/child. Do not let your baby/child be exposed to any cigarette smoke. Never allow anyone to smoke in the room where your baby/child sleeps.

The Sudden Unexplained Death in Childhood (SUDC) Program
c/o CJ Foundation for SIDS, The Don Imus-WFAN Pediatric Center, 30 Prospect Avenue, Hackensack, NJ 07601
Tel. (800) 620-SUDC Fax. (201) 996-5326 E-mail. info@sudc.org Web. www.sudc.org



- Use safe bedding for your baby/child to sleep on. This is a firm mattress, covered with a fitted sheet and without fluffy materials in the crib. Keep all bumpers, quilts, beanbags, soft mattresses, pillows, stuffed animals, etc. out of the crib. Your baby can play with these when he/she is awake, but they should not be around your baby when he/she is sleeping. Do not cover your baby's head with a blanket. It is best to use a one-piece suit for them to sleep in, or place your baby's feet to the foot of the crib and only bring a blanket to the mid-chest level.

- Keep your baby's sleep area close but separate from where you and others sleep. Your baby should not sleep in a bed or on a couch or armchair with adults or other children, but he/she can sleep in the same room as you. If you do bring your baby into bed with you to breastfeed, put him/her back in their separate sleep area, such as a bassinet, crib or bedside co-sleeper (infant bed that attaches to adult bed) when finished.

- Do not let your baby get too hot. Temperatures that are comfortable for you are best for your baby. Dress your baby like you dress yourself. If it is hot outside, and you are wearing cool clothing, dress your baby in cool clothing as well. This is less important after one-year of age. Keep your baby's room at a temperature that is comfortable for an adult.

- Breastfeed your baby if possible. Human milk has a number of health benefits for your baby.

- Recent studies have shown a decreased risk of SIDS among babies who use pacifiers. Think about using a clean, dry pacifier when placing your infant down to sleep, but don't force the baby to take it or reinsert it once the baby falls asleep. If you are breastfeeding, wait until your baby is 1 month old or is used to breastfeeding before using it.

These recommendations have been shown to reduce the risk of SIDS in all infants. Therefore, we recommend them for siblings of SUDC children as well.

Some Home Monitoring Options at a glance:

- A home apnea-bradycardia monitor is a medical device, prescribed by a Doctor that records chest movement (breathing) and the baby's heartbeat. The word "apnea" means a period of not breathing, and the word "bradycardia" means slow heart rate. However, the monitor's computer can detect high and low rates of both breathing and heart rate. Doctors can download the data it records to determine if the baby is having any episodes of concern.

- Sound Monitors- Available at most baby stores. They have a microphone that allows you to hear sound in the room with the baby by carrying a remote receiver.

- Temperature Monitors- Are included in some of the new sound, video and motion sensors.

- Video Monitors- Allows you to see what is going on in the room from a remote location.

- Motion Sensors- Detect motion of the baby often by a force plate placed under the mattress. Nothing is attached to the baby. If no motion is detected for more than 20 seconds, then an alarm sounds. It also has a green blinking light when it detects motion.

Medical Device: The Apnea-Bradycardia Monitor

Many SUDC parents ask about the use of a home apnea-bradycardia monitor to alert the caregiver should a life-threatening event occur, and/or to reduce parental anxiety.



A home **apnea-bradycardia monitor** is a medical device, which connects two electrodes to your baby's chest with a soft band or tape. The electrodes monitor your baby's heartbeat and movement of the chest (breathing). The monitor sounds an alarm if the heart rate goes below a set rate or if the baby's chest does not move for 20-25 seconds (apnea - or period of not breathing). However, these monitors are not perfect. They monitor movement of the chest, not air going in and out of a baby's lungs. A baby can have an obstructive apnea (tongue falling back against the back of the throat blocking the airway) in which the baby's chest is still moving. The monitor

will think the baby is breathing, and it will not sound an alarm. In addition, there can be a number of "false alarms", where the monitor sounds an alarm, but nothing is actually wrong with the baby. **The monitor does not do anything to save your baby.** The monitor sounds an alarm, and the parent needs to come to the baby, observe to determine if the alarm is real, and then intervene by arousing the baby or performing CPR if necessary.

Though studies have been conducted, there are no studies, which show that home apnea-bradycardia monitors prevent death in SIDS siblings (reference: CHIME study). In contrast, there have been no studies which have evaluated SUDC siblings and monitor use, and therefore there is no data of their use on this rare population is limited. In their 2005 policy statement, the American Academy of Pediatrics does acknowledge the benefits of apnea-bradycardia monitors to "allow rapid recognition of apnea, airway obstruction, respiratory failure, interruption of supplemental oxygen supply, or failure of mechanical respiratory support."

However, we do know that some babies have died while using home monitors, and their use did not prevent a SIDS death. Research studies have shown that babies have apneas (periods where the baby stops breathing) earlier than the peak age when SIDS occurs (2-4 months). Therefore, these types of apneas do not seem to be related to SIDS. Because these monitors are made for infants, they do not work as well for toddlers and older children. They can have frequent false alarms, and they do not accurately detect apneas in older children.

It should be emphasized that the only research to date is on siblings of SIDS infants, not siblings of SUDC children. Since we do not know the cause of SUDC, this leaves open the possibilities for diagnosis and management. Some physicians may prescribe home apnea-bradycardia monitors for infant siblings of SUDC children for the first few months of life as a diagnostic test to see if the baby has any apneas or bradycardias. There are no research studies to support or refute this practice, but it is reasonable to consider. Parents should discuss this with their pediatrician.

Since the goal of such monitoring is to see if a baby has any apneas or bradycardias, it is probably sufficient to monitor babies for the first 3-6 months of life, even though the SUDC child died at an older age. If a baby shows apnea or bradycardia alarms, which are real, then this may prompt further diagnostic testing. Since home apnea-bradycardia monitors do not work as well for toddlers and older children, the primary benefit would be to use these from birth until 3-6 months of age.

Psychological Factors to Consider

SUDC parents may require home monitors for emotional reassurance. They want to know that if an event occurs- they can respond as quickly as possible. It has been suggested that SUDC parents may be sufficiently anxious about suddenly finding their subsequent baby dead and that the use of a home monitor will reduce their anxiety and improve their parenting. There are no studies that have objectively evaluated the results of anxiety among parents who chose to use monitoring devices compared to those who do not.

Non-Medical Monitoring Devices Many SUDC parents report, using some form of monitoring, and often beyond the age of the death of the SUDC child, which may be well into the toddler years. Parents consider their child's medical need for apnea-bradycardia monitors, as well as the effectiveness of "over the counter" monitors available through baby stores.

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c/o CJ Foundation for SIDS, The Don Imus-WFAN Pediatric Center, 30 Prospect Avenue, Hackensack, NJ 07601
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Of these commercially available monitors, parents often consider using a **motion sensor type monitor**. An example is the “Angel Care” monitor. It senses **motion, sound** and also has a **thermometer** in the newest version. The Angel care utilizes a force-plate that is positioned under the mattress, and on top of box spring. Sometimes to improve sensitivity, a piece of plywood is recommended over the box spring and under the force plate and mattress. It detects motion of the baby through the mattress. Unlike the apnea monitor, nothing is attached to the baby, There are **video monitors** as well as simple sound monitors. None of these monitors are perfect. There are no studies on their ability to prevent death and parents should be fully aware of this when choosing how to monitor and supervise their child’s sleep. However, if parents, understanding this, derive reassurance, reduced anxiety, and rest, they may be an advantage.

SUDC parents can understandably report feelings of anxiety related to sleep related issues in their living children as a result of finding their child dead after a sleep period. They may worry each time they walk into their new baby’s room: “What will I find? Will they be alive?” Sometimes the use of a monitor may help with these issues. However, some families find the occasional false alarms increase their anxiety. As in grief, each person copes differently and therefore there is no one recommendation for all. Families may consider several options to help them achieve a peaceful, safe and hopeful home environment after the death of a child.

In summary, the best thing you can do is to obtain optimal pediatric care for your child and follow the Back to Sleep recommendations in the first-year of life. This is for all children, and therefore includes siblings of SIDS and SUDC. There is no scientific evidence that home apnea-bradycardia monitoring prevents infant or child deaths, and therefore it is not recommended for prevention of SIDS or SUDC. However, due to a lack of research on SUDC siblings, some physicians and parents may wish to use home apnea bradycardia monitors for diagnostic reasons, and/or emotional reassurance. In these instances, the monitors need not be used after 3-6 months of age unless abnormalities are found. Other types of monitors such as video, motion, sound and temperature are also available through most baby product stores. These are not medical devices and do not require medical assistance to obtain them. Ultimately, parents considering the use of monitors for their SUDC sibling should discuss all these issues with their pediatrician, who can help them make a choice based on their specific situation and needs.

Thomas G. Keens, M.D.
Professor of Pediatrics, Physiology and Biophysics
Keck School of Medicine of the University of Southern California
Childrens Hospital Los Angeles

Laura Crandall, PT, NCS
Program Director and Co-founder
The Sudden Unexplained Death In Childhood (SUDC) Program

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