Family Stories of Sleep-Related Loss

A Facilitation Guide for Using their Digital Stories



About the Project



The digital stories included in this guide were created by parents who lost an infant due to unsafe sleep. Through a workshop facilitated by StoryCenter (URL: https://www.storycenter.org/), the parents:

- Learned how to use video editing software and turned their stories into short videos.
- Wrote the stories they shared.
- Picked their own pictures, video clips, and music used in the videos.
- Recorded their own voices in the videos.

About the Guide



This is a facilitation guide for professionals who provide education on safe sleep to other professionals or parents. It is also for professionals who provide education and support to other professionals assisting a family after a death occurs. It provides guidance on how to use the included digital stories in a variety of settings.



Why Talking About Safe Sleep is Important



Every day in the United States, about nine babies die from sudden unexpected infant death (SUID), approximately 3,400 deaths per year. In 2020, SUID occurred more than deaths from suicide or homicide in all children under 18 years of age. In Michigan, a baby dies every two to three days due to sleep-related causes, approximately 145 deaths per year.

Sleep-related infant deaths occur when something in the sleep environment (sleep location, blankets, pillows, people) likely contributes to the death.

Why Using Stories Works



Stories have the power to connect with your audience in a way that simply sharing data and guidelines cannot.

Stories can be used to:4

- Raise awareness of an issue who is affected, what caused it, and how to change it.
- Help your audience remember the information being presented.
- Provide motivation for action.

Why Using Stories Works



Using one of the stories along with teaching the safe sleep guidelines can provide perspective and have a greater impact than data and/or the guidelines alone.

The stories remind us why we promote and follow safe sleep guidelines, because far too many families have been devastatingly changed forever.

Infant Safe Sleep Guidelines



Keep babies 0-12 months of age safe while sleeping at night and during naps by following the <u>American Academy of Pediatrics guidelines</u> (URL: https://shorturl.at/ehDK2) for every sleep time:

- **A A**lone (no toys, pillows, bumpers, blankets, other objects).
- **B** On the **B**ack on a flat surface.
- **C** In a **C**rib, bassinet or pack and play with a firm mattress and tightly fitted sheet.



For more information on the safe sleep guidelines, visit Michigan.gov/SafeSleep.

Warning

These stories were created for use with professionals and families. However, they can be difficult to watch. **Prior to showing the videos, they should be previewed by the presenter.**

Always provide your audience with a warning that the video you are showing is sensitive in nature - it talks about the death of an infant. Remind your audience that it's okay to turn off their camera or step away while the stories are being shared.

If appropriate, provide resources for additional support.

How to Use the Stories



Suggestions for use are provided because each story offers a unique perspective that may work better for different groups. The digital stories can be used in a variety of ways such as:

- Training sessions for professionals.
- Presentations for child death investigators.
- Education (group or 1:1) sessions for parents.

Background for Each Family's Story



To give some background to the digital story, each family shared details about their infant's death. Please share the background details of the family's story prior to showing their video.

Anthony's Story

Suggestions for Use Anthony's Story



- This video addresses safe sleep practices and co-sleeping. This video could be shared in presentations with families or professionals on infant safe sleep.
- The video addresses the grief and healing process and could be shared with grief support professionals or in a grief support group.

Background for *Anthony's Story*Written by his mom, Carole

View Anthony's Story

(URL: https://youtu.be/QiZaZCTsIO4)

Anthony was a happy 2.5-month-old baby. He loved music and being held. He was an amazingly good baby as well; he was almost always happy. Anthony passed away in 2016. Just a short 2.5 months of time we got to spend with him. He passed away due to unsafe sleep. We were co-sleeping with him and he became trapped beneath his blankets. Safe sleep is now a part of our family's story, and we try to spread the message of safe sleep for all babies. Anthony should have been sleeping in his own safe sleep space, without blankets. Anthony will always be remembered as a fresh start, a new beginning. His life still has meaning to us all, and we will continue to share his story in hopes to save just one more baby.

Discussion Prompts Anthony's Story



Note: These questions aren't recommended for use with grieving families.

- 1. What thoughts come to mind after hearing *Anthony's Story*?
- 2. What changes in your thinking or understanding about sleep-related infant death has taken place after watching this video?
- 3. How does this story help you understand the importance of following the safe sleep guidelines?
- 4. What does this story teach you about the grief and healing process?

Moments of You (Haddie's Story)

Suggestions for Use Moments of You



This video addresses the grief and healing process and highlights the importance of ensuring families have time with their deceased child. This video could be shared with first responders, hospital staff, medical examiner offices, grief support professionals, and others who initially care for the family after the death occurs.

Background for *Moments* of You Written by her mom, Sandy

Haddie was a bright-eyed, 9-monthold baby girl with the biggest toothy grin. She loved to laugh, cuddle, and bite (kiss) the people she loved the most.

In June 2015, Haddie fell asleep at day care for her nap and she woke up in the arms of Jesus. Haddie's death was unexpected, very sudden, and has changed our family's life forever.

Haddie suffocated on a blanket that shouldn't have been anywhere near her. Haddie had been napping for three hours, and it was estimated that she had been dead for an hour before she was found.

Background for *Moments* of You

Haddie loved to cuddle and that's exactly what she was doing when she died. She didn't know the blanket would kill her.

There are many safe sleep rules required by all licensed day care providers that were violated that day. If they had been followed, Haddie would still be alive today. We thought this tragedy would never happen to us, but our lives were changed forever in a blink of an eye.

Please take the time to educate yourself on the safe sleep guidelines and educate anyone who will care for your precious child. Our goal is that by sharing Haddie's Story that EVERY CHILD WAKES UP.

View Moments of You

(URL: https://youtu.be/stiCDvcO8U8)

Discussion Prompts Moments of You



- 1. What thoughts come to mind after hearing *Moments of You*?
- 2. What does this story teach you about the grief and healing process?
- 3. What does this story teach you about supporting families after a death has occurred?

Remember Xavier (Xaiver's Story)

Suggestions for Use Remember Xavier



This video addresses safe sleep practices and accidentally falling asleep while caring for an infant. This video could be shared in presentations with families or professionals on infant safe sleep, including planning for when the parent is tired.

Background for Remember Xavier Written by his mom, Renita

Xavier was born in 2020. He was healthy and strong and arrived in the world fist first like superman flying in the sky. Xavier's demeanor and presence was so happy and calm. He was my Sonshine.

One evening, my little Sonshine wanted to fight the sandman. He would not lay in his bassinet. He just wanted to be held. I sat on my bed and rocked him in my arms as I scrolled through the television to find something to watch until he fell into a deep sleep. I didn't know I would soon follow him in slumber.

On that early morning when Xaiver was 2 months old, I woke up and noticed it was daylight. My first thought was Xavier. I noticed I was still holding him the same way, cradled between my right arm and side breast. He looked asleep,

Background for Remember Xavier

so precious. I thought he was sleeping in because he was in his mommy's arms. I soon and quickly realized Xavier was not asleep. My one and only, my Sonshine, was no longer shining. My heart stopped. I immediately began CPR and called for help, but it was too late.

The plan was NEVER to co-sleep with Xavier. I knew the ABCs of safe sleep. He had a bassinet and a crib. My child and I were never to be a part of this statistic, yet somehow became part of the unfortunate numbers. Xavier's family and friends would like to ask you to join us in educating and advocating for safe sleep. It will help us protect and save precious lives.

Peace Love and Grace, Xavier's Parents

View Remember Xavier

(URL: https://youtu.be/3piFjQ9U-pw)

Discussion Prompts Remember Xaiver



- 1. What thoughts come to mind after hearing *Remember Xaiver*?
- 2. What changes in your thinking or understanding about sleep-related infant death has taken place after watching this video?
- 3. How does this story help you understand the importance of following the safe sleep guidelines?
- 4. What does this story teach you about helping families plan for what to do when they are tired?

Use of the Digital Stories



How do you plan to use these digital stories? How did you use these digital stories? How did it go?

If you'd like to share, please email the Infant Safe Sleep Program at MDHHS-InfantSafeSleep@michigan.gov.



Bereavement Resources



When the heartbreaking loss of an infant occurs, it is important that families receive grief and bereavement support. Below is a list of bereavement resources. It is not an exhaustive list.

- Bereavement Resources from the Fetal Infant Mortality Review Program (URL: https://www.michigan.gov/mdhhs/adult-child-serv/childrenfamilies/familyhealth/fimr/resources)
- What's your Grief A Grief Website for the Rest of Us (URL: https://whatsyourgrief.com/)
- New Hope Center for Grief Support (URL: https://newhopecenter.net/)

Contact Us

If you want to learn more about the stories or connect with the parents, email the Infant Safe Sleep Program at MDHHS-InfantSafeSleep@michigan.gov.





Gratitude & Appreciation

Words cannot adequately express our gratitude to the parents and families of Anthony, Haddie and Xavier. Your bravery, honesty and willingness to share your story has touched our lives forever and will help many babies safely reach and celebrate their first birthday.

References



¹Centers for Disease Control and Prevention, National Vital Statistics System, Mortality Files 2020, Retrieved from Data and Statistics for SIDS and SUID | CDC.

²Centers for Disease Control and Prevention, National Center for Health Statistics, Mortality 2020 on CDC Wonder Online Database.

³Centers for Disease Control and Prevention (CDC) SUID Case Registry – 2010 to 2020, Michigan Public Health Institute, 2023.

⁴Public Health Reaching Across Sectors (2020, July). *Strategic Storytelling for Public Health Messengers A Research-Based Toolkit*. https://www.phrases.org/wp-content/uploads/2020/07/Storytelling-Toolkit-Final.pdf.