



NAVIGATING LIFE AFTER

SIDS

SUDDEN INFANT
DEATH SYNDROME



COUNTY OF LOS ANGELES
Public Health

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A LETTER FROM LA COUNTY PUBLIC HEALTH

There are no words that can fully capture the pain and heartbreak of losing a child. The **Los Angeles County Public Health Department Sudden Infant Death Syndrome (SIDS)** Program wishes to express our deepest sympathy for what you are going through. It's a loss that no one expects. The sudden and unexpected nature of SIDS leaves many unanswered questions. Your feelings of sadness, confusion, anger, and/or numbness are valid and shared by others who walk this difficult path.

During this profound sorrow, you are not alone. Just like you, other parents have faced this unimaginable loss. However, due to the uniqueness of everyone, no one will truly know the depth of your experience, and the closest we can get to your understanding is a community who has a similar journey of loss. We encourage you to seek support, whether through counseling, support groups, or trusted loved ones. Speaking about your baby, and expressing your emotions are all part of a healing journey.

When you are ready, please review the enclosed folder with resources and information about SIDS.

Remember, SIDS happens without warning and without blame. You did everything you could to protect and love your child. The love you have for them continues to exist, even in their absence, and honoring that love can bring small steps toward healing.



INTRODUCTION

This handbook has been created to walk with you through this journey, to provide a space of compassion, and to offer comfort in the face of this profound loss.

Within these pages, you will find gentle guidance and supportive insights drawn from professionals, other bereaved parents, and resources dedicated to helping you find solace.

While no words can replace what you have lost, we hope this e-book can serve as a small light on your path toward healing, a resource that acknowledges your pain, respects your experience, and serves as a reminder that you are not alone in your grief.



QUOTES

These quotes may provide some comfort. These words can offer solace, understanding, and support through this difficult journey.

"Grief, I've learned, is really just love. It's all the love you want to give but cannot. All that unspent love gathers up in the corners of your eyes, the lump in your throat, and in the hollow part of your chest. Grief is just love with no place to go." — Jamie Anderson

"There is no footprint so small that it does not leave an imprint on this world."

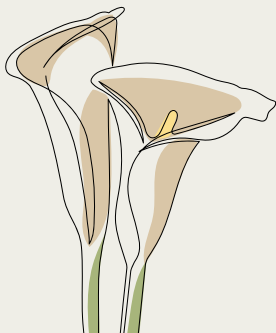
"Your child may have been here for a moment, but their memory will live on forever in your heart."

"Grief never ends... But it changes. It's a passage, not a place to stay. Grief is not a sign of weakness, nor a lack of faith... It is the price of love."

"When you lose someone you love, you gain an angel you know."

"No matter how brief a life, the impact of a child's love leaves an indelible mark on our hearts."

"Though we may never understand why, we carry the love and the memories with us always, finding new ways to honor them."



DEFINING SIDS

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WHAT IS SUDDEN INFANT DEATH SYNDROME (SIDS)?

SIDS is the sudden and unexpected death of a baby who seems perfectly healthy. Even after an autopsy, the reason for the baby's death is unexplained.

SIDS happens quickly and quietly. The baby is put to bed for a nap or for the night. When the baby is checked sometime later, it is discovered that the baby has died while sleeping.

Most babies have no sign of serious illness before the SIDS death. Some babies may have a slight cold or other mild illness. The autopsy may find little breaks in the blood vessels of the lungs or some swelling of the airway. None of these things would account for the death.

SIDS is one of the leading causes of infant death in infants between the ages of one month and one year. Most babies who die of SIDS are between 2 and 4 months of age. A few thousand babies die of SIDS every year in the United States alone. SIDS happens in families of all social, economic, and ethnic groups. SIDS happens everywhere in the world.



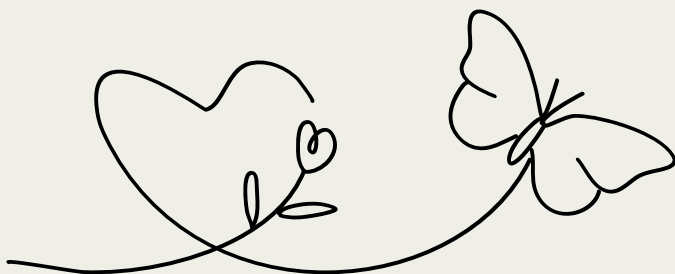
WHAT CAUSES SIDS?

No one really knows what causes SIDS. A great deal of research is going on. Scientists are studying babies and how their brains, hearts, and lungs work. They are learning about breathing and sleeping patterns. They are also looking into autopsy findings, among many other things.

SIDS is a natural cause of death.

- SIDS is not due to infections.
- It is not caused by immunizations.
- SIDS is not contagious.
- It is not hereditary.

Researchers are beginning to believe that SIDS may have something to do with how all babies normally breathe while asleep. However, the reason or the way babies die of SIDS is not yet understood. At this time, there is no way to predict or prevent SIDS.



FACTS ABOUT SIDS

SIDS IS ...

- The second leading cause of death for infants from one month to one year of age in California. Most of these infants die of SIDS during the first five months of life.
- Responsible for taking the lives of nearly two hundred babies each year in the state.
- A cause of sudden death for infants which can happen to any family, regardless of race, ethnic origin, income or background.
- A recognized medical disorder. No one can predict which babies will die from SIDS.
- Sudden and silent-the infant was seemingly healthy.
- Seasonal. In California, more SIDS deaths occur in the months of October through March.
- A death often associated with sleep and with no signs of suffering or crying out.
- Sometimes called “crib death” because babies who die of SIDS are often found in their crib.
- An infant death that leaves unanswered questions, causing intense grief for parents and families.

SIDS IS NOT ...

- A new disease. References have been noted dating back to 950 B.C.
- Caused by the diphtheria, pertussis, tetanus (DPT) vaccines or other immunizations.
- Caused by vomiting and choking or by minor illnesses such as colds or infections.
- Suffocation.
- Caused by cribs.
- Contagious or hereditary.
- Child abuse or neglect.
- The cause of every unexpected infant death.



GRIEF

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WHAT IS GRIEF?

There is no right or wrong way to feel. Each person's experience of grief is different and finding the support you need is important. Discuss with your healthcare provider how you are feeling and what supports are available to you.

Everyone grieves differently. There are no rules about how you should feel or behave.

You and your partner may show your grief in different ways. The way you grieve is affected by many things including your gender, culture, personality, and outlook.

Grief may occur after the death of your baby but may also be delayed and not appear until sometime after the loss has occurred. Some parents say that their grief is stronger at some times than others. For many parents, the death of their baby brings a grief that is unexpected, deep, intense, overwhelming, and often long lasting.

Try to talk about your thoughts and feelings, and how you would like to remember your baby. Be patient and caring with each other. It is important to talk with each other, as relationships can be affected by grief.



SIGNS OF GRIEF

Some people find it easy to express their feelings and ask people for support. Some people can be more reluctant to talk and may want to remain private in their grief. Strong feelings are very common.

Some signs of grief may include:

- crying and sadness
- anger, anxiety, or guilt
- feeling numb or unable to enjoy things as you usually do
- trouble getting to sleep or staying asleep
- changes to your eating habits (increase in unhealthy foods or no appetite at all)
- having trouble concentrating or making decisions
- feeling sick or tense

It is important to recognize the difference between grief, depression, and post-traumatic stress disorder (PTSD) after a significant loss. The symptoms can be very similar, and it is not always easy to tell them apart. Seek support from your healthcare provider if you are struggling to cope with everyday life, have feelings of self-harm, or your symptoms of grief are getting worse.



HOW LONG CAN GRIEF LAST?

Everyone is different. There is no 'right' length of time for grief to last. At times it might seem you will never feel 'normal' again. Many parents say their grief is lifelong and they just find ways of coping with it. Some may even feel guilty when there are happy life moments again. Parents who have had a baby that has died often recall many ups and downs before they began to enjoy life again.

Sometimes this means creating a new 'normal'. Allowing yourself the time and space to grieve and finding the support you need from others is important.



YOUR GRIEF IS AS UNIQUE AS YOU ARE

GRIEVING PEOPLE GO THROUGH MANY DIFFICULT FEELINGS

After the shock and numbness of the first few days begin to wear off, you may be left with depression. This can be brought on by thoughtless or innocent remarks from people who do not understand SIDS. You may go through these low points when it is the day of the week or the date your baby died. At times like these, it may help to talk to another SIDS parent or a public health nurse who understands SIDS.

You may find it hard to concentrate. It may be hard for you to read or write or make decisions. You may feel dizzy or have headaches. You may worry that you are losing your mind. These feelings are all normal for people in grief.

You may not be able to sleep. Bad dreams may replay over and over in your mind. You may become overtired. Even with sleep, you may always feel exhausted.

You may have muscular problems or other physical symptoms, especially around your heart or stomach. You may have no appetite. You may feel “tied in knots” inside. Your arms may ache to hold your baby.



GRIEVING PEOPLE GO THROUGH MANY DIFFICULT FEELINGS CONT...

You may feel like just running away. You may be afraid of being alone. You may worry that you or those you love are in danger. If you have other children, you may feel overwhelmed with fear for their safety. At the same time, you may not want the responsibility of caring for them. You may be irritated or impatient with the children's behavior.

You may lean on your family and friends for help. But at the same time, you may resent that help or feel guilty. If your friends and neighbors don't know about SIDS, they may end up saying the wrong thing. You just may not feel comfortable around these other people.

At times your grief may seem unbearable. You may feel that you can't go on. **Call your local SIDS group or LA County SIDS Program.**



STAGES OF THE GRIEF CYCLE

A framework for describing emotional and psychological responses to significant loss or change.

DENIAL

An individual may feel initial feelings of shock, disbelief, numbness, and difficulty accepting the reality of the loss or change.



ANGER

As reality sets in, feelings may turn to anger, frustration or helplessness. Individuals may feel a sense of injustice and blame themselves or others.



BARGAINNING

In an effort to regain control of the situation, an individual may attempt to negotiate with a higher power or others, and try to undo the loss.



DEPRESSION

Feelings of sadness, despair, emptiness and loneliness may set in as the individual comes to terms with reality.



ACCEPTANCE

An individual begins to accept the loss and finds a way to move forward, making plans for the future and finding a new purpose in life.



COMMON QUESTIONS

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COMMON QUESTIONS

I FEEL SO GUILTY AND ANGRY AT THE SAME TIME. WAS ANYONE AT FAULT?

No one is to blame for SIDS. Almost all parents or caregivers feel in some way to blame for the baby's death until they begin to understand the facts about SIDS. Sometimes parents blame each other. Sometimes families blame the caregiver, or the doctor who said the baby was healthy.

It is important to know that:

- No one can tell ahead of time whether a baby will die of SIDS.
- No one can stop SIDS from happening.

Nothing you did caused the baby's death.



COMMON QUESTIONS

DID OUR BABY SUFFER?

SIDS happens very suddenly and all at once. The baby may move a little in the last few seconds. This would account for the crumpled covers or unusual positions in which babies are sometimes found. Babies do not cry out and show no sign of having been disturbed in their sleep. They simply stop breathing and die very peacefully.

COULD THE BABY HAVE VOMITED AND CHOKED?

SIDS is not caused by vomiting or choking. Sometimes milk or a blood-tinged froth is found around the baby's mouth, nose, or on the bedding. This happened after the baby died. The autopsy shows that the airway was not blocked by this fluid.



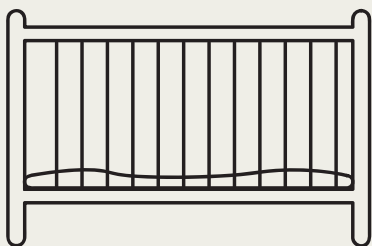
COMMON QUESTIONS

I HAVE HEARD THAT THE BACK TO SLEEP RECOMMENDATIONS COULD HAVE PREVENTED MY BABY FROM DYING OF SIDS. IS THIS TRUE?

There is no way to prevent a SIDS death. Researchers have learned that parents can reduce the risk of SIDS by placing babies to sleep on their backs, avoiding cigarette smoke, breastfeeding, not letting their babies get too hot, keeping soft blankets and pillows out of the crib, and not sleeping in the same bed with their baby.

Sleeping on the stomach, exposure to cigarette smoke, over-bundling, etc. are risk factors for SIDS, but they do not cause SIDS. By avoiding these risk factors, parents have greatly decreased the overall number of babies dying from SIDS. However, there are still babies that die from SIDS, even those who have avoided the risk factors. We do not know why.

Current research is looking at why these risk factors increase the risk of SIDS which may lead to finding the cause(s). For now, there is nothing a parent could have done to prevent their baby from dying of SIDS. Parents can only reduce the risk.



COMMON QUESTIONS

IS SIDS CONTAGIOUS?

COULD OUR OLDER CHILDREN GET IT TOO?

SIDS is not contagious. It cannot be spread from person to person. There is no need to be afraid of touching the clothing, bedding, or furniture of the baby who died of SIDS. SIDS only happens to babies up to the **age of one**. Older children do not die of SIDS.

OUR BABY HAD JUST GOTTEN HER DTP SHOT.

IS SIDS CAUSED BY DTP?

SIDS is not caused by the DTP shot or any other immunization. This has been shown by several studies. SIDS happens in babies who have never had shots of any kind. SIDS happens at the same rate in countries where DTP is given at a later age or not at all.

MY BABY SEEMED SO BRUISED. COULD SIDS HAVE BEEN CAUSED BY CHILD ABUSE?

SIDS is not caused by child abuse or neglect. Sometimes a SIDS death may not be discovered for a few hours. The changes that happen in the baby's body after the death may make it look like the baby was injured. But everyone, the police, paramedics, parents and caregivers should realize that these changes after death are normal.



COMMON QUESTIONS

WOULD IT HAVE HELPED IF OUR BABY HAD BEEN BREASTFED?

While breastfeeding does not prevent SIDS, it has been shown to significantly reduce the risk. SIDS has happened all through recorded time even when nearly all babies were breastfed. SIDS happens to both breastfed and bottle-fed babies.

WHAT IS THE RISK FOR BABIES WE MIGHT HAVE IN THE FUTURE?

SIDS is not hereditary. Most future babies (over 999 out of 1000) will not die of SIDS. You can learn more about it by talking to your doctor or by calling the California SIDS Program.



OTHERS AFFECTED

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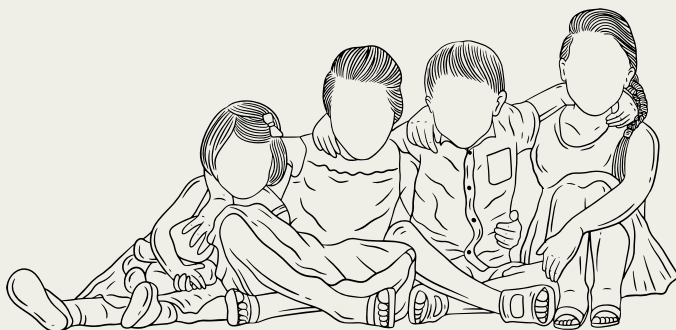


SIBLINGS WILL ALSO BE AFFECTED DEEPLY BY THE DEATH OF THE BABY

Smaller children need love and affection. They may have some very frightening thoughts that they cannot express: Did I cause the baby to die? Will I die, too? Will Mommy and Daddy die? Who will take care of me now? They may cling to their parents and do other things to get attention. It is very important for them to know that they are loved and secure.

Older brothers and sisters will go through their grief in different ways depending on their ages and past experiences. Sometimes they feel guilty because they think they may have caused the baby's death. They may be very sad or may not show their feelings at all.

Children should be told as much about the death as they are able to understand. It's a good idea to be open in talking about thoughts and feelings.

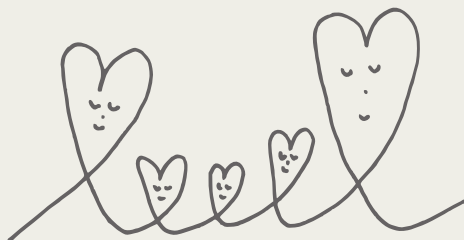


SIBLINGS WILL ALSO BE AFFECTED DEEPLY BY THE DEATH OF THE BABY

As adults talk freely, children will better be able to talk about how they feel. They will feel free to ask questions about the death. It is best to be clear about the baby's death, as children can worry and be confused about statements like: "The baby went away" or "The baby is sleeping in peace." It is important to explain that SIDS happens only to babies and not to older children or adults.

Many children have been sources of strength for their families. They have written poetry and often show an amazing faith and understanding of the pattern of life and death. They may also show their sorrow in other ways. They may have nightmares, wet the bed, or have a hard time in school. A doctor or counselor may have good ideas for helping children through this difficult time.

Even years after the baby's death, children will need to talk about what happened. As they grow up and have new questions, they will need more information.



SOMETIMES THE BABY IS WITH ANOTHER CAREGIVER WHEN SIDS HAPPENS

It is important for that person to get help and support, too. SIDS groups have volunteers who can give that kind of help. Literature and counseling can be very reassuring for anyone going through this.

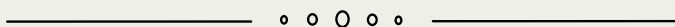
EVERYONE GOES THROUGH THEIR GRIEF IN DIFFERENT WAYS.

Some people may need to “talk out” their grief. Others may keep their feelings to themselves. Some parents may even take on extra work to keep from thinking about the loss all the time. Some parents find it hard to ask for help and support from others.

Often the loss of the baby is the first loss either parent has gone through. Grief is very intense and each person’s experience is different. This may cause tension and a feeling of being all alone. It may be a struggle to find ways to understand and support each other. It helps to be able to talk about feelings openly, even though that can be difficult.



RESOURCES



TALKING TO OTHERS

Explaining SIDS to others can be incredibly difficult. An option can be having a close friend or relative to provide information to others for you. This time can also be used to educate others as there are misconceptions about SIDS.

Here are some tips you may consider:

- **Set boundaries:** It's okay to decide how much you want to share and with whom.
- **Educate gently:** Many people may not understand SIDS. Sharing factual information can help reduce stigma or misconceptions.
- **Express your needs:** Let others know how they can support you—whether you need someone to listen or simply acknowledge your loss.

**Remember: You did not do anything wrong.
SIDS is unexpected and at times unexplainable**



MY STORY

My name is Rachel Strickland, and I lost my son Hayden to AIDS, September 27, 2003. I know how hard it is to be in the situation you're in today. I remember the feeling of being lost, scared, angry, and empty. Having another parent to talk to who had lost a child was one of the best things in my healing process.

My husband Shawn found Hayden in his crib that fateful night and I remember the night as if it was yesterday. I can't promise you a happily ever after life but I can tell you, that you will be able to breathe a little easier as each minute, hour, day goes by.

This is what I call my "new normal"; life as we knew it and now you know it, is over and will never be the same. I hope that when you feel the strength to do so, you will reach out to me. I am here for you, if you have questions, want someone to cry with, or be angry with.

Feel free to e-mail me, call me, or text me at any time.

In his name,

Rachel Strickland
714-305-0421
rstrickland41@gmail.com



WHERE CAN I CALL FOR HELP AND TO GET MORE INFORMATION?

The California SIDS Program can help:

- Connect you with your local SIDS support group or your local public health nurse.
- Answer questions you may have.
- Assist you with helpful booklets and pamphlets.



COUNSELING AND MENTAL HEALTH RESOURCES

Seeking counseling can provide crucial support for navigating grief and other feelings. A counselor can offer coping strategies, a safe space to process emotions, and help in finding a path toward healing

SIDS 24/7 Grief line:

- 1-800-221-7437

Virtual Support Group Return to Zero: H.O.P.E.

- <https://rtzhope.org/>

Empty Cradle Support Group

- <https://www.emptycradle.org/support-meetings>

Los Angeles County Mental Health

- 24/7 help: LACDMH Help Line (800) 854-7771
- <https://dmh.lacounty.gov/resources/grief-loss/>

Kaiser Permanente

- <https://meetmonarch.com/therapists/grief-kaiser-permanente/california>

Our House Grief Support Center

- <https://www.ourhouse-grief.org/groups-at-our-centers/>

Pregnancy and Infant Loss Support Group (PSI) Online Support

- <https://www.postpartum.net/group/pregnancy-and-infant-loss-support-for-parents/>



COUNSELING AND MENTAL HEALTH RESOURCES CONT...

Maternal Mental Health Now-Supporting Parents

- Call or text 1-888-823-7262
- <https://www.maternalmentalhealthnow.org/sana/>

The Healing Hearts Infant Bereavement Group:

- healinghearts@cribsforkids.org
- <https://www.facebook.com/groups/healingheartsinfantbereavement/>



IN PERSON SUPPORT GROUPS

Little Angel of White Memorial

- <https://www.facebook.com/littleangelesofwhitememorial/>

Compassionate Friends

- <https://www.facebook.com/compassionatefriendsla/>
- <https://www.compassionatefriends.org/find-support/chapters/chapter-locator>



RESOURCES

California State Department of Public Health, SIDS program:

<https://www.cdph.ca.gov/Programs/CFH/DMCAH/SIDS/Pages/default.aspx>

GENETIC TESTING

Genetic testing can provide answers in some situations, such as identifying genetic vulnerabilities, understanding underlying conditions, family history insights, advancing research, and personalized risk assessment.

The following are resources to help you obtain more information:

- **Roberts Program at Boston Children's Hospital**
 - robertsprogram@childrens.harvard.edu
- **Cardiogenomics Program at Children's Hospital Los Angeles**
 - 323-361-2461
- **Aeron's Foundation**
 - info@aeronsfoundation.org



WAYS TO REMEMBER YOUR BABY

You will always be reminded of the baby that died and wonder what they would have been like if they had lived.

Some things that may help are:

- Collecting things that remind you of your baby
- Having a service for your baby
- Writing your thoughts and feelings in a journal
- Lighting a candle
- Planting a small shrub in a pot to honor your baby
- Choosing a symbol to remember your baby, such as a bird or butterfly, that feels closely connected to you when you see it
- Having a piece of jewelry made with your baby's initials or birthstone



JOURNAL

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Journaling can be a powerful tool for healing and processing grief. Here are some prompts to help you get started.

- Describe your feelings today. How have they changed since your loss?
- What are some things you wish you could say to your child right now? Write them a letter.
- Describe a simple moment that, looking back, means so much more now.
- List three things or people that have supported you through this difficult time. How have they helped?
- What is one promise you'd like to keep in your child's memory?

Remember, there's no right or wrong way to write in your journal. It's a space for you to feel, reflect, and honor your journey. Be gentle with yourself. 💜



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