

SUDC

FOUNDATION

Sudden Unexplained Death in Childhood

FAMILY RESOURCE GUIDE

The SUDC Foundation provides all services at no cost to the people it serves.

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www.sudc.org

Dear Family Member,

We extend our deepest condolences to you and your family during this time. We understand what a confusing and tragic time this can be for you and want to provide you support.

At the SUDC Foundation, you are not alone.

Since 2014, the SUDC Foundation has opened its doors to assist families dealing with the inexplicable tragedy of sudden unexpected death – whether still under investigation, explained or unexplained. **We hope to help all families pursue a clear understanding for their profound loss and support them in their grief.** Regardless of where your family finds themselves now or in the future, please know that our services are available to you.

Services are available at no cost to you due to the generosity of private donations and fundraising efforts. Those efforts also allow us to advocate for the many needs of SUDC. Through our years of service, we have supported more than 1,700 families residing in 21 countries. Sadly, our SUDC community continues to grow every year. Our current services for families include:

- Individualized case advocacy to assist families with navigating the death investigation process.
- Personalized support by our social worker.
- Unique private web-based support groups.
- Peer Connection Program matching trained family volunteers with newly bereaved.
- Resources for siblings, grandparents, and extended relatives.
- Children's memorial page.
- DNA banking services.
- SUDC research opportunities.
- Support for hosting events to benefit SUDC.

Some of the information enclosed may be too difficult to read or digest right now. Everyone grieves differently. **Utilize what is helpful to you now and revisit it again when it is right for you.** As we get to know you and discuss how the services of our organization might be of assistance to you, please know that all information is kept confidential. If you have any questions regarding the enclosed, or the SUDC Foundation, please contact us, so the Foundation can help to meet your specific needs.

In great sympathy and support,

The SUDC Foundation

TABLE OF CONTENTS

PAGE 1

SECTION 1: We Raise Awareness

- 1.1 Local / Regional Advocacy: Strength by the Numbers
- 1.2 Collaborations and the SUDC Foundation's Volunteer Ambassador Program
- 1.3 Legislative Advocacy
 - 1.3a Scarlett's Sunshine on Sudden Unexpected Death Act
 - 1.3b Reflections on a Six-year Journey of Advocacy

PAGE 5

SECTION 2: We Fund Research

- 2.1 The SUDC Foundation Funds Research
 - 2.1a The SUDC Registry and Research Collaborative
 - 2.1b Cardiac Channelopathies & Testing Options
- 2.2 SUDC Statistics
- 2.3 Evaluating Research Publications

PAGE 13

SECTION 3: Family Advocacy Services

- 3.1 Family Advocacy Services
 - 3.1a Individual Case Advocacy
 - 3.1b Is Your Investigation Still Pending?
 - 3.1c Caring for the SUDC Family During Investigation
- 3.2 When the Death Investigation Is Complete
- 3.3 DNA Banking
- 3.4 What You Need to Know if You Are Expecting

PAGE 19

SECTION 4: We Serve Families

- 4.1 Introduction and Overview of our Services
 - 4.1a Member Services Access and Summary
 - 4.1b Reflections on SUDC Family Day 2020
- 4.2 What is Grief?
 - 4.2a Prolonged Grief Disorder
 - 4.2b When to Seek Immediate Assistance
 - 4.2c Suggestions for Coping with Grief and "Active" Coping
 - 4.2d Ways to Help Fathers Grieve
 - 4.2e Dos and Don'ts for Family & Friends
 - 4.2f Suggestions for Communicating with the Bereaved
- 4.2g Additional Resources for the Bereaved

- 4.3 Understanding Trauma & Loss
 - 4.3a Professional Support & Interventions When Needed
 - 4.3b Helping Someone through Emotional & Psychological Trauma
 - 4.3c Trauma and Your Brain
 - 4.3d Grief, Stress, and Relationships
 - 4.3e Another Birthday Letter
 - 4.3f One Moment at a Time
 - 4.3g Picking up the Pieces
 - 4.3h Returning to Work: One Mom's Experience
 - 4.3i Additional Resources

4.4 Telemarketing and/or Mailing List Removal

- 4.5 Supporting Children in Grief
 - 4.5a Understanding Grief in Children

- 4.6 Suggestions on How to Tell a Child Someone Died
 - 4.6a Don't Forget the Kids
 - 4.6b Sibling Grief
 - 4.6c We're Not Really Alone: The Importance of SUDC Awareness
 - 4.6d How Children React to Emotional & Psychological Trauma
 - 4.6e Additional Resources for Children

- 4.7 Supporting Grandparents in Grief
 - 4.7a Insights from a Grandmother's Grief Journey: Ronnie Was the JOY in Our Lives
 - 4.7b Sudden Unexplained Death in Childhood for Grandparents ... a "Double" Grief
 - 4.7c Locating Additional Local Resources
 - 4.7d Additional Resources for Grandparents

- 4.8 Remembering Your Child with an Event
 - 4.8a Finding Gratitude Through the Love of Strangers

- 4.9 Memorial Tribute Pages
 - 4.9a Memorial Tribute Page
 - 4.9b Memorial Instagram Page

PAGE 61

SECTION 5: Reflections of Hope

- 5.1 Stories
 - 5.1a Amy Was the Centre of Our Family, And Suddenly She Was No Longer Here
 - 5.1b Mom's Search for Meaning
 - 5.1c Life After Tragic Loss

- 5.2 Poems
 - 5.2a Support

- 5.3 Quotes

WHO WE ARE & WHAT WE DO

OUR VISION:

A world without Sudden Unexplained Death in Childhood (SUDC).

OUR MISSION:

Raise awareness, fund research, and serve those affected by sudden unexpected or unexplained death in childhood.

OUR VALUE:

We are the only organization worldwide whose purpose is to raise awareness, fund research, and serve those affected by SUDC. SUDC is the fifth leading category of death in children ages 1 to 4, yet SUDC receives no public funding. The SUDC Foundation provides all services at no cost to families.

THE SUDC FOUNDATION:

- **Funds Research**

The SUDC Foundation provides grants that will further our understanding of the cause(s) and ways to prevent SUDC.

- **Serves Families**

The SUDC Foundation currently supports over 1,700 families in 21 countries. It provides personalized comprehensive care from clinical social workers and cultivates a community of support for bereaved families, so no one grieves alone. The Foundation also helps families navigate the difficult and often confusing investigation into their child's death by being a liaison between families and the medical examiner or coroner. It also assists families in accessing research and DNA banking services, which could lead to answers on what may have happened to their child.

- **Assists Medical Professionals**

The Foundation provides resources to help medical examiners and coroners, pediatricians, and other doctors care for and communicate with families experiencing the sudden, unexpected, and unexplained loss of a child.

- **Raises Awareness & Advocates for the SUDC Community**

The Foundation supports efforts, including legislative, to ensure comprehensive and standardized death investigations. It also advocates for fair treatment of and appropriate medical care for families and thorough data collection to improve our understanding of SUDC.

The SUDC Foundation provides all services at no cost to the people it serves.

★ Section 1

We Raise Awareness

1.1 Local / Regional Advocacy: Strength by the Numbers

The SUDC Foundation helps local advocacy efforts focused on improving the care of families and the investigation process by connecting our network of registered families living in the same region and working with local organizations with common goals.

1.2 Collaborations and the SUDC Foundation's Volunteer Ambassador Program

The SUDC Foundation partners with organizations that share common goals to further our reach in advocacy, awareness, and education. The SUDC Foundation's past and current Board of Directors actively participate in attending, presenting, and exhibiting at related conferences to provide a platform to educate on both a small and large-scale basis and to network with individuals who can help support our mission.



You can also help by becoming a member of our Ambassador Program. You can learn more at www.sudc.org/ambassador-program.



The SUDC Foundation Ambassador Program is the Foundation's formal volunteer program. It was created to empower SUDC advocates to raise awareness of SUDC and support the mission of the SUDC Foundation. The program will:

- Leverage our growing community worldwide.
- Create an army of advocates to support the organization.
- Highlight the many faces and voices of SUDC (families affected, medical examiners, coroners, pediatricians, researchers, and all supporters of SUDC awareness and advocacy).
- Support consistent messaging for SUDC.
- Increase outreach efforts.
- Strengthen connections across the SUDC community.

1.3 Legislative Advocacy

SUDC advocacy extends into the legal system and public policy. The SUDC Foundation works to advocate, support, and promote state and national legislative efforts to improve comprehensive and standardized investigations, fair treatment of families, and thorough data collection to improve our understanding of these rare tragedies, and aid in their prevention.



1.3a: Scarlett's Sunshine on Sudden Unexpected Death Act

One such piece of legislation is Scarlett's Sunshine on Sudden Unexpected Death Act, which was signed into law on December 31, 2020. This bipartisan, bicameral legislation strengthens existing efforts to better understand Sudden Unexplained Infant Death (SUID) and SUDC, facilitate data collection and analysis to improve prevention efforts, and support children and families.

Spreading Scarlett's Sunshine

By Stephanie Zarecky, Mother of Scarlett (08/31/15 - 01/08/17)

In the fall of 2018, a little girl with big, blue eyes, a smile that could light up a room, and a personality to match her name left her mark on history when Scarlett's Sunshine on Sudden Unexpected Death Act was introduced into Congress. And in the waning days of 2020, her spirit toddled back through the halls of the Capitol when it was officially signed into law to combat sudden, unexpected infant and child deaths.

Scarlett's Sunshine on Sudden Unexpected Death Act is intended to supply grants to help states and municipalities improve data collection and death scene investigations related to unexpected infant and child deaths, promote safe sleep practices, and ensure death reviews are completed for 100 percent of infant and child fatalities. Currently, there are no nationwide standards in the United States for investigating and collecting data following an infant or child death. This makes it often impossible to determine the causes of these deaths, and what strategies the country can implement to prevent these tragedies.

Scarlett's Sunshine Act is bipartisan, bicameral federal legislation introduced by U.S. Senators Bob Casey (D-PA), Johnny Isakson (R-GA), Sherrod Brown (D-OH), and Doug Jones (D-AL) in the U.S. Senate, and Representatives Gwen Moore (WI-04), Tom Cole (OK-04), and Jaime Herrera Beutler (WA-03) in the U.S. House of Representatives.

This legislation is very important to me personally because I am Scarlett's mother. Scarlett was a happy, healthy, thriving little girl until January 8, 2017, when she passed away in her sleep when she was just 16 months old. We still do not know why.

Scarlett's Sunshine Act was named after her at the request of Senator Casey, for whom I used to work. During my time working for him, I got to know Senator Casey as a doting father to his four beautiful daughters and a dedicated public servant with a devotion to issues involving children's health. After we lost Scarlett to SUDC, the Senator and his wonderful staff wanted to find a way to help. They worked with other congressional offices and infant and child health advocates, including the SUDC Foundation, and Scarlett's Sunshine Act was born.

The bill was given its name after Scarlett's favorite song, "You are my Sunshine." Since losing her, we have referred to our efforts to honor her and raise awareness of SUDC as spreading her "sunshine" in her memory, and this legislation allows it to continue to spread throughout the country.

The bill is also important to me because of my devotion to the SUDC cause. Through my work for the SUDC Foundation, as well as establishing the Scarlett Lillian Pauley Foundation with my husband, it has become my life's purpose to care for Scarlett by working toward a future when no more children are lost to SUDC and no more families suffer the pain we do.



Stephanie and daughter Scarlett



Like many SUDC families, the loss of our precious daughter is magnified by the fact that we don't know what happened to her. And it is amplified by the fact that most people have never heard of the medical mystery that took her from us. In addition to the attributes of the bill itself, the greatest piece, at least for our family, is that it helps to bring a national spotlight to SUDC.

As more people learn about SUDC, it is our hope it will help more families to find the support we have found in the SUDC Foundation. And perhaps even more people will find it in their hearts to support the cause that is so dear to ours, not only for Scarlett, but for all the beautiful children lost to SUDC who are deeply loved and dearly missed.

To learn more about Scarlett's Sunshine Act and other legislative activities underway, go to sudc.org > What We Do > Raise Awareness > Legislation > Policy. You can also help with our advocacy efforts by becoming a member of our Ambassador Program. You can learn more at www.sudc.org > How to Help > Ambassador Program.



1.3b Reflections on a Six-year Journey of Advocacy



Laura Gould stands to the right of President Obama and Congressman Pallone in the Oval Office, Washington, D.C., on December 18, 2014.

The Sudden Unexpected Death Data Enhancement and Awareness Act Becomes Law

By Laura Gould, SUDC Foundation Co-founder & President (ret.)

After six years of tireless advocacy, the SUDC Foundation celebrated federal legislation in the United States signed into law by President Obama on December 18, 2014; legislation that is deeply personal to all those who have lost a child to stillbirth, Sudden Unexplained Infant Death (SUID) and Sudden Unexplained Death in Childhood (SUDC).

The Sudden Unexpected Death Data Enhancement and Awareness Act (SUDDEAA– S.2746/HR.669) was first introduced into Congress in 2009 by the late Senator Frank Lautenberg (D-NJ) and by Congressman Frank Pallone (D-NJ). In the wake of Senator Lautenberg's death in 2013, the

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SECTION 1: We Raise Awareness

bill found new champions – Senator Sherrod Brown (D-OH) and Senator Kelly Ayotte (R-NH) – to carry it forward.

Looking back, I doubt anyone could have convinced me where my journey following the death of my daughter would lead. I never would have imagined a meeting in the Oval Office with the President of the United States, as he signed into law an Act that would be the first acknowledgment by our government that SUDC exists. The Act builds upon existing activities at the Centers for Disease Control and Prevention (CDC) to improve the quality and consistency of data collected during death investigations to better inform prevention and intervention efforts. This enables doctors and researchers to better track, research and prevent these tragic losses, and is a vital step forward for all efforts. Family advocates worked together, partnering with scientists and over 25 endorsing organizations to educate Congress on the critical needs that exist in our current system. We spoke from the heart with sobering facts to pave our way. These facts included:

- In 2013, over 3,500 infants and over 230 toddlers died suddenly and without explanation, and over 26,000 babies were lost to stillbirth.
- Sudden infant death rates first decreased in the mid-1990s during the “Back to Sleep” campaign but have remained unchanged since the late 1990s.
- Inconsistent data collection of fetal, infant, and childhood deaths limits our ability to fully inform parents and address these public health issues.
- Death investigations of these children need to be standardized and resourced, and the resultant data centralized and specifically studied for us to see progress.

Bereaved parents and grandparents came to Washington showing their incredible bravery and determination. They shared their stories of loss in the hope that it might somehow help spare someone else from knowing their deepest pain. The capacity of the human spirit to both endure and show compassion to our fellow man was exhibited in every one of the congressional visits, phone calls, and emails sent, and I wish I could thank every single person who helped make our voices heard in Washington. Through broken hearts – we did it!

It was an amazing and surreal experience to be in the White House receiving a hug from the leader of the free world, as we marked the signing of the SUDDEAA into law. I will never forget it and will always feel like I am floating a bit when I retell the story. But if I live to be 100, I think I will still feel most grateful and proud to have been a part of a journey with so many wonderful people selflessly helping to make the world a better place.

To learn more about the SUDDEAA, visit sudc.org >What We Do > Raise Awareness > Legislation & Policy.



★ Section 2

We Fund Research

The SUDC Foundation is dedicated to identifying and funding research grants that will further our understanding of the cause(s) and ways to prevent SUDC. The SUDC Foundation provides research grants to projects endorsed by the Foundation's Scientific Advisory Board and approved by the SUDC Board of Directors. Through an aggressively funded research agenda, the SUDC Foundation is committed to one day living in a world without SUDC.

What Is SUDC?

Sudden Unexplained Death in Childhood (SUDC) is a category of death among children between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy. Most often, a seemingly healthy child goes to sleep and never wakes up. At this time, we do not know what causes SUDC, or how to predict or prevent it. A medical examiner or coroner could rule a child's death SUDC when they complete a thorough evaluation and find no other cause of death. They may also describe the death as being "undetermined" because the specific cause was unable to be determined.

Any questions? We're here to help!

2.1 The SUDC Foundation Funds Research

The SUDC Foundation frequently educates its registered families on the potential benefits of research opportunities available to them and refers the family to enrollment resources if they choose to participate.

2.1a The SUDC Registry and Research Collaborative



At the SUDC Foundation, we often address questions – from the families we serve, in particular – on the relationship between the SUDC Foundation and the SUDC Registry and Research Collaborative (SUDCRRC). While the two entities frequently partner together to foster high-quality research and to promote family bereavement support



throughout research participation and beyond, they are each their own independent entities.

The SUDCRRC is a research study of New York University (NYU) Langone Health and is funded by the SUDC Foundation. The study operates under the direction of Dr. Orrin Devinsky.

The study was created in 2014 and is a multi-site collaborative with research partners at the NYU Langone Health, Columbia University, the Mayo Clinic in Minnesota, forensic pathologists across the U.S., and medical examiner and coroner partner offices.

The purpose of the SUDC Registry and Research Collaborative (SUDCRRC) is to increase the understanding of the characteristics, circumstances, medical histories, and pathologies of children from ages 11 months through 18 years who have died suddenly and unexpectedly, and, in some cases, without explanation.

The SUDCRRC will analyze cases of sudden unexpected deaths in these children to understand risk factors and causes, and to develop preventative measures. By bringing together these rare cases, the SUDCRRC hopes to support grieving families with a greater understanding of their child's death and to support medical research efforts into all causes of SUDC. The goal is to study 400 children to enable new discoveries.

The SUDCRRC will also do the following:

- Review the child's death, medical, and family history. Our pathologists (including forensic, pediatric, cardiac, and neuropathologists) will use this information to determine whether a possible, probable, or definite cause of death can be identified, and whether additional studies might be helpful in determining a specific cause of death.
- Offer cardiac pathology and neuroimaging/neuropathology consultations, for case investigations that are open/active.
- Perform genetic analysis (whole exome sequencing) when viable samples are available on the child who died, both biological parents, and some close relatives when clinically indicated. Clinically significant results are returned to families to assist in their clinical care. For more information, please see our Genetics Frequently Asked Questions.
- Study the risks that lead to SUDC.
- No cost to families who enroll.
- Provide families with a secondary review of their child's death through a case review report.
- Identify at-risk individuals with the hopes of gaining knowledge to establish prevention strategies to reduce the chances of sudden unexplained death in the future.

Requirements to participate in research include:

- Must be a parent or guardian of a child from 11 months through 18 years of age who has died suddenly and unexpectedly.



- The cause of death is unknown or unclear/speculative.
- An autopsy was conducted, and information is available for review.

Exclusion criteria are: cases of apparent suicide or homicide, or accidents where the external cause was the obvious and only reason for death.

If you would like to learn more about SUDC research or have questions about possible enrollment for your family, please contact: support@sudc.org.

For more information on the SUDCRRC, you can also visit: www.sudc.org > What We Do > Fund Research > SUDC Registry Collaborative.

2.1b Cardiac Channelopathies & Testing Options

What Is Long QT Syndrome?

By Michael Ackerman, M.D., Ph.D.

Long QT Syndrome (LQTS) is a disorder of the electrical system in the lower chambers of the heart (ventricles). The mechanical or pumping function of the heart is normal. However, the recharging (repolarization) system of the heart is either slow, taking longer than normal to recharge, or inefficient (disorganized). It is just one type of cardiac channelopathy.

LQTS can be divided into two broad categories: congenital and acquired. In acquired LQTS, the electrical recharging abnormality is secondary to medications, abnormalities in electrolytes, or other illnesses, like anorexia nervosa, that prolong the QT interval. In contrast, congenital LQTS is known as a primary cardiac ion channel disease due to mutations in the genes encoding the proteins (ion channels) responsible for this electrical recharging process. It is estimated that one in 3,000 people may have congenital LQTS.

Overall, in congenital LQTS, approximately 40 percent of patients experience a long life with no symptoms. However, five to 10 percent of patients encounter sudden death the first time the heart “spins electrically out of control.” Symptoms depend entirely on whether the long QT heart remains in normal rhythm albeit with abnormal recharging or degenerates into a potentially lethal rhythm like ventricular tachycardia or ventricular fibrillation. If the dangerous rhythm is ever so brief before the heart “catches itself,” the person may not even notice it or sense brief rapid heartbeats (palpitations). The most common symptom is fainting spells usually in the setting of the “fight-flight-fright” response, such as fainting during an athletic or recreational activity like baseball, the 100-yard dash, swimming, or following a sudden startle like the doorbell, alarm clock, or telephone ring. Again, the person wakes back up rather than die because the heart “snaps back” into a normal rhythm on its own. Occasionally, LQTS can be misdiagnosed as seizures or epilepsy.

Postmortem Evaluation of Long QT Syndrome (LQTS), CPVT, Brugada Syndrome and Other Cardiac Channelopathies Today

Today, two options exist as set forth below to diagnose Long QT Syndrome in a person that has died. Both have their pros and cons. Discuss these options with your doctor so you can come to the best decision for your family.

- I. Commercial, clinical LQTS genetic testing via private companies. It generally requires out of

[continued...](#)



pocket payments as health insurance Usually does not cover the costs of a person who has died.

- II. Research Options, including genetic analyses through enrollment in the SUDC Registry and Research Collaborative (Section 3.4a) participation. There is no cost to participants, but the time commitment is longer.

References:

Ackerman MJ, Priori SG, Willems S, Berul C, Brugada R, Calkins H, Camm AJ, Ellinor PT, Gollob M, Hamilton R, Hershberger RE, Judge DP, Le Marec H, McKenna WJ, Schulze-Bahr E, Semsarian C, Towbin JA, Watkins H, Wilde A, Wolpert C, Zipes DP. HRS/EHRA expert consensus statement on the state of genetic testing for the channelopathies and cardiomyopathies this document was developed as a partnership between the Heart Rhythm Society (HRS) and the European Heart Rhythm Association (EHRA). Heart Rhythm. 2011 Aug;8(8):1308-39. doi: 10.1016/j.hrthm.2011.05.020. PMID: 21787999.

2.2 SUDC Statistics

Although less common than Sudden Unexpected Infant Death (SUID), SUDC is critically deserving of attention and commitment from the field of medicine, public health, and society as a whole. In fact, according to the 2020 statistics referenced below, it is the fifth leading category of death among children aged 1 to 4 years in the United States but has yet to receive any specific public research funding to date.

SIDS and Undetermined Child Death Crude Rates/100,000**, 2011-2018 in the US

Year	Under 1 yr	Age 1-4 yrs	Age 5-9 yrs	Age 10-14 yrs	Age 15-19 yrs
2011	69.7	1.5	.1	.1	.4
2012	69.6	1.4	.2	.1	.6
2013	66.4	1.4	.1	.1	.5
2014	66.8	1.3	.1	.1	.4
2015	69.6	1.4	.2	.2	.5
2016	69.3	1.5	.1	.2	.7
2017	67.3	1.5	.2	.2	.4 (15-18yo)
2018	67.9	1.4	.2	.2	.4 (15-18yo)

Statistics above are based on ICD-10 Codes R95-R99 from CDC Wonder Database

*Death rates for infants less than 1 year of age are calculated per 100,000 live births; death rates for children over the age of 1 are age adjusted per 100,000 children.



For more information on SUDC statistics, go to:
www.sudc.org > What Is SUDC > SUDC Facts and Statistics.



Sudden Unexpected Infant Death (SUID) is the death of an infant less than 1 year of age that occurs suddenly and unexpectedly, and whose cause of death is not immediately obvious before investigation. Most SUID cases have a final cause of death reported as one of three types: Sudden Infant Death Syndrome, unknown/undetermined cause, or accidental suffocation and strangulation in bed.

Based on the above statistics, those affected by sudden unexplained death in 2021 occurred in:

- 249 children ages 1 to 4 years.
- 50 children ages 5 to 9 years.
- 44 children ages 10 to 14 years.
- 107 teens ages 15 to 18 years.

10 Leading Causes of Death By Age Group, United States- 2019

Rank	Age Groups										All Ages
	<1	1-4	5-9	10-14	15-24	25-34	35-44	45-54	55-64	65+	
1	Congenital Anomalies 4,301	Unintentional Injury 1,149	Unintentional Injury 714	Unintentional Injury 778	Unintentional Injury 11,755	Unintentional Injury 24,516	Unintentional Injury 24,070	Malignant Neoplasms 35,587	Malignant Neoplasms 111,765	Heart Disease 531,583	Heart Disease 659,041
2	Short Gestation 3,445	Congenital Anomalies 416	Malignant Neoplasms 371	Suicide 534	Suicide 5,954	Suicide 8,059	Malignant Neoplasms 10,695	Heart Disease 31,138	Heart Disease 80,837	Malignant Neoplasms 435,462	Malignant Neoplasms 599,601
3	Unintentional Injury 1,266	Malignant Neoplasms 285	Congenital Anomalies 192	Malignant Neoplasms 404	Homicide 4,774	Homicide 5,341	Heart Disease 10,499	Unintentional Injury 23,359	Unintentional Injury 24,892	Chronic Low Respiratory Disease 133,246	Unintentional Injury 173,040
4	SIDS 1,748	Homicide 284	Homicide 155	Homicide 191	Malignant Neoplasms 1,368	Malignant Neoplasms 3,577	Suicide 7,525	Liver Disease 8,098	Chronic Low Respiratory Disease 18,743	Cerebrovascular Disease 129,193	Chronic Low Respiratory Disease 156,979
5	Pregnancy Comp. 1,245	Heart Disease 133	Heart Disease 91	Congenital Anomalies 189	Heart Disease 872	Heart Disease 3,495	Homicide 3,446	Suicide 8,012	Diabetes Mellitus 15,508	Alzheimer's Disease 120,090	Cerebrovascular Disease 150,005
6	Placenta Cord Membranes 742	Influenza & Pneumonia 122	Chronic Low Respiratory Disease 69	Heart Disease 87	Congenital Anomalies 390	Liver Disease 1,112	Liver Disease 3,417	Diabetes Mellitus 6,348	Liver Disease 14,385	Diabetes Mellitus 62,397	Alzheimer's Disease 121,499
7	Bacterial Sepsis 603	Perinatal Period 57	Influenza & Pneumonia 52	Chronic Low Respiratory Disease 81	Diabetes Mellitus 248	Diabetes Mellitus 887	Diabetes Mellitus 2,228	Cerebrovascular Disease 5,153	Cerebrovascular Disease 12,931	Unintentional Injury 60,527	Diabetes Mellitus 87,647
8	Respiratory Distress 424	Septicemia 53	Cerebrovascular Disease 37	Influenza & Pneumonia 71	Influenza & Pneumonia 175	Cerebrovascular Disease 585	Cerebrovascular Disease 1,741	Chronic Low Respiratory Disease 3,592	Suicide 8,238	Nephritis 42,230	Nephritis 51,565
9	Circulatory System Disease 406	Cerebrovascular Disease 36	Septicemia 31	Cerebrovascular Disease 48	Chronic Low Respiratory Disease 168	Complicated Pregnancy 532	Influenza & Pneumonia 951	Nephritis 2,269	Nephritis 5,857	Influenza & Pneumonia 40,399	Influenza & Pneumonia 49,783
10	Necrotizing Enterocolitis 354	Neoplasms 49	Neoplasms 31	Benign Neoplasms 35	Cerebrovascular Disease 158	HIV 496	Septicemia 812	Septicemia 2,176	Septicemia 5,672	Parkinson's Disease 34,435	Suicide 47,511

SUDC* = 203

SUDC* = 39

*R96-99 is defined in ICD-10 as "ill-defined and unknown cause of mortality" and is currently our only measure of the incidence of SUDC. If included in the leading cause of death ranking chart, SUDC would be ranked 5th in 1-4yo and 9th in 10-14yo.

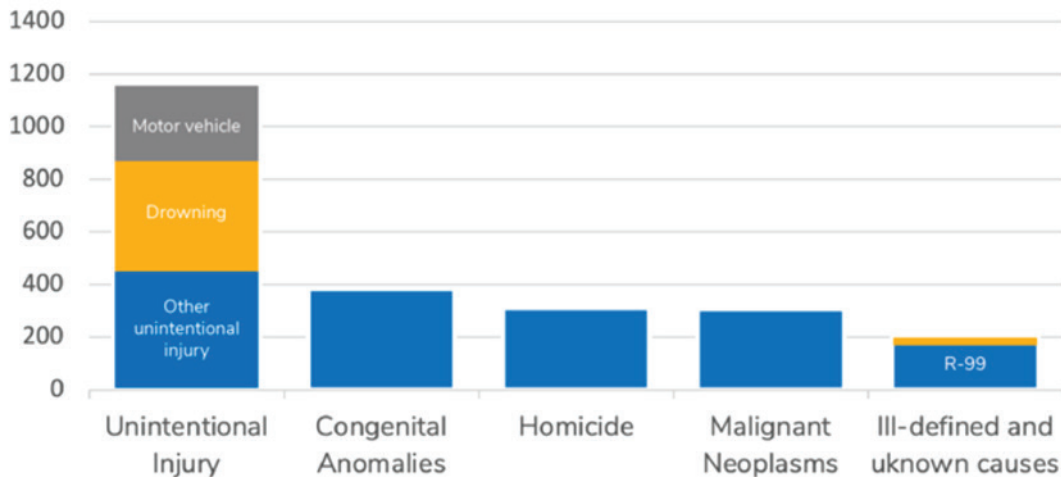
Data Source: National Vital Statistics System, National Center for Health Statistics, CDC.
 Produced by: National Center for Injury Prevention and Control, CDC using WONDER™.





Leading Causes of Death

Ages 1-4: US 2020



Source: CDC, National Vital Statistics System, 2020

2.3 Evaluating Research Publications

We all want answers. We desperately want to understand what happened to our child and know how to prevent it. For this, we need to know the truth that is only uncovered by good science.

Laura Gould, former President of the SUDC Foundation (ret.), wrote a blog article titled, “Don’t Board the Roller Coaster of Media Headlines” to assist bereaved families in navigating media headlines.



Below, we also provide guidance on being a critical reader of scientific research to help guide you as you learn more about what is scientifically known about SUDC and the quality of the science available.

Being a Critical Reader of Scientific Research

Take caution in digesting the meaning and quality of any research publication by the abstract alone. This is the brief summary of the article that is listed at the beginning of the paper. If you don’t have access to the actual papers but would like to read them, please contact the SUDC Foundation.

Be a critical reader of research and channel your inner detective. Whether someone you know is the author or not, read it from the standpoint that this paper needs to prove to me what they did was reasonable and above all be “good science” – with sound methods and analyses.



Just like viewing newspaper headlines that leave you without critical details and objectivity, so do media reports around research “discoveries” and the real credibility or lack of credibility of the findings. How often have we heard about new research proving the cause of SIDS is A, B, or C? Try not to believe what the media says. Read the full scientific article, contact the author, if need be, or ask SUDC Foundation staff and then make your own conclusions.

Usually, research publications follow the same general format: abstract, background, methods, results, and discussion. All sections are important, and you don’t need to be a scientist to notice when something doesn’t add up. Ask yourself, “Do the methods make sense?” The discussion can never consider every question a reader might ask, but do you notice anything else in the data that is not discussed? And why do you think that is? I often read papers where SUDC deaths are only a minority of the cases included, and don’t often get a lot of attention, but the data is often there to learn from. The discussion also needs to describe one of the most important things; the limitations of the paper. Look through them carefully as they usually put the data in a more realistic and less than perfect light. YouTube has some good videos on being a critical reader of research. We encourage you to watch some.

Two examples to watch are:



Critical Evaluation of Scientific Articles

Six-minute video that is good for understanding the structure of a scientific article



Critical Appraisal of Evidence

Four-minute video discussing bias

Two things to note and understand about these papers are: the value of population-based data and the difference between correlation and causation.

Population-based studies are highly regarded because they are considered to reflect the true incidence of what is being studied versus a possible bias in the study’s sampling. For example, we can look at the incidence of febrile seizures in the families registered at the SUDC Foundation, but that percentage may be higher, lower, or the same amount than the actual incidence in the general population. Maybe more families who have experienced febrile seizures are looking for support and contact the SUDC Foundation in higher numbers. Maybe more have read some of the papers associating febrile seizures with some cases of SUDC. The SUDCRRRC and the national “Sudden Death in the Young Registry” collect some population-based data as they try to find the real incidence of sudden death in children and their underlying causes.



SECTION 2: We Fund Research

Correlation is a connection or relationship between two things. Causation is the relationship where one thing causes another (the effect) to happen. Causation is much harder to prove scientifically.

Finally, as SUDC families we are always looking for answers; sometimes with desperation. Try to be conscious of your emotional needs and how they may affect your perception of what you are reading or watching on the news or hear about in general. We have many more questions than we have answers today, but we are finally seeing more research into SUDC, and that is a huge step in the right direction.

Recent Publications related to SUDC can be found on our website. Please go to www.sudc.org > What We Do > Advocate for Research > Published Research. You can also use this QR code.



★ Section 3

Family Advocacy Services

3.1 Family Advocacy Services

3.1a Individual Case Advocacy

Advocating for families is at the core of the SUDC Foundation's mission. Since medicolegal investigations – which are official investigations or inquests into the manner, cause, and circumstances surrounding death – vary widely across regions and countries, the SUDC Foundation offers its assistance to help families navigate this often confusing and stressful process. At a time of chaos, we are here to:

- Provide accurate information to help you navigate and understand the investigation process and beyond.
- Provide communication assistance between you, your investigative professionals, and your pediatrician or other medical professionals involved in caring for surviving family members and providing referrals to clinical specialists.
- Assist professionals with information and resources to support a comprehensive investigation.
- Provide research opportunities to those interested.
- Assist with your specific requests (e.g., “Do you know how I can get my child’s blanket back?”).

Advocacy at the SUDC Foundation continues to evolve according to the needs of the SUDC community.

Family advocacy is always geared to the specific needs of each family given their specific circumstances. To learn more, go to www.sudc.org > Family Services, or email support@sudc.org for assistance.

3.1b Is Your Investigation Still Pending?

For families experiencing the recent loss of a child, this is not only a time of extreme grief, but often one of chaos, confusion, and questions. Why did my child die? What about the health of remaining family members? What should I do?

If your child's death is recent and the investigation is still ongoing, please consider reviewing the following information and discussing it with the SUDC Foundation Family Services staff by reaching out to support@sudc.org. We can help you and even help communicate with your office.

Assist the medical examiner or coroner in their investigation. The more information they have about your child, the more thorough the investigation can be, which will assist them in attaining the most accurate understanding of their death.

What you should consider asking.

Ask them when/how you will receive updated information and provide them feedback on your preferences. In particular, ask them when/how you will be informed of their final opinion on your child's cause of death. Sometimes people are caught off guard with how they are informed, whether it be an unexpected phone call or letter/report in the



mail. Let them know if you have preferences, such as a scheduled phone call when both parents will be available and together, a letter in the mail, or sometimes families prefer the office informs your pediatrician, family doctor, or the SUDC Foundation first. If you would like the SUDC Foundation to help in any way, please let us know. We are familiar with the process and can help guide you in this.

Some Frequently Asked Questions about the Investigation:

How long will the death investigation take?

- Timeframes vary greatly from state to state and even office to office. It is best to ask your investing office how long their current timeframes are for case completion. Each case investigation is unique and will vary based upon testing being pursued by the pathologist.

What does it mean to have “pending further investigation” listed on the initial death certificate?

- Investigations will include an evaluation of the scene when the person was found unresponsive or where the terminal incident occurred by law enforcement and other agencies as dictated by local policies or statute. If the death is sudden and unexpected, most jurisdictions charge the local medicolegal death investigating agency (often medical examiner or coroner) to investigate the death. For a sudden child death, this will/should include interview(s) with caregivers, review of the scene, review of the medical records, and circumstances of death followed by an autopsy with ancillary testing as clinically indicated. When the initial or gross autopsy (what the pathologist can determine on the day of the procedure) is inconclusive and the cause and manner of death is not understood, they will issue a preliminary death certificate and describe it as “pending further investigation,” which allows for burial/cremation and conveys that further investigation/testing must be performed to determine the cause and manner of death and the creation of a final death certificate.

What is the gross autopsy?

- Gross autopsy means the anatomical examination of a body without microscopic examination and/or additional ancillary testing.

What is ancillary testing, and what kind of additional/ancillary testing is performed?

- Ancillary testing refers to the additional tests ordered by the pathologist to assist them in understanding the cause and manner of death. This may include, but is not limited to, toxicology, x-rays, metabolic testing, microbiology (to assist with understanding infection), vitreous studies and genetic studies. The pathologist will determine what ancillary tests to order on a case-by-case basis. The finalized autopsy report will usually include the list of all tests or order, but this should not be assumed.

Consider viewing our blog section on sudc.org for related articles like: Understanding “Cause” and “Manner” of Death (July 23, 2019), Understanding Genetics (3-part series May to July 2019), Why Can’t they Tell Me “when” my child died? (January 28, 2020) and others that may be helpful to you during this time.



3.1c Caring for the SUDC Family During Investigation



“Caring for the SUDC Family: Medical and Bereavement Information for the Clinician’s Consideration” is a document provided at www.sudc.org > What We Do > Serve Those Affected > Medical Care After SUDC. Please review, share, and discuss this document with your doctor. This will aid you and your physician in assessing and developing an appropriate screening plan for your family. There are some types of sudden death that have a genetic predisposition, and

these screenings can help to better evaluate your family, including surviving and future siblings, and address their care and safety needs. The document also provides guidance on mental health needs for all family members.

Contact your primary care physician and pediatrician. Inform them of your child’s death. They probably were already contacted by the Medical Examiner and Coroner to provide your child’s medical records as part of the investigation, but they may not have been and may not be aware of their patient’s death. Provide, and review with them, the above document to design an appropriate screening plan for your family and how they can support you through the death investigation process.

3.2 When the Death Investigation Is Complete

When the death investigation is complete and autopsy report is finalized, regardless if a specific cause of death is identified or not, many families feel a wave of grief that brings them back to the early days after their child’s death. Once again, your body and mind are forced to process the unthinkable.

The final cause of death opinion, as determined by the medical examiner or coroner, also brings forth many new questions and feelings. The SUDC Foundation Family Advocacy services are available to discuss any of the issues below and can provide assistance with obtaining a copy of the report for you.

- **Reading or Not Reading the Autopsy Report** – The autopsy report is a medical investigative document. They are usually clinical and sterile in nature – like a surgical report. The report is graphic in ways that are often surprising to parents. It will provide weights and measurements and findings from inside the child’s body. Pictures could be or could be not included, but reading about the procedures performed does create images in one’s mind. Some also include drawings and/or sketches of the person who died to indicate findings on visual inspection (e.g. abrasions or evidence of trauma, tattoos, evidence of medical interventions are some examples).

Unfortunately, once you have read it, there is no way to “unread” it and to get those thoughts and visions out of your head. There is no right or wrong regarding reading the autopsy report, as everyone needs to choose what is best for them. But beforehand, please consider:

- Why do you want to read it? Do you have reasonable expectations of how it will help you? For example: Reading an autopsy report to find out why your



child died, when the cause of death was undetermined, will not meet your expectations.

- Not reading it at first but reviewing it with a medical professional who will be able to better answer your questions.
- Ask the medical examiner or coroner for a phone call to explain their findings. Or ask SUDC staff to help facilitate a meeting, or to review the report with you.
- Another option is to consider having your pediatrician or primary care provider review the report and discuss the findings. After a verbal review with a medical professional, you may be able to decipher better if reading the report is the right thing for you.
- Provide the final opinion to the SUDC Foundation and send us a copy of the report. If you have additional questions that you need help with, we can assist you and provide guidance on attaining a second opinion or research options.
- The report will always be available. Whether you read it today, next year or five years from now, it will still be there. Don't put pressure on yourself to make a decision if you are not sure of what would be best for you.
- **Contact your local police office or coroner's office.** Once the case is closed and finalized, if you would like to obtain any of your child's belongings that might have been taken during the investigation, they should be able to be returned to you at this time. The SUDC Foundation can also help you with this process.
- **Contact your primary care physician, pediatrician, and the SUDC Foundation** with your child's final cause of death opinion. Your child's pediatrician may have also received a copy.
- **"Caring for the SUDC Family: Medical and Bereavement Information for the Clinician's Consideration"** is a document provided at www.sudc.org > What We Do > Serve Those Affected > Medical Care After SUDC. Please review, share, and discuss this document with your doctor. This will aid you and your physician in assessing and developing an appropriate screening plan for your family. There are some types of sudden death that have a genetic predisposition, and these screenings can help to better evaluate your family, including surviving and future siblings, and address their care and safety needs. The document also provides guidance on mental health needs for all family members.
- **Consider research opportunities.** In cases of SUDC, the finality of the autopsy report does not provide clarity on why your child died. Often families want to pursue additional avenues to gain insight into their child's death, as well as help medical research to prevent other children from dying. Our website, www.sudc.org, contains information on research opportunities known to us, including the SUDC Registry and Research Collaborative (SUDCRRC). If your child's death is "explained," depending on the specific cause of death, research options may or may not be available. Please visit the website and contact us if you have any questions.
- **Services are available to you.** In cases where a final cause of death opinion does yield a specific diagnosis, this may lead to many more questions. Please contact us so we can assist you. **Whether your child's death is explained or**





unexplained, services of the SUDC Foundation are available to anyone with an unexpected death of a child ages 12 months to 18 years. About 25% of our families do obtain a specific diagnosis. Our experience is that whether your child's investigation yields a specific diagnosis or not, the support of others who have lost a child unexpectedly can be a vital resource in your grief journey.

3.3 DNA Banking

The SUDC Foundation encourages DNA banking of the child who died whose cause of death is unclear. DNA banking secures a genetic sample from your child (possible specimens include but are not limited to specimens stored as part of autopsy, their newborn screening card, and/or cord blood). Stored DNA can possibly provide you with additional options to pursue more information about his or her death. As clinical testing advances and research options improve, you may want to access these opportunities.



Securing a genetic specimen (DNA) from your child may provide:

- The opportunity for genetic testing to uncover specific cause of death and appropriate testing of family members.
- The opportunity for genetic testing to provide negative results – which may assist in decreasing some anxiety.
- The opportunity for storing a genetic specimen or banking DNA, which can:
 - Instill hope for cases that currently defy understanding.
 - Allow for participation in present or future research.
 - Allow families to benefit from potential benefit of future discoveries.

Through DNA banking, you will know the quantity and quality of DNA available, which will allow you to make informed decisions on its use. The SUDC Foundation's Family Advocate works closely with families to coordinate and manage this process for them. This is another service of the Foundation for you if interested. Financial support for this service is also available for families in need.

Upon completion of DNA banking, the child's DNA will be stored in a DNA banking facility. Access and approval of any withdrawals can only be authorized by the parents and/or legal guardians of the child. The SUDC Foundation helps families with the process of DNA banking, but we have no authority over its use. Those decisions are entirely under the parents'/legal guardians' control.

For more information on how to learn more about DNA banking, go to: www.sudc.org > Serve Those Affected > Securing & Banking DNA.



If you are interested in pursuing DNA banking, contact: support@sudc.org.



3.4 What You Need to Know if You Are Expecting

If you are pregnant or become pregnant, we look forward to hearing of your child's safe arrival! We also know that pregnancy after a loss can be a very different pregnancy, an often-bittersweet time, that can bring up questions and anxiety that can seem overwhelming at times.

Please discuss this information with your doctor. It can be helpful in providing appropriate medical care for you and your new baby. It can also be a tool to discuss your concerns and possibly lower your anxiety.

The SUDC Foundation has specific support groups to connect families during pregnancy and when caring for a new baby. For many, connecting with others in similar circumstances can be helpful. It can also be a resource for concrete strategies for parenting following a loss.

Newborn Screening Considerations

Go to www.sudc.org > Serve Those Affected > Medical Care After SUDC.

Support for Expectant Parents

After a family has suffered the death of a child to SUDC, the decision to have another child can be daunting. Pregnancy can often bring a mix of hope, excitement, anxiety, and stress. These feelings often permeate, in some fashion, through the newborn period and the early years of life or the age of your child who died. Parents often describe the time as “bittersweet.” They may have feelings of happiness for their precious new child, but tremendous sadness that the child who died is not there. It is another definable mark that life is going on, despite their immense loss.

Parents may also express new concerns regarding their ability to parent again. They may worry about becoming so overprotective that they create an environment that limits their child's freedom and creativity. They may fear that “it” will happen again. Parents often think: “If doctors can't tell me why my child died, how can anyone be sure it won't happen again?” They may be afraid to love this child, in fear of being hurt again if this child were to die, too. At times, the worry can seem all-consuming. For mothers, this worry may be compounded by the hormonal shifts of pregnancy and the postpartum period. These are feelings that most parents cannot understand, unless they, too, have had a child die.

Since its creation, the SUDC Foundation has provided support and information to hundreds of families. It is important for parents to know they are not alone. Many of our families have subsequent children that grow up to be thriving, happy, and healthy adults. Some of these families will volunteer in our peer connection program and can be a comforting and hopeful ear for those experiencing pregnancy and caring for a new baby. We also have an online email group especially for parents who are expecting or are caring for a new baby. Please contact the SUDC Foundation with any concerns or questions you may have. Know you are not alone.



Our Family Support Services

The SUDC Foundation provides comprehensive services to meet the needs of those impacted by the sudden, unexpected, or unexplained death of a child. There is no cost for families to receive any of our services. We are an international foundation working with families in over 21 countries. The SUDC Foundation family community is a welcoming, safe, and supportive place for any family who has lost a child.

4.1 Introduction and Overview of our Services

Services for our families include, but are not limited to:

- **Individualized care** to meet the unique needs of the families we serve. Our staff, including our social worker, will work with you to determine the best ways our services can support you. If you are looking for help with something that is not covered by the below, please contact us! If we can't help, we will try to assist you in finding out who can.
- **Private support network and closed Facebook Group** for registered members providing family support, advocacy, and information surrounding SUDC.
- Assistance with helping you find additional **local services** as an adjunct to the SUDC Foundation's services. (See Section 4.7)
- The **Peer Connections Program**, which connects newly bereaved families with trained peer connection friends who have been affected by SUDC.
- Ongoing **grief resources** emailed to you during the first year, and extensive information available on sudc.org.
- Your **personal liaison with the Medical Examiner or Coroner office**, to ensure sensitive care of families during the investigation process, advocate for our needs now, and opportunities moving forward. We know that just calling them can be overwhelming. We can help. (See Section 3)
- **Webinars** to assist families affected by SUDC to cope with their traumatic loss, understand the scientific issues around SUDC, and be informed.
- Assistance accessing **medical information** (Section 3), **DNA banking** and **the SUDC Registry and Research Collaborative (SUDCRRC)** (Section 2).
- Information and training resources to help families get involved through advocacy, events, volunteerism, and fundraising to help honor their child. (See Section 5)
- Ongoing information through the **SUDC Foundation's blog, our public SUDC Foundation Facebook page, our monthly e-newsletters, and our semi-annual print newsletters**. They can all be accessed through sudc.org.

For more information and training resources to help families get involved through advocacy, events, volunteerism, and fundraising to help honor their child, please email development@sudc.org.



SECTION 4: We Serve Families

4.1a Member Services Access and Summary

Our Member Services Access page is a centralized location on our website to access any/all of our services. It is available only to registered families through their personal login information. After your initial registration, our social worker will contact you to ensure you can freely access all of the below.

The Member Services Access Page can be found by going to www.sudc.org and entering your username and password on the “Log In” page located in the top left corner of the screen. Then, go to the “Member Services” tab on the top right. If you can’t locate your username or password, please call 800-620-SUDC or email support@sudc.org. We are happy to help you.

We have organized the page to meet your most pressing needs, including enrollment in Family Services.

On the next page is a summary of what you will find on the Members Services Access area. Log in today and contact us with any questions you may have.

Family Services



Introduction to Family Services

New to the SUDC Foundation? Start here by completing our Services Enrollment Form to sign up for the Foundation's valuable support services.

- ✓ Fill out our Services Enrollment Form
- ✓ Family Resource Guide



Community Support

Connect with other families that have experienced SUDC through our supportive programs. No matter where you live in the world, or how often you'd like to chat, there is an option to meet your needs.

- ✓ Facebook Family Support- Closed Groups
- ✓ The SUDC Foundation Network
- ✓ Peer Connections Program
- ✓ New Jersey Area Monthly Support Meeting



Information Resources and Family Events

Utilize these helpful resources for education and support. Need more information, or not finding what you are looking for? [Contact us](#) and we will have the answer.

- ✓ Webinars & Videos
- ✓ Grief Resources & Book Lists
- ✓ Pediatric Monitors for Siblings
- ✓ Upcoming Events on Our Calendar
- ✓ SUDC Family Day 2020
- ✓ SUDC Family Retreat 2019
- ✓ SUDC Family Retreat 2018



FAMILY SERVICES

- **SUDC Foundation Family Support Facebook Group:** Our organization moderates a private Facebook group, which is easily found at www.facebook.com and available to registered SUDC family members (parents, grandparents, and relatives.) Once approved, group members can take part in an interactive forum to communicate with and support other SUDC families, as well as learn about relevant health and science information surrounding SUDC. Privacy for families is of the utmost concern to our organization, so please consider the information below as you sign up for Facebook groups.
 - » **Closed Facebook Group FAQs**
 - *The SUDC Foundation Family Support Group is considered a “closed” group. What does that mean?* When joining a “closed” group, only pre-approved group members can see who is in the group. General Facebook users can see that a group exists and request to be a member of the group but cannot see who is in the group. Those who request to join SUDC Foundation groups must complete registration with SUDC Foundation staff and submit a services consent form to be admitted to the group.
 - *I do not have Facebook (or I do not want my current Facebook account associated with SUDC Foundation groups for outsiders to see), but I’d like to talk to other SUDC families. How do I make sure that my Facebook account is privately used for SUDC groups, but my activity will not be seen by family/friends?* There are several ways to edit your settings so that you can feel comfortable using Facebook at your own comfort level of involvement and privacy. To have a private profile on Facebook, edit your “privacy” settings by going to the top right arrow and clicking “Settings,” and then choosing “Privacy.” Then, navigate through each option, selecting “Only Me.” You will also find many customizable options where you can be totally hidden to everyone except those in the SUDC Foundation groups, or you can be seen by family and friends who you want to remain connected to, but they will not know you are in the SUDC Foundation groups or see what you are posting/commenting on within these groups. “Timeline and Tagging” settings can also be edited by going to the top right arrow and clicking “Settings,” and then choosing “Timeline and Tagging.”
 - *I use Facebook regularly, but am receiving notifications of prior child memories, and no longer wish to see them. How do I turn them off?* To turn off notifications, go to www.facebook.com/memories, click “Notifications,” select “All Memories” or select “None.” You can also select “Highlights” to only see memories from top friends.
- **The SUDC Foundation Network:** This online platform is private, secure, and built exclusively for sharing ideas and information, fostering conversations, and providing a network of community support.
 - » Visit network.sudc.org to register for the SUDC Foundation Network and start building your profile.



- » Once you're logged in, your first step should be to request access to the groups that are relevant to you. While some of our groups are public and open to all members of the SUDC community who wish to join, others are private and require approval. To request access to a group:
 - Click on Groups (on desktop, in the left-hand column of the page; or in the app, by clicking on the menu icon in the top left corner).
 - Click the Join Us button (public) or Request Access button (private) for each group you're interested in.
 - Once your request has been approved by a member of our staff, you will receive an approval notification, and you will be able to view and interact with each approved group.

A list of groups you can join are:

- | | |
|--------------------------------|---------------------------------|
| o Adoptive Parent Support | o Parent of Older Child Support |
| o Ambassador Program | o Parent Support |
| o Dad Support | o Extended Family Support |
| o Expectant Parent Support | o SUDC Parents of Multiples |
| o Grandparent Support | o Military Parent Support |
| o Health & Science Information | |

From there, we hope you will explore the Network, introduce yourself to the community, and engage in conversation with your fellow members.

The SUDC Foundation Network



Home

Featured	Groups	Topics	Discovery
Articles, resources, and other helpful links	Topic-specific feeds for users with common interests or backgrounds	Used to organize posts	Explore the Network
START HERE Welcome to the SUDC Foundation Network!	Parents	Advocacy	Members
Family Resource Guide	Ambassador Program	Fundraising	Upcoming Events
Community Guidelines	2021 Family Retreat	Educational Videos & Webinars	Top Posts
Fundraising & Event Planning	Grandparents	Science	Featured Articles
Grief Resources & Book Lists	Expectant Parents	Awareness	To change your personal account settings, such as notification preferences, click on your profile picture (on desktop: top right corner, on mobile: bottom right corner) then Your Settings
and more!	Extended Family	Family Support	
	Health & Science Info.	Medical Press	
	Parents of Older Children		

Access via desktop: network.sudc.org

Download the Mighty Networks app:



- **SUDC Zoom Support Sessions:** The SUDC Foundation offers monthly opportunities for registered SUDC Foundation families to meet virtually using the Zoom platform. Access is available using a desktop computer, laptop, tablet, or smartphone. For the respect of all members, we ask participants to be in a quiet place, away from distractions during the chats. A social worker attends the chats; however, the primary purpose is to provide a safe and supportive opportunity to talk amongst peers. To access the SUDC Zoom Support Sessions, please visit the SUDC Foundation website at www.sudc.org, Main Page > Calendar. Find the specific event you want to attend, noting the date, time, and title.
 - Option 1: Email support@sudc.org to obtain the Zoom link or for further assistance.
 - Option 2: Log in to the SUDC Foundation Network, go to the “Events” section, and locate the event to access the Zoom link or for further instructions.
- **Grief Education During the First Year:** During your first year of grief, we will provide you with additional articles to assist you. They will be emailed to you. Some of these may be in the back-cover pocket of this resource guide. Additional articles you receive can be printed and kept in the back-cover pocket of this guide for easy reference.
 - Topic 1 – Week 2: An Overview of the Foundation – What We Can Offer
 - Topic 2 – Week 3: Your Grief Journey
 - Topic 3 – Week 4: The Medical Examiner’s Role
 - Topic 4 – Week 7: Coping with Friends and Family
 - Topic 5 – Week 11: Where Have All My Supporters Gone?
 - Topic 6 – Week 12: What Is Normal Now?
 - Topic 7 – Month 4: Where Are You Now?
 - Topic 8 – Month 6: Changes
 - Topic 9 – Month 9: Holidays, Birthdays, and Events
 - Topic 10 – Month 11: Memorializing Your Child
 - Topic 11 – Month 12: One Year: The Magic Date
- **Grief Resources and Book List:** In addition to the services provided by the SUDC Foundation, we maintain a list of national and international resources for bereaved families, as well as books that have been reviewed and recommended by SUDC families and staff online. Access these book lists at www.sudc.org > Support Those Affected > Grief Resources. Choose parents, siblings, or grandparents.
- **Webinars:** The Foundation hosts live educational webinars that are recorded and made available for you.
 - Visit www.sudc.org > Member Services > Registered Families > Webinars & Videos
 - On the SUDC Foundation Network, visit Topics > Educational Videos & Webinars



Research & Medical Information



SUDC Research

Learn more on how the SUDC Foundation Advocates for research. The SUDC Foundation supports the SUDC Registry and Research Collaborative at NYU Langone Health through research grants. Its purpose is to understand the risk factors of SUDC that enable the development of preventative strategies. To learn more about the study and enrollment, click the link.

[Learn More about the SUDCRRC](#)



Medical Care After SUDC

Let us help you to better understand the death investigation process, medical testing consideration for family members, and medical testing considerations for subsequent pregnancies and newborn SUDC siblings.

[Medical Care After SUDC](#)



DNA Banking

The SUDC Foundation retains a family advocate on staff to help you with this entire process if you choose to pursue DNA Banking. Learn why the SUDC Foundation advocates for you to consider DNA banking...

[Securing & Banking DNA](#)

RESEARCH AND MEDICAL INFORMATION

- **SUDC Registry and Research Collaborative:** The purpose is to increase the understanding of the characteristics, circumstances, medical histories, and pathologies of children from ages 11 months through 18 years who have died suddenly and unexpectedly, and in some instances, without explanation. The SUDC Registry and Research Collaborative will analyze cases of sudden unexpected deaths in these children to understand risk factors and causes and develop preventative measures. (See Section 2)
- **Medical Information:** Information to better understand the death investigation process, medical testing consideration for family members, and medical testing considerations for subsequent pregnancies and newborn SUDC siblings.
- **DNA Banking Services:** The SUDC Foundation encourages you to bank your child's DNA to protect your ability to pursue more information as clinical testing advances and research options improve. Securing a genetic specimen (DNA) from your child may provide opportunities for: genetic testing to uncover specific cause of death and appropriate testing of family members; genetic testing to rule out specific causes, which may decrease the family's anxiety; and storing a DNA sample to allow for participation in current or future research. Knowing how much DNA is available and the quality of it will also allow you to make informed decisions on if and when it is used. Our family advocate will work with you and your Medical Examiner/Coroner to coordinate these services and ensure you more opportunities into understanding your child's death. (See Section 3)



GET INVOLVED

- **Event Planning Resources:** Many families have chosen to host an event that benefits the SUDC Foundation, while also honoring the memory of their child. The Member Services Access section of our website also lists resources and tips to help with your planning to ensure a successful event.
- **Raising Awareness Through Photo and Name Consent Form:** The SUDC Foundation hosts or supports projects where we include photographs and/or names of our precious children, including events hosted by others.
- **Memorial Tributes and Instagram Memorial Page:** The SUDC Foundation has dedicated a part of its website, as well as an Instagram account, for families to create loving tributes in memory of their children. The Member Services Access section of our website has registration information under the topic of Memorial Activities.
- **Ambassador Program:** The SUDC Foundation Ambassador Program is the Foundation's formal volunteer program. It was created to empower SUDC advocates to raise awareness of SUDC and support the mission of the SUDC Foundation. (See Section 1.2)
- **Peer Friends Connection Program:** The SUDC Foundation Peer Friends Connection Program is the Foundation's formal peer program. It was created to provide peer support.



SUDC Foundation Events

SUDC family hosted events are charitable events organized by families or friends in memory of a beloved child on behalf of The SUDC Foundation. The purpose of these types of events is to create awareness around SUDC and raise funds which directly support the Foundation.

The SUDC Foundation provides fiduciary oversight, financial management, resource kits and other administrative services to assist families when organizing an SUDC family hosted event. The SUDC Foundation is grateful for the many families and friends who choose to host an event on behalf of the Foundation.

Registered families can access our event planning resources guides in the private access area of our website. If you would like more information, please contact us.

[Contact Us](#)



4.1b Reflections on SUDC Family Day 2020

Reflections on SUDC Family Day 2020

By Michelle Emerson, Mother of Alexander (05/03/07 - 12/20/08)

Dear Alexander,

I can't believe it's been nearly 12 years since I've held you in my arms and last saw your smile! My heart aches for you every day. I mourn the loss of all we never got to do together and I'm sad you and your brother, Daniel, never had the chance to meet. We talk about you often. I think the two of you would have been fast and best friends.

Today, we attended the first ever SUDC Family Day. Because of the current global pandemic, the SUDC Foundation wasn't able to host its annual in-person retreat and created its inaugural worldwide virtual event instead. It was so nice to connect with other families who share a similar experience to ours. I want to share some reflections from the day with you.



Alexander at 12 months

Prior to the start of Family Day, registered attendees were sent a welcome kit, which included a memorial craft project. Our family was able to sponsor this craft through the memorial fund we have set up in your name. You're still making an impact even if you're not here to see it. At one point during the morning, families shared their memorial jars. People were so creative and added elements to their jars that were significant about their SUDC child. Seeing their creativity inspired Daniel and me to want to go back and add more to the jar we made for you.

One of my best experiences from Family Day was being part of the parent panel. As one of the families who lost a child during the December holidays and also being many years out from our loss, your dad and I were asked to participate as panelists on the panel about "Coping with the Holidays." Over the years, friends have been understanding of how we handle the holidays, which in the early days meant hibernating from the world. They support our transition to our newer tradition of hosting Cookies with Santa, where we invite friends and their families over to our house to decorate cookies and have a visit from Santa, in honor of us decorating cookies with you on your last night with us. It has been a long, slow road. Holidays will never be the same for us but it was good to be able to share with other families that it does get easier to manage. It's even ok to have guilt-free joy in the midst of the sadness. When I wasn't speaking or listening to the other panelists, I was trying to respond to some of the comments the audience was making in the virtual chat box. I loved hearing about how others deal with these major life events and could have continued on this topic for much longer. All the parents seemed to appreciate the opportunity to share with others who "get it" what has and hasn't worked for them through the years. I look forward to continuing this conversation with fellow SUDC families through our online and virtual support groups.

We wrapped up the day by meeting another local SUDC family at a nearby park. This would be our first time meeting this family in person and I didn't know how things would go. Even with those who know me best, I tend to keep a lot to myself and have trouble opening up. I enjoyed being able to share thoughts about the day and what parts we each liked best. Though Daniel is a few years older, he had a great time playing with the son of the other family. I was happy to see the two of them get along so well, but it was yet another sad reminder of you not being here to be Daniel's big brother.



As I sat at the end of the night, thinking about the day, I found this quote and it felt right.

“Grief is like the ocean, it comes in waves, ebbing and flowing. Sometimes the water is calm, and sometimes it is overwhelming. All we can do is learn to swim.” —Vicki Harrison

I’m still trying to learn to swim...

4.2 What is Grief?

Grief is a natural process of emotions that occurs when someone dies. Grief integrates into normal routines at variable timeframes for each person. It is an intense, lonely, and personal experience. No two people will experience the death of a child the same way. A sudden, unexpected death of a child is different from any other death because children are “not supposed to die.” The death is incomprehensible. There is no right or wrong way to grieve. When your child dies, not only does the death destroy the dreams and hope you had as parents, but it also forces your family to face an event for which you are not prepared. Many parents wonder if they will be able to tolerate the pain, to survive it, and to be able to feel that life has meaning again.

Grief can have its ups and downs. Intense reactions may return on specific dates (birthdays, holidays, anniversaries, etc.) or in connection with milestone events (moving from the home where the child died, the growth of a subsequent sibling beyond the age of the child that died, etc.). As time moves on, the pain from grief becomes less sharp and more integrated into your life. Happiness does return very, very slowly at first. At some point, you begin to laugh and to appreciate life again. You are a changed person and will never be the same. Family, friends, and your community at large can also help you to slowly start your journey to healing.

Initial grief reactions: Shock, disbelief, denial, or numbness. These reactions are normal. Others who are unacquainted with the grieving process may incorrectly assume that you are strong and holding up well, or that you are insensitive and incapable of experiencing the loss. What they do not understand is that shock, disbelief, denial, and numbness allow you to begin to face the tragedy without losing control. These reactions may last from minutes to weeks. You will decide when you are better able to face the reality of your child’s death.

When your child’s death becomes a reality, intense suffering and pain begin: Crying, weeping, and incessant talking are all normal reactions. You may feel very alone. Your spouse, children, family, and friends will all express grief differently. Some may have trouble sharing feelings, be uncomfortable talking about death, or unable to meet your need for comfort and support. Help may be obtained from clergy, counselors, or other bereaved parents.

Some of the emotions you may experience: There is no “correct time” to express emotions. It is important for you to allow yourself full expression of the emotions that you feel when you feel them.



- **Guilt:** You blame yourself or each other for something you did or did not do in the past or present. “If only” becomes a familiar saying or thought. Many times, you feel guilty thinking of all the things that you wish you had done with your child.
- **Anger:** You can feel angry with yourself, your spouse, the doctor or even the child for having died. You may be angry with a God who allows children to die. These thoughts may cause great anxiety, though they are normal. It is important to express your anger in healthy ways. Screaming in private, hitting a pillow, or exercise may help.
- **Fear:** After the death of your child, you may experience an overall sense of fear that something else horrible is going to happen. You may become extremely protective of your other children. At the same time, you may fear your adult responsibilities.
- **Difficulty concentrating:** Your mind may wander, making it difficult to read, write, and make decisions. Sleep may be disrupted, leaving you edgy and overly tired. Even with sleep, you may feel exhausted. You may feel as if you are “going crazy.”
- **Depression:** Depression may take different forms for different people. You may feel constantly “down,” unhappy or sad, worthless, or like life has little meaning. You may have changes in appetite. Thoughts of suicide may arise. Thoughts of your child are always on your mind. Aching arms, hearing your child cry, and finding yourself doing some familiar tasks to care for your child are all normal. As you begin to recover, depression will slowly ease and the “down” times will be less frequent. It is a long, slow process. You need to be patient with yourself and those around you. If you feel like you want to hurt yourself or are thinking of how you might hurt yourself, notify someone immediately and call 911 (U.S.) or visit your local emergency room immediately.

The tasks of grieving: There are many different theories about grief. You may be familiar with grief described as a series of five phases put forth by Dr. Elisabeth Kubler-Ross during the late 1960s. Another theory that was developed by Dr. J.W. Worden in the early 1980s identifies grief not as a succession of phases through which a person passes, and over which they have little or no control, but as a series of four tasks, which a person must work hard to complete.

Below is the series of four tasks:

- I. **Acknowledge the reality of loss:** After any death, grieving family members and friends usually express disbelief: “I can’t believe this is happening to us,” or “How could my child be dead? My child was fine when I put him down for his nap just 20 minutes before.” Grieving family members often experience strong feelings of wanting their child back at all costs or wanting to know, or assign, a certain cause to (or blame for) their child’s death. Their first task is to acknowledge that their child has died. Ultimately, our hope is that they accept that there was no way to know their child was going to die and that they will not ever have their child back.
- II. **Experiencing the pain of grief:** While grieving family members begin feeling the pain of grief from the moment they discover their child has died, the full extent of their pain may initially be “numbed” by the shock or disbelief surrounding the



death. Many family members experience their most intense pain (both physical and emotional) after they have acknowledged their loss and are trying to resume “normal living.” Unfortunately, it is also generally at this time that the family ceases to receive comforting calls and notes from friends. They are expected to return to their usual productivity at work or home. Such a sudden absence of attention and increased (often unrealistic) expectations from others leads family members to feel isolated and may cause them to suppress their pain. By allowing themselves to express and release their pain, family members are better able to move forward through grief.

- III. Adjusting to a life without your child:** As the pain of grief is released, family members begin finding ways to accommodate the changes in their lives brought on by their child’s absence. They begin to weigh the options related to issues such as what to do with the child’s room or things; returning to (or taking on new projects at) work; or how to answer the question, “How many children do you have?” They once again turn their full attention to parenting their surviving children or may start planning to become pregnant. Such adjustments may be difficult because they require the family members to develop a degree of detachment from their child. Many families may take some time to make these adjustments and may struggle with their issues for a while before they make these decisions.

Moving forward: As they begin to move forward with their new decisions, family members will eventually begin enjoying the people and activities that brought them pleasure before their child died. However, their new sense of happiness may be interspersed with periods of guilt or regret because they fear that by enjoying themselves, they are forgetting the presence and devastating loss of their child. Many grieving family members will describe moving forward as a process, rather than a decision. It may take months, sometimes years, to acknowledge the changes. One indication that they have incorporated the grief into their lives may be demonstrated through their realization that: “There are other people in the world who want and need my love – and loving them does not mean I love my child any less.”

4.2a Prolonged Grief Disorder

Grief is normal and most people cope with their loss effectively. Prolonged grief disorder is “a form of grief that is persistent and pervasive and interferes with functioning. It’s characterized by persistent intense yearning, longing and/or preoccupation with thoughts and memories of the person who died, along with other symptoms such as identity disruption, a marked sense of disbelief, avoidance of reminders of the loss, intense emotional pain related to the death, difficulty engaging in ongoing life, emotional numbness as a result of the death, feeling life is meaningless because of the death, or intense loneliness as a result of the death. Prolonged grief continues to dominate a bereaved person’s mind. The future seems bleak and empty, and the bereaved person feels lost and alone.”¹



Some common thoughts, feelings, and behaviors that can become stuck points that can derail the process of adapting to a loss and lead to prolonged grief are:

Thoughts and Feelings

- Disbelief or protest
- Imagining alternative scenarios
- Caregiver self-blame or anger
- Judging grief
- Survivor guilt

Behaviors

- Avoiding grief triggers
- Inability to move forward
- Inability to connect with others

¹ The Columbia Center for Complicated Grief. The Center for Prolonged Grief. (2021, April 27). Retrieved March 8, 2022, from <https://prolongedgrief.columbia.edu/professionals/complicated-grief-professionals/overview/>

Everyone who has experienced the death of a child has one, some, or all of these feelings at some time during the grief process. Determining when to seek professional help is a very personal issue. Many people find that they are understood for the first time in the presence of an unbiased, trained counselor. Certainly, when grief becomes overwhelming and no longer manageable, professional counseling should be sought. Help can be found in your community through mental health agencies, churches, and hospitals. With the assistance of a professional, your grief can become more manageable.

4.2b When to Seek Immediate Assistance

Be aware that during this process, it is normal to occasionally express thoughts that may initially feel or sound alarming, such as “I just want to be with my child,” or “Life’s not worth living anymore now that my child is gone.” This is a normal part of grief.

HOWEVER, if you express any of the below, IMMEDIATELY notify a family member and go to your local emergency room. You can also call 911 (U.S.).

- You want to die, and you have a plan.
- You want to hurt your spouse/child or someone else.

You are not alone.

The SUDC Foundation was created to help you through this most difficult, lonely and overwhelming time in your life. We have a complete program of support, advocacy, case management, and a peer-based support network. Please call us with your needs or questions at (800) 620-SUDC (7832).

4.2c Suggestions for Coping with Grief and “Active” Coping

1. Whatever you are feeling, it is normal. There is no right or wrong way to grieve.
2. Your body requires food and fluid even if you do not want it. It is important to eat small, nutritious snacks and meals at regular times and drink plenty of fluids.
3. Sleeping is often difficult. If you cannot sleep, it is important to rest throughout the day. However, try to maintain normal sleep patterns by sleeping longest at night.



4. Your energy level will probably be low. Give yourself permission to rest when you need it.
5. Seek out supportive family and friends who will listen to you talk about your child.
6. Be patient with yourself. It is okay to say “no” to things that are overwhelming. When you are stronger, then you can say “yes.”
7. You will not forget your child. Your child will always be part of your life. Choose personal ways to memorialize your child.
8. Keep a journal – write how you feel and what you are doing. Write as often as needed.
9. If you feel that you cannot cope on your own, consider a professional counselor who can give you support and insight.
10. Staying connected (e.g., volunteer, social activities, group classes such as yoga or choir).
11. Keeping the mind occupied (e.g., resume daily routine, exercise).
12. Support groups.
13. Patience.
14. Practical support – accepting support with concrete tasks (e.g., grocery shopping, laundry).
15. Find the support of other bereaved parents through local support groups, or through the SUDC Foundation’s online support group, monthly virtual chats, or Peer Support Program.

Finding Helpful Activities During Your Journey

Thank you to all the parents and grandparents for sharing the following activity suggestions. You are as unique as your grief. Try to be patient with yourself while you are learning which coping mechanism works best for you.

- Journaling
- Scrapbooking
- Exercising
- Making a book about your child
- Going back to work
- Creating a memorial website
- Speaking to others about your child
- Doing rituals in honor of your child
- Writing yourself a letter to open a year later
- Giving a gift in memory of your child on their special day or holiday
- Writing a blog
- Creating a photo collage
- Spending time with friends
- Gardening
- Reading
- Attending grief support groups
- Seeing a counselor
- Listening to songs that your child liked
- Planting a tree or donating a bench at a park
- Having a favorite photo of your child made into a painting



4.2d Ways to Help Fathers Grieve

Ways to Help Fathers Grieve

By Lisa Capizzi-Marain, M.S.W, LCSW, Senior Licensed Clinical Social Worker,
The Joseph M. Sanzari Children's Hospital, Hackensack University Medical Center,
Hackensack, NJ

- Encourage open discussion.
- Let fathers speak about their pain.
- Remind fathers that they are not alone.
- Just listen; do not try to solve their problems.
- Encourage fathers to reach out to other grieving fathers.
- Allow fathers the time to process what has happened to them.
- Allow fathers to turn to, or away from, their faith as needed.
- Let fathers cry.
- Let fathers know you are there for them, always.
- Encourage fathers to talk about their pain and allow them time to be alone with their pain.

Not all of these strategies will work for every individual. Perhaps none of the above will be helpful to a certain individual you know. Help them brainstorm to discover activities that may be a match for them. Grief is such a personal and unique journey. Often times, just letting them know you care can make a difference.

Additional Resources for Dads

- Grieving Dads Project – www.grievingdads.com
- Bereaved Parents of the USA – www.bereavedparentsusa.org. Information is also offered in Spanish.
- Compassionate Friends – 1-877-969-0010 or www.compassionatefriends.org
- Grief Share – Locator for support groups – www.griefshare.org
- GriefNet.org – Locator for groups, resources, and books – www.griefnet.org

4.2e Dos and Don'ts for Family & Friends

The Compassionate Friends, a support group for parents and grandparents who have lost children of all ages to various causes, devised a list of “DOs and DON'Ts” for the families and friends of bereaved parents. Their suggestions, along with a few of our own, include:

DO...

- Let your genuine concern and caring show.
- Be available...to run errands, to listen, to help with the other children, to do whatever else needs to be done at the time.
- Allow them to express as much grief as they are feeling at the moment and are willing to share.
- Say that you are sorry about what happened and about their pain.
- Encourage them to be patient with themselves, not to expect too much of themselves, and not to impose any “shoulds” on themselves.
- Allow them to talk as much and as often as they wish about their child.



- Reassure them that they did everything they could, that there was nothing that they missed, and that there was nothing else ANYONE could have done to save their child's life.
- Help them let go of the questions and the guilt.
- Remember the child's birthday and anniversaries with the parents.
- Do give special attention to the child's brothers and sisters (they are hurt and confused, too, and in need of attention which their parents may not be able to give at this time).

DON'T...

- Let your own sense of helplessness keep you from reaching out.
- Say you know how they feel, unless you have also lost a child.
- Say, "You ought to be feeling better by now," or anything else which implies a judgment of their feelings.
- Change the subject when they mention their child.
- Remove pictures of the child from your own home (they need their child remembered).
- Avoid mentioning the child out of fear that you will remind them of their pain (they haven't forgotten it!).
- Point out that at least they have their other children (children are not interchangeable).
- Say that they can always have another child (even if they want to, or can, another child will not replace the child that died).
- Make any comments that suggest that the care given to their child at home, in the emergency room, etc., was inadequate.
- You can't make the pain go away and you can't bring the child back, but you can help make the bereaved parent's adjustment to the loss much easier. By grieving together, you reaffirm that grief is normal, and that life will go on. Someday there will be peace again.

4.2f Suggestions for Communicating with the Bereaved

DO...

- Acknowledge the child's death by telling the parents of your sadness for them and by expressing love and support; try to provide comfort.
- Visit and talk with the family about the child who died; ask to see pictures or mementos the family may have.
- Extend gestures of concern, such as bringing flowers or writing a personal note expressing your feelings; let the parents know of your sadness for them.
- Attend the child's funeral or memorial service.
- Remember anniversaries and special days.





- Donate to a specific memorial in honor of the child.
- Offer to go with the parent(s) to the cemetery in the days and weeks after the funeral, or find other special ways to extend personal and sensitive gestures of concern.
- Make practical and specific suggestions, such as offering to stop by at a convenient time, bringing a meal, purchasing a comforting book, offering to take the other children for a special outing, or treating the mother or father to something special.
- Respect the dynamics of each person's grief. Grief is an ongoing and demanding process.

DON'T...

- Tell them you know just how they feel.
- Avoid the parents or the grief.
- Refrain from talking about the child who died or referring to the child by name.
- Impose your views or feelings, or set limits about what is right or appropriate behavior.
- Wait for the parents to ask for help or tell you what they need.

4.2g Additional Resources for the Bereaved

A comprehensive list can be found on the SUDC Foundation website at www.sudc.org > What We Do > Serve Those Affected > Grief Resources.

"There is a sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than ten thousand tongues. They are messengers of overwhelming grief, of deep contrition, and of unspeakable love."

—Washington Irving

4.3 Understanding Trauma & Loss

Trauma is defined by the Center for Anxiety and Mood Disorders² as the "psychological, emotional response to an event or an experience that is deeply distressing or disturbing." Reactions to trauma are also individualized, but commonly include intrusive re-experiencing of the event, avoidance of trauma-related reminders, hyperarousal, and strong negative emotions such as fear, anger, guilt, and shame. These reactions are common after a traumatic event and typically diminish over time. Psychologists categorize persistent trauma reactions as post-traumatic stress disorder when symptoms are ongoing past the first 1-3 months.

Trauma can also be a component of grief when someone dies suddenly and unexpectedly, especially a child. This can leave survivors to feel helpless, vulnerable and often powerless. Trauma symptoms typically last from a few days to a few months, gradually fading as the emotional trauma is processed. Acceptance, processing the event, and time are a part of the recovery process.



Emotional and Psychological Symptoms of Trauma May Include:

- Shock, denial, or disbelief
- Anger, irritability, mood swings
- Guilt, shame, self-blame
- Feeling sad or hopeless
- Confusion, difficulty concentrating
- Anxiety and fear
- Withdrawing from others
- Feeling disconnected or numb
- Difficulty experiencing positive emotions

Physical Symptoms of Trauma May Include:

- Insomnia or nightmares
- Flashbacks or other dissociative reactions
- Being startled easily
- Racing heartbeat
- Aches and pains
- Fatigue
- Difficulty concentrating
- Edginess and agitation
- Muscle tension

² Posted by Dr. Andrew Rosen, Rosen, D. A., Johnson, J., Holt, P., Clark, C., George, Li, S., Dusk, Muro, Thabede, X., Costantine, D. R., Alison, A., Stephanie, Davis, E., Peterson, D., Coolidge, T., vilecroide, H., Booker, R., Tomlinson, Z., ... Packer, S. (2021, August 23). What is trauma. The Center for Treatment of Anxiety and Mood Disorders. Retrieved March 8, 2022, from <https://centerforanxietydisorders.com/what-is-trauma/>

4.3a Professional Support & Interventions When Needed

When Professional Support Is Required

- Trouble functioning at home or work after an extended period
- Suffering from severe fear, anxiety, or depression
- Unable to form close, satisfying relationships
- Experiencing terrifying memories, nightmares, or flashbacks
- Avoiding more and more things that are related to the trauma
- Emotionally numb and disconnected from others
- Using alcohol or drugs to feel better

What Does Trauma Treatment and Healing Involve?

- Processing trauma-related thoughts, beliefs, and feelings (cognitive)
- Reducing and eliminating the physical impacts and symptoms of the trauma (somatic)
- Learning how to regulate strong emotions (affective)
- Building or rebuilding the ability to trust other people, and engaging in healthy behaviors and coping skills (behavioral and relational)

Therapeutic Approaches

Trauma disrupts the body's natural equilibrium due to the myriad of hormones that get released in its aftermath. The purpose of specific therapeutic approaches is to help address the dysregulation that occurs in all the areas mentioned above.

The trauma-focused psychotherapies with the strongest evidence are:³

Prolonged Exposure (PE)

Teaches you how to gain control by facing your negative feelings. It involves talking about your trauma with a provider and doing some of the things you have avoided since the trauma.



Cognitive Processing Therapy (CPT)

Teaches you to reframe negative thoughts about the trauma. It involves talking with your provider about your negative thoughts and doing short writing assignments.

Eye Movement Desensitization and Reprocessing (EMDR)

Helps you process and make sense of your trauma. It involves calling the trauma to mind while paying attention to a back-and-forth movement or sound (like a finger waving side to side, a light, or a tone).

Working through trauma can be scary, painful, and potentially re-traumatizing. **Because of the risk of re-traumatization, this healing work is best done with the help of an experienced trauma-informed specialist.**

³ PTSD: National Center for PTSD. PTSD Treatment Basics. (2018, August 8). Retrieved March 22, 2022, from https://www.ptsd.va.gov/understand_tx/tx_basics.asp

Finding the Right Therapist

Locating the right therapist for you can take some time. **It is important that the therapist you choose has experience treating trauma.** However, the quality of the relationship and connection with your therapist is equally important. Choose a trauma-informed specialist you feel comfortable with. Trust your instincts. If you don't feel safe, respected, or understood, discuss other options within the practice or find another therapist. There should be a sense of trust and warmth between you and your counselor.

When searching for a therapist, consider the following:

- If you have health insurance, call or check online to find out which mental health providers your insurance company will cover.
- Ask family, friends, physicians, and other professionals that you trust for referrals in your area
- Use local 211.org (U.S.) and Google with keywords “bereavement” and “grief”
- Ask if the provider has experience treating people who have been through a trauma.
 - » Look for providers who focus on evidence-based practices through effective talk therapy for Post Traumatic Stress Disorder (PTSD), such as Cognitive Processing Therapy (CPT), Complicated Grief Treatment, or Eye Movement Desensitization and Reprocessing (EMDR).
 - These services would be provided by licensed professionals such as:
 - o LCSW, LSW, LAC, LPC, ARN, etc.
- See organizational resources below

After meeting a potential trauma-informed therapist, ask yourself these questions:

- Did you feel comfortable discussing your problems with the therapist?
- Did you feel like the therapist understood what you were talking about?
- Were your concerns taken seriously, or were they minimized or dismissed?
- Were you treated with compassion and respect?



- Do you believe that you could grow to trust the therapist?
- Do they have specific experience in working with trauma, including traumatic loss and/or child loss?

See Also Section 4.7c: Locating Local Resources

4.3b Helping Someone through Emotional & Psychological Trauma

It can be difficult to know how to help a loved one who's suffered a traumatic or distressing experience, but your support can be a crucial factor in their recovery. **Be patient and understanding.** Healing from emotional or psychological trauma takes time. Be patient with the pace of recovery and remember that everyone's response to trauma is different. Don't judge your loved one's reaction against your own response or anyone else's.

Offer practical support to help your loved one get back into a normal routine. That may mean help with collecting groceries or housework, for example, or simply being available to talk or listen.

Don't pressure your loved one into talking but be available when they want to talk. Some trauma survivors find it difficult to talk about what happened. Don't force your loved one to open up, but let them know you are there to listen whenever they feel ready.

Help your loved one to socialize and relax. Encourage them to participate in physical exercise, seek out friends, and pursue hobbies and other activities that bring them pleasure. Take a fitness or yoga class together or set a regular lunch date with friends.

Don't take the trauma symptoms personally. Your loved one may become angry, irritable, withdrawn or emotionally distant. Remember that this is a result of the trauma and may not have anything to do with you or your relationship.

4.3c Trauma and Your Brain

Your Brain—It's Doing the Best It Can

Bob Baugher, Ph.D., Dept. of Psychology, Highline Community College

Trauma. A frightening word, especially for anyone who's experienced it. Traumatic death is even more frightening.

How does a family cope with this? The brain is an amazing thing. More than ten billion cells work together to keep us alive and moving. I believe that the brain has two major functions. First and foremost is to protect itself and the body around it from pain – any type of pain: physical, mental, emotional, and spiritual. The second major function is to make sense of the world around it. As you read



continued...



this article, your brain is trying to make sense of what these words are saying to you. Your brain is seeking meaning. Given these two major functions, consider what a traumatic event does. It causes pain and is often without meaning. Next add death to the formula. And then add unexplained. The brain cannot grasp a sudden, unexplained trauma. Finally, add child to this horrendous alignment of words: traumatic, sudden, unexplained death of a child. The brain and all the brains of everyone who knows the grieving family and their precious child are left to try to understand this senseless, unexplainable horror.

Our brain hates pain – unless it can understand a good reason for it – such as putting up with an exercise regimen or studying a boring subject. I don't have to tell you that grief is very painful. The brain wants to understand it and will turn it over and over in an attempt to do so. Researchers on sleep have found that, even during deep sleep, the brain is working, processing, and consolidating the day's events – or should I say attempting to do so. The death of a child is horrible, and the brain has likely never come close to experiencing that much pain. It is a pain that, while subsiding over time, lasts a lifetime. The brain "knows" that humans die. But, within seconds of learning of their child's death, the parents' brain has requested – no, demanded – to begin to know why. Why? WHY? With no clear answer, their brain has shifted into a frenzy of attempts to make sense, at least some sense, of the fact that their child died.

Next, they become hyper vigilant to any clue, any hint of what could have contributed to the death of their child. They comb through the medical examiner's report, the doctor's notes, the internet looking for something – anything – that can begin to ease the demand that their brain has for answers. One way to understand the search is to think of the categories of possible contributing factors, such as: genetic, biological, environmental, and spiritual. Let's briefly consider each.

Genetics – One thinks there must be a hidden genetic defect that one or both parents transmitted. So, what do they do? They look into their family tree and, of course, find something. They may not have considered the fact that we all would find something. Is this something significant enough to contribute to the death of a child? Their brain turns this over in thousands of different ways and may even come up with its own hypothesis – one not shared by the experts. Yet, they wonder...

Biological – Is there something they gave or failed to give to their child? Food? Medication? Inoculation? Perhaps their brain has convinced them that it's something they did to their body years ago that was somehow transmitted to their child. Drugs are common culprits that their brain settles on, especially illegal drugs. Their brain doesn't need much nudging to take them back to the time(s) they took an illegal drug.

Remember, despite the fact that hundreds of studies have shown that drugs taken years ago have no effect on offspring, their brain doesn't care. In its incessant demand to make sense of its world, the drug hypothesis provides some relief. The biggest problem with this is that no matter what people say, their brain will grab on to any possible reason. What do they get out of it? A sense of relief? Hardly. Instead, they get what most people get when a child dies for any reason: Guilt. If they have kept this "reason" a secret, I call this Unmentionable Guilt. Their brain has "found" the problem – and it's them!

Environmental – The medical examiner is the expert in determining the cause of death. But in the case of their child, no clear evidence emerged. Unlike hundreds of other investigations, no conclusion is reached in what caused this child to die. Why? Again, their brain finds a way to create its own answer. For example, maybe, the medical examiner missed something. Suffocation? Disease? An animal? Toxins?

Spiritual – Did God do this? Again, their brain scans their past, looking for evidence and, of course, there it is! They did some bad things when they were younger. Only they know what they are. If they have a belief in God, it doesn't take much for their brain to connect two events: the terrible thing they did years ago somehow must have been a contributing factor that God would let their



child die. This is another type of guilt called Moral Guilt. Again, their brain has taken the senseless death of their child and made it less so.

Do any of the examples resonate with you? Have you heard or seen a parent do this? Don't blame their brain. It's only doing its job. During the years following the death of a child, the parents' brains will perhaps test hundreds of hypotheses about the cause, turning each one over and over, inspecting each one inside out and upside down. My hope in writing this article is that you will realize that what the brain has been doing is NORMAL. It must go through these investigations again and again and again, until it doesn't need to anymore. Therefore, for someone to tell a parent to "stop thinking that way" is the same thing as saying, "Don't think."

I've met hundreds and hundreds of parents whose children have died, some with unknown causes. So, I guess I'm asking you to trust me when I say the following: If you know a parent whose thoughts are disrupting their ability to accomplish activities of daily living, help them find help: Encourage the parents to join a support group, to talk to another parent who has been coping with this longer than them, or to seek a counselor who understands bereaved parents. As the years go on, they will never forget their child; but their brain will gradually get to a point where it doesn't need to ask "Why?" as often. And finally, remind them to be good to their brain. It's doing the best that it can.

4.3d Grief, Stress, and Relationships

Grief, Stress, and Relationships

By Chelsea Hilbert, LCSW & SUDC Parent

Grief has a way of working its way into every fabric of our lives, and our relationships with our mates are no exception. The grief following the loss of a child will undoubtedly test parents in ways their relationship has never encountered. There is no way around this, but know that many relationships weather this storm, and those relationships grow stronger as a result.

My years of education and experience as a licensed clinical social worker and co-founder of the SUDC Program, a program of the CJ Foundation, as well as my personal experience with the death of my son, Zach, have helped me to formulate some relationship building strategies that may be helpful to grieving families.

- Love without judging. Realize that you cannot control or prevent some of the experiences in life. You can, however, determine how you respond to them.
- Try to be the best listener you can be. It can accomplish more than you may realize. Take care of yourself.
- Maintaining your own emotional and physical health will better enable you to meet the changing demands of your relationship during this time of stress.
- Have fun together! There is nothing wrong with smiling or laughing together. It does not mean that you have forgotten your pain or your child. It just means that you have given your heart a chance to rest.
- Find time when you can meet and relax without discussing your pain. Set boundaries for topics that need to be kept "off limits," like having more children, medical testing, or autopsy information. These might be conversations that your mate may not want to discuss at this time.



Relationship strategies can be helpful

continued...



If this is the case, perhaps a good friend would be a better choice for that topic right now.

- People may tell you that the death of a child can doom a relationship, but that is not necessarily true. Every relationship is going to experience stress at one time or another, but rather than being destructive, the relationship can become deeper and stronger.
- During the grief process, things will change over time, including your needs. Respect that your mate is overwhelmed and may not be able to be as tuned in with your needs as he/she once was. Put extra effort into keeping the lines of communication open.
- It can be difficult for you and your mate to think as clearly as you did before your loss. Grief is overwhelming, so you will need to be more patient and forgiving.
- You may feel isolated at times. Sitting down together and talking about it can help. Remember that everyone grieves differently, and that is okay. Find ways to show your mate that you love him/her and how important he/she is in your life.
- You are the only one who knows your pain. Everyone progresses at their own pace, and each journey is unique. Respect the differences in you and your mate. When it gets too hard to manage alone, get help through a professional and licensed marriage counselor and/or grief counselor. Realize that you may need to try out a few counselors before you find the “right fit,” but your relationship is worth it!

Resources

- The American Association for Marriage and Family Therapy. AAMFT is the professional association for the field of marriage and family therapy since 1942. AAMFT has been involved with the problems, needs and changing patterns of couples and family relationships. The association leads the way to increasing understanding, research and education in the field of marriage and family therapy and ensuring that the public's needs are met by trained practitioners. Clinical Members have met the highest standards of the profession for education and clinical experience. The website can help you locate a therapist in your area. www.aamft.org
- Seven Principles for Making Marriage Work by John Gottman, Ph.D. www.gottman.com

4.3e Another Birthday Letter

Another Birthday Letter

By Anna Sweat, Mother of Evelyn (06/10/77 - 08/02/17)

My beautiful girl,

Your birthday is only days away. I haven't written you in some time. I can't say why. I walk around with my head full of thoughts I want to share with you. But when I open my mouth, it seems like the only things that come out are “I love you,” “I’m sorry,” “I miss you.” You must be so tired of hearing that.

In the beginning, I wrote to you every week. Do you remember? Always on a Wednesday – the day that you died. I think it was a way for me to mark time, a way for me to stay connected to you. I would count the weeks for a long time. Somewhere along the way, I stopped counting. It became too painful. And I believed I had your permission to stop punishing myself. If only so I could be a better mother to your brother and sister.

We used to have such deep conversations. You were always my “big question girl.” We could talk until our throats got sore, laugh until our stomachs hurt. I delighted in you. I hope you know that. I hope I found a way to let you know. Between the constant reminders to do your chores and doling out motherly advice, I hope I stopped once in a while and said, “You are a marvel and a delight and everything about you is perfect.” I’m not sure I did. We always think we have more time.

I don't have a plan for Sunday. That is what the therapist worked so hard to impress upon me when it comes to the BIG days – birthdays and holidays and the anniversary. “You have to have a plan, Anna.” But here I am without one. I think my brain pushes it away until it's right on top of me.



I hate that actually. It feels like I'm pushing you away. Like you're an afterthought. You're anything but an afterthought, baby. You're in my heart constantly, a refrain it can't stop reciting.

The only thing I want to do for your birthday is spend it with you. Isn't that cruel? When the one thing we want is the one thing we can't have? When our only real comfort is somehow beyond our reach? I think you would understand the wanting. Maybe you experience it too.

I hope not. I hope that you are too busy experiencing the fulfillment of every desire. That is my prayer for you. Fullness. I can't give to you anymore, so I pray that someone or something is. It's one of the worst things for a mother, not to be able to give to her child.



These days always shine a light on a particular facet of my grief. This year it is the guilt. Terrible feelings of failure and inadequacy. My heart tells me I'm not to blame, but my mind is chasing a solution at all costs. A solution that will never come. And the cost is my sanity. It is a constant exercise to redirect it. So many missed opportunities, it says. Where might any one of them have led? We'll never know. But it is convinced that the right detour would have saved you if only I'd taken it. All those sayings about hindsight are so haunting now. I kind of despise them.

You would be 23 this year. I imagine 23-year-old Evelyn would be just as fun and bright and delightful as 18-year-old Evelyn. Maybe busier. Probably more traveled. Definitely not taking any of my shit. Full of laughter and high hopes and an enormous amount of love and sarcasm. God, I miss the sound of your voice. What I wouldn't give to hear you speak a wholly original sentence to me in real time instead of replaying your videos and recordings.

I may not have gotten everything right, and my brain likes to argue that I got the most important test wrong, but I loved you with a fury. With an immensity of feeling that just cannot be equaled anywhere in the universe. The way a mother loves a child, the way that I love you – it's such a force. I think I live in daily astonishment that it has not brought you back to me, knit your cells from the ashes, and filled you again with life and breath and verve. I know that somehow I have to find a way to start looking forward and stop looking back. And I am. I am. I build a future in my mind for your sister and brother, your father and I. I see it until it makes my head ache. I want that bubble of joy for us. But when it comes to you, I can't seem to look anywhere but over my shoulder. That has to change, I know. Help me understand what a future with you looks like. Help me believe we have one still.

I should wrap this up. It's long and it's pitiful and it's divergent. I think all I really wanted to say was happy birthday, baby girl. My heart is yours. Forever and ever. We'll be celebrating beside you on Sunday in whatever way we come up with. Holding you between us with all the tenderness, all the affection, all the reverence we can muster. Keeping you close in whatever ways we can. Show up. Show up for us, Ev. Let us know you're still right here. Because however we get by, we still need you. We still want you. We still love you. Desperately. Fiercely. Doggedly.

We are one heart.

-Mom



4.3f One Moment at a Time

One Moment at a Time

By Lisa Capizzi-Marain, M.S.W., LCSW, Sr. Licensed Clinical Social Worker, The Joseph M. Sanzari Children's Hospital, Hackensack University Medical Center, Hackensack, N.J.

With the turn of each calendar page, the holidays will be here sooner than we realize. While the world is celebrating, many SUDC parents and those in grief will be experiencing pain and sorrow. In my role as a licensed clinical social worker who has worked with bereaved parents since 1995, I have found that a vital key to coping is a philosophy I call: *One Moment at a Time*.

One Moment at a Time is a mindset for bereaved parents. It allows you to grieve at your own pace despite what you perceive society and others may be encouraging you to do. It is the ability to spend parts of your day remembering, crying, laughing, going to work, or carrying on your day without the fear of judgment from others. It is a tool to create a personal journey toward healing. Many parents who cultivate a personal grief process through *One Moment at a Time* report feeling relieved that they do not have to follow a set timetable for grief. They also have reported feeling close to their child and better able to manage day-to-day grief.

For *One Moment at a Time* to work, bereaved parents need to seek out and surround themselves with compassionate and loving people who can support and empower them during their personal bereavement process. These personal connections – whether they involve a family member, a professional or a friend – can lighten their daily struggles with pain and suffering. But what if the individual's pace of grieving does not match that of the spouse, family member or friend – the very person that may provide the most support? One of the best ways to navigate this situation is with open communication between both people.

Opening the lines of communication between grieving people is not always easy. Grief will magnify the challenges that a relationship already faces, and this conflict may affect one's ability to grieve *One Moment at a Time* successfully. A therapist or member of the clergy can be very helpful to families during these times. A therapist is trained to help families with a variety of therapeutic techniques that can teach communication, empowerment, compassion, and empathy.

Movies, books, and resources can also assist families in grieving *One Moment at a Time*. *Rabbit Hole* is a good example. Released in 2011, it starred Nicole Kidman, for which she received an Oscar nomination for best actress. The plot deals with a couple struggling to survive after the sudden death of their young son and how grief intersects with their lives as individuals, as a couple, and as family members. The movie is a wonderful tool which eloquently portrays the effort, compassion, and compromise that relationships can endure after experiencing the unthinkable.

Comfort can also be found in many excellent books. Access to resources is also a vital tool in the healing process.

To help those in grieving *One Moment at a Time*, here are some strategies from people who have successfully developed their own personal grief journeys. Thank you to those SUDC family members who have shared so willingly!

- Journal feelings, scrapbook memories, blog, etc. As time passes, many parents have expressed their fear of others, or even themselves, not remembering their child's memory. This is a way to remember and decrease that fear.



- Create a lasting memorial for your child, such as setting up a scholarship, planting a tree, starting a garden, or designing a website.
- Seek professional support, either individually or through groups.
- Encourage a new hobby.
- Use the child's name and speak about them as often as you like.
- Celebrate the child's birthday in a special and meaningful way to the family.
- Exercise. It is a stress reducer, energy enhancer, and also releases certain hormones which can combat depression.
- Encourage yoga. It is a way to calm the mind, find focus, and strengthen and stretch tense muscles. Yoga can help promote an overall sense of wellbeing.
- Get enough sleep – it will help restore the body and mind.

Not all of these strategies will work for every individual. Perhaps none of the above will be helpful to you. Help each other to brainstorm to discover activities that may be a match for you. Taking grief *One Moment at a Time* brings comfort and helps the bereaved to create their unique grief journey.

4.3g Picking up the Pieces

Picking up the Pieces

By Beth Adamo, SUDC parent of Natalie (07/29/05 - 03/18/07)

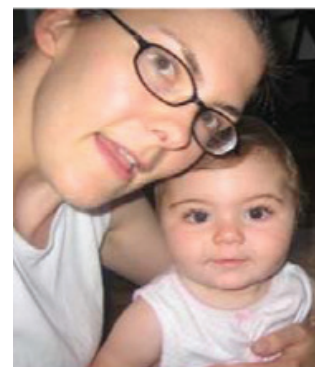
The only thing in life that's certain is that nothing is certain. Things can change in a heartbeat: a sudden car crash, an accidental drowning, an act of violence, a terminal disease. When someone we love dies, nothing is ever the same again.

For me, this painful fact of life hit hard on the morning of March 18, 2007, when I went to check on my 19-month-old daughter, Natalie. Expecting to find her just waking up from a peaceful night's sleep, to my absolute horror, I found her cold, lifeless body. There were no warning signs, no explanation for how a perfectly healthy child could just stop breathing. Suddenly, my life as I knew it was over, and a new life – a life permeated with grief – had begun.

Since that dreadful March day, I have searched – for understanding, for help, for comfort, for ways to cope with my terrible loss. I've read books about grief. I've talked with professional therapists, and I've listened to others who are grieving. Here's what I've learned along the way.

Everyone grieves differently. To grieve is universal, but everyone grieves in their own personal way. "People who are grieving need reassurance that what they are experiencing is normal," says Christine Miller, Bereavement Field Coordinator at Beacon Hospice. There are a lot of factors that play into how we all deal with grief. "You look at the nature of the relationship with the deceased (was it a child, a spouse?), their death (was it sudden, accidental, suicide, homicide?), an individual's personality, experience, and concurrent stressors in their life."

Depending on the circumstances, some people may experience complicated grief, which is a more intense and prolonged grief reaction. "In these cases, symptoms haven't lessened or may have grown worse over time," says Miller. For people experiencing complicated grief, it's especially



Beth and daughter Natalie

continued...



important to get professional help. Time loses its normal sense of order. Something can happen – a smell, a sound, a touch – to trigger your grief, and it suddenly comes flooding back even years later. And through it all, there is an unrelenting sadness that has become part of your life. It is the ‘new normal.’”

Grief does not just go away. You won’t wake up one day and be “over it.” Your loved one is still gone and her place in your heart will always be there. “Part of the healing process is learning how to emotionally relocate the deceased,” says Miller. This means that you form a new relationship with the memories of your loved one. You won’t ever forget, but you will be able to find happiness again. Like it or not, life does go on. It may be hard to accept the fact that the rest of the world keeps on going, especially in the beginning. A driver who cuts you off in traffic doesn’t know about your loss. Innocent, everyday questions like, “How are you?” can leave you tongue-tied. Sometimes it’s all you can do to just keep breathing. To function in the world requires you to put on a brave face, what some people refer to as “the mask.”

You are not alone. Although your grief is all yours, you do not have to, and you should not, walk the journey alone. Here are strategies for coping:

- Be easy on yourself, emotionally and physically.
- Try to educate your friends about how they can help. (See “What Can I Do?”)
- Consider attending a peer support group or seeing a professional counselor.
- Find what comforts you. It could be creating a memorial website or garden, starting a charitable foundation, taking up painting, or writing in a journal.
- Do things when you’re ready. There is no timetable for grief.
- Keep in mind there is no right or wrong way to grieve – only your way.

Of love and loss. In the years since my daughter died, I have had good days and bad days. Such is the nature of grief and I have learned to live with it. Alfred Lord Tennyson aptly wrote, “Tis better to have loved and lost than never to have loved at all.” I am forever grateful that Natalie was a part of my life. I wouldn’t trade that for anything.

What Can I Do?

When someone you know is grieving, it’s natural to help. But, it’s hard to know the right thing to say or do. While a loaf of banana bread is always welcome, here are more ways you can support someone who is grieving:

- “Don’t try to give advice,” says Miller. “Just say you’re sorry, listen, and be there.”
- Avoid offering easy answers or platitudes, like, “He’s in a better place.” Or “Everything happens for a reason.”
- Do not judge or comment on the way your friend is grieving.
- Be mindful of holidays, birthdays, anniversaries, and other markers of time that may be especially difficult.
- Understand that grief has no time limit.
- Don’t be afraid to talk about the deceased or say his or her name. One of the greatest comforts comes from knowing that a loved one is remembered.

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4.3h Returning to Work: One Mom's Experience

Returning to Work

By Shan Gao, Ph.D., Mother of Maxwell (04/28/17 - 07/20/18)

When should I go back to work?

This really depends on the job you have. Bereavement leave is often only three to five days, which is way too short. If you don't have flexibility in your job, you may have no choice on when you go back to work. If you have the flexibility, then the answer is still a bit unclear. Some people go back quickly after the death, and some take a long time. Some never go back.

For me, after my 14-month-old son Maxwell died, I went back after about a month. This decision was highly personal. I was a psychiatry resident at the time. I risked a delay in graduation if I took too much time off. I was also newly pregnant with my second child, and I wanted to save my time off for my maternity leave. I also wanted to go back to work because I needed a break from my grief.



Shan and son Maxwell

What will the transition be like at first?

Interactions with coworkers can feel hard, difficult, and painful.

Normal day-to-day interactions with coworkers, at times, may feel intolerable. Your interactions will get easier with time, but there will be painful moments. Try to remind yourself that these are normal reactions after a traumatic loss of a child, and the days will get easier.

Example: I saw an attending physician on the elevator, and he asked, "How's it going?" in a joyful tone. Before death, I would have perceived his question as friendly and innocuous. That day, I perceived his question as a painful denial of my pain and grief.

Interactions with coworkers can also feel loving and connected.

One of my friends/coworkers decided to start walking with me to clinic on Tuesdays. He had attended my son's celebration of life. The first day back, he asked, "How are YOU doing?" The way he asked the question felt curious, holding, spacious. I was able to receive his care and love in that moment. "Terrible!" I said, and we were able to talk honestly about how it's been. I am brought to tears just thinking about those walks right now. We are still good friends to this day.

Are there ways to make the transition back easier?

I have some concrete advice, but overall, try to be loving, patient, and compassionate toward yourself. I felt, thought, and behaved in ways that weren't my usual self. Looking back, I am both grateful that I am less reactive now, AND I miss that time of vulnerability and intensity. That time was the closest I had been to my son after his death.

- Allow others to help you (ambassadors, point person, HR).
 - I was in a psychiatry residency program with over 75 residents and fellows. This was too many people to navigate for one person. My program director sent out an email to my department about the death of my son before I returned so everyone already knew about my situation.
 - My chief resident helped me navigate which rotation to come back on and made sure every staff member knew what had happened.
 - My closest friend in my residency was the point person for the residency class.

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- Allow yourself to take breaks when needed.
 - My son died at the children's hospital. My program director generously offered me to skip call that year at that hospital. Although I had some initial guilt, not doing call really helped with my mental health.
 - I returned on an easier six-week rotation and just took Fridays off. The time off from clinic was supposed to be for research, although I did no research and just cried in bed.
- Have designated spaces (plural) to cry.
 - I was lucky to have had my own office. I cried a lot in there. I cried in my car driving to and from work. My parking lot was a 10-minute walk to my office, and I'd cry walking to and from the parking lot as well.
- Therapy.
 - You can get really busy at work. It's important to have a designed time and space to sort through your grief and your experience of a traumatic loss.
 - Couples therapy can also be helpful.

Deciding when to go back to work after the death of your child is a highly personal decision and may be influenced by factors such as job flexibility and financial constraints. It's important to be patient, compassionate toward yourself, and allow others to help you during this time. Ultimately, there's no right or wrong way to navigate this difficult time, and it's okay to take the time you need to grieve and heal. Remember that your experience of grief is unique and personal, and it's important to prioritize your own well-being as you navigate this challenging time.

4.3i Additional Resources

- Five Important Questions About FMLA & Bereavement Leave – <https://evermore.org/five-important-questions-about-fmla-and-bereavement-leave-and-the-family-and-medical-leave/?eType=EmailBlastContent&eld=1d9896d3-c67b-4e9e-b1f1-cd92567a7473>
- National Center for Post-Traumatic Stress Disorder – www.ptsd.va.gov
- The Complicated Grief Program at Columbia University – www.complicatedgrief.org
- American Psychiatric Association – www.psychiatry.org
- National Center for Post-Traumatic Stress Disorder - <http://www.ptsd.va.gov>
- EMDR International Association (EMDRIA): www.emdria.org. EMDRIA lists training programs and a database of certified members for client referrals.

4.4 Telemarketing and/or Mailing List Removal

If you want to be taken off national mailing lists, your first step is to contact the Direct Marketing Association's (DMA) Mail Preference Service (MPS). You must re-register after three years. To assist those who are managing this process, DMA created (in October 2005) a Deceased Do Not Contact List (DDNC), which all DMA members are required to honor. The Deceased Do Not Contact List is available to companies and nonprofit organizations for the sole purpose of removing names and addresses from their marketing lists.

What are the expected results?

When you register a name with DDNC, the person's name, address, phone number, and email address is placed on a special do not contact file. All DMA members are required to eliminate these individuals from their prospecting campaigns. The service is also available to non-members of DMA so that all marketers may take advantage of this



service to eliminate names. A new, updated file is distributed to the members at least once every three months. Therefore, the number of commercial contacts from DMA members should begin to decrease within three months.

How to Register

Friends, relatives, and caregivers are encouraged to register the information about deceased individuals as soon as possible. We encourage funeral directors, hospitals, doctors' offices, and others to provide this internet link to the bereaved, as well.

Verification Fee

There is no charge to register for the Deceased Do Not Contact List. Consumers will be asked for an email address when registering. An email will be sent to this address, which will have a link to verify registration. The DMA will not keep personal, identifiable information and will not use the information for marketing purposes.

Register Names of Deceased

The Direct Marketing Association also gives you the ability to register the names of deceased loved ones with their Deceased Do Not Contact list (DDNC) at www.ims-dm.com/cgi/ddnc.php

4.5 Supporting Children in Grief

4.5a Understanding Grief in Children

Understanding Grief in Children

By Lisa Capizzi Marain, M.S.W, LCSW, Senior Licensed Clinical Social Worker, Hackensack University Medical Center, Hackensack, New Jersey

Many parents have reported that one of the most daunting tasks is to inform the surviving children that their sibling, cousin, friend, or schoolmate has died. Our hope is to provide you with guidelines to help families find the most effective way that feels right for your situation. Typically, children will have varied responses regardless of what their age/developmental ranges are. If the child is not your own, it can be very beneficial to coordinate with their parents and share this information. Most importantly, if a child says that they want to kill themselves, immediately take them to your local emergency room where a professional can assess their mental health. If you are unable, call 911 (U.S.) or your local police department immediately for assistance.

Ages and Stages

Age 2 to 4:

- Developmental Stage/Task – Egocentric. Believe world centers around them. Narcissistic. Lack cognitive understanding of death and related concepts. Limited language skills.
- Concept of Death – Death seen as reversible, as abandonment, not permanent. Common statements: “Did you know my mom died? When will she be home?”
- Grief Response – Intensive response but brief. Very present oriented. Most aware of changes in patterns of care. Asking questions repeatedly.
- Signs of Distress – Regression: changes in eating and sleeping patterns, bed wetting, general irritability, and confusion.
- Possible Interventions – Short, honest answers, frequent repetition, lots of reassurance and nurturing. Consistent routine. Play is their outlet for grief.

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Age 4 to 7:

- Developmental Stage/Task – Gaining a sense of autonomy. Exploring the world outside of self. Gaining language. Fantasy wishing and thinking. Initiative phase seeing self as the initiator. Concerns of guilt.
- Concept of Death – Death still seen as reversible. Personification of death. Feeling of responsibility because of wishes and thoughts. Common statements: “It’s my fault. I was mad and wished she’d die.”
- Grief Response – More verbalization. Great concern with process. How? Why? Repetitive questioning. May act as though nothing has happened. General distress and confusion.
- Signs of Distress – Regression: nightmares, sleeping and eating disturbed. Possible violent play. Attempts to take on role of person who died.
- Possible Interventions – Symbolic play using drawings and stories. Allow and encourage expression of energy and feelings through physical outlets. Talk about it.

Age 7 to 11:

- Developmental Stage/Task – Concrete thinking. Self-confidence develops. Beginning of socialization. Development of cognitive ability. Beginning of logical thinking.
- Concept of Death – Death seen as punishment. Fear of bodily harm and mutilation. This is a difficult transition period, still wanting to see death as reversible but beginning to see it as final.
- Grief Response – Specific questions. Desire for complete detail. Concerned with how others are responding. What is the right way to respond? Starting to have ability to mourn and understand mourning.
- Signs of Distress – Regression: school problems, withdrawal from friends. Acting out. Sleeping and eating disturbed. Overwhelming concern with body. Death thoughts (desire to join one who died). Role confusion.
- Possible Interventions – Answer questions. Encourage expression of range of feelings. Explain options and allow for choices. Be available but allow alone time. Symbolic play. Allow for physical outlets. Listen and allow for talk about the death.

Age 11 to 18:

- Developmental Stage/Task – Formal operational problem solving. Abstract thinking. Integration of one’s own personality.
- Concept of Death – A more “adult” approach. Ability to be abstract. Beginning to conceptualize death. Work at making sense of teachings.
- Grief Response – Extreme sadness. Denial. Regression. More often willing to talk to people outside of family and peer support. Risk taking. Traditional mourning.
- Signs of Distress – Depression. Anger often towards parents. Suicidal thoughts. Non-compliance. Rejection of former teaching. Role confusion. Acting out.
- Possible Interventions – Encourage verbalization. Allow for choices. Encourage self-motivation. Listen. Be available. Do not attempt to take grief away.

Helpful Guidelines

Be honest, open and clear. Whenever possible, adults should give children the facts regarding the death. While there is no need to describe a lot of detail, the important details should be given.

This may be horrifying, but it is always important to give factual information to the child. The imagination of a child will “fill in” the details if they are not given. Too often, these imagined details are distorted, inaccurate and more horrifying than the actual details, and can ultimately interfere with the long-term healing process.

Do not avoid the topic when the child brings it up. Like other trauma, the adults around the child need to be available when the child wants to talk but should avoid probing when the child does not want to talk. This may mean answering one question or struggling with a very difficult question. “Does it hurt when you burn to death?” Don’t be surprised if in the middle of your struggle for



the “right” answer, the child returns to play, and acts disinterested. The child has been unable to tolerate the level of emotional intensity and is coping with it by avoiding it at that point. Children will sense if the topic is emotionally difficult for adults around them. A child will try to please adults by either avoiding emotional topics or persisting with topics that she senses they find more pleasant. Try to gauge your own sense of discomfort and directly address this with the child. It is reassuring to children that they are not alone in some of their emotional upset.

Children look to adults to understand and interpret their own inner states. Younger children will even mirror the nature and intensity of an adult’s emotions. So, if you feel you will be unable to control your emotions when you are trying to help the child, you will need to use some coping strategies yourself. Take a few moments, collect yourself and then try to help the child. It is only human to lose control and be very emotional in these moments. After you feel more composed, you can help the child understand how you were overcome with emotion, “Just like you feel sometimes.” Explain that you struggle to understand too, that, “We need to help each other when we are sad.”

Be prepared to discuss the same details again and again. Expect to hear things from the child that seem as if they didn’t “hear” you when you told them the first time. The powerful, pervasive implications of death for the child can be overwhelming indeed. The child’s responses to death of a parent, sibling, or other loved one will be like the child’s responses to other traumatic events. This will include emotional numbing, avoidance, sadness, and regression, episodic manifestations of anger, frustration, and fear of the unknown (e.g., the future), helplessness, and confusion.

The child will have recurring and emotional recollections of the loved one, and about the death of the loved one. If there is no clear image of the death, the child will imagine various scenarios. These images will return repeatedly. As they do, the child (if she feels safe and supported by the adults around her) will ask about death, the specifics of the death and the loved one.

Patently repeat clear, honest facts for the child. If you don’t know something – or if you also have wondered about the nature of death or a detail in this specific loss – tell the child. Help the child explore possible explanations, and help the child understand that you and others can and do live with many unknowns. In this process, let the child know, however, that there are things we do know – things we can understand. Bring positive memories, images, and recollections of the loved one into the conversation.

Be available, nurturing, reassuring and predictable. These things make the child’s grief easier. They feel safe and cared for. The loss of parents, siblings, and other loved ones is extremely traumatic, and will forever change these children’s lives. The child has, in some sense, a lifelong task of working, re-working – experiencing and re-experiencing the loss of these loved ones. Each holiday, each family occasion, will bring the loss and the death of the loved one to this child. Available, nurturing, and caring caregivers, teachers, therapists, and adults will all make this journey easier.

Understand that surviving children often feel guilty. A child surviving when family members die may often feel guilty. This can be a very destructive and pervasive belief. The guilt children feel is related to the false assumptions they make about the event. An important principle in this process is that children do not know how to verbalize or express guilt in the same fashion as adults. Guilt, as expressed by children, may often be best observed in behaviors and emotions that are related to self-hatred and self-destruction. The child will not likely be able to articulate that survivor guilt is intimately related to their sense of worthlessness or self-abusive or destructive behaviors.

The children surviving a sibling’s sudden death will have great survivor guilt. “Was there something wrong or bad about me? I could have been there – I should have been there.” These thoughts will recur in any variety of permutations. And most of the time, the outcome of these thoughts will be guilt. If these children’s caregivers, teachers, and therapists can minimize these potentially escalating and destructive ideas, the child’s recovery will be eased.

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Take advantage of other resources. There are many other well-trained professionals willing to help you and the child in your care with these problems. Take advantage of them. Always remember that the loss does not go away, but the way children experience loss will change with time, hopefully maturing in ways that make it easier to bear. The traumatic loss of a parent, a sibling and a peer will always be with these children. With time, love, and understanding, however, children can learn to carry the burdens of traumatic loss in ways that will not interfere with their healthy development.

4.6 Suggestions on How to Tell a Child Someone Died

1. When death happens, have a close relative, preferably a parent, tell the child about it immediately.
2. Understand that children do indeed grieve, can comprehend loss, and experience grief processes.
3. Stay close to the child, giving them physical affection.
4. Let the child see you grieve; it gives them permission to grieve on their own. "It will help the child to see the remaining parents, friends, and relatives grieve. Grief shared is grief diminished...if everyone acts stoically around the child, he or she will be confused by the incongruity. If children get verbal or nonverbal cues that mourning is unacceptable, they cannot address the mourning task."
5. Avoid euphemisms such as "passed on," "gone away," "departed." In and of itself, the concept of death is difficult enough for a child to understand; using euphemisms will only add to the difficulty.
6. Discuss the funeral with the child. Do NOT force him or her to go. Decide what is right for your family based on the child's development and personality. If you decide they will go, explain in detail what they will see and hear, and your expectation of them. If you are struggling with the decision to allow any children to attend the funeral or related services, discuss this with a grief counselor if available.
7. Gently help the child grasp the concept of death. Avoid vague explanations to the child's questions, but answer each question as honestly as possible.
8. Keep other stressful situations, such as moving or changing schools, to a minimum; after the ceremonies, continue the child's regular routines.
9. Be honest with the child about the depth of the pain he or she will feel. "You may say, this is the most awful thing could happen to you." Contrary to popular belief, minimizing the grief does not help.

4.6a Don't Forget the Kids

Like adults, children and teens may feel intense sadness and loss, or grief, when a person close to them dies. And like adults, children and teens express their grief in how they behave, what they think and say, and how they feel emotionally and physically. Each child grieves differently, and there is no right or wrong way or length of time to grieve. Some grief reactions cut across all age groups and developmental levels, and children may show their grief in many ways.

Bereaved children may also act in ways that those around them may not recognize as grief reactions. Whatever a child's age, s/he may feel guilty about having caused the death. Sometimes bereaved children take on adult responsibilities and worry about



surviving family members and who would care for them if something happened to their caregivers.

Professional involvement is warranted if grief reactions seem to continue without any relief and significantly impact ability to function. At this point, the child may be suffering from trauma associated with grief.

4.6b Sibling Grief

Sibling Grief

By Alissa K. Sandler, M.S.W., LCSW Section Chief, SIDS Center of NJ, Supervisor of Pediatric Social Work, Hackensack University Medical Center

The sibling relationship is unique. The death of a sibling therefore presents a unique experience that has been left virtually unexplored in the literature. While parents are grieving the death of their child, they may not be available to attend to the grief of their living children. This can lead to a feeling of isolation, leaving a brother or sister to work through their grief alone. More recently, parents of grieving siblings and grief counselors have begun to address this issue. The impact is immense. The legacy that a grieving sibling carries forward is immeasurable. If allowed to be explored, it may provide insight for future generations about family grieving. The living sibling also plays a role in educating society about the conditions that a brother or sister succumbed to. Most of the information that is available regarding sibling bereavement is anecdotal. Parental attitude determines how a deceased sibling is incorporated into the family. As parents and families have been allowed to openly grieve, so have siblings.

It is important to recognize that children grieve. The way they grieve is determined by their age. However, children, even infants and toddlers, experience sadness especially if their caretaker is sad, distant, or distraught. Therefore, acknowledging siblings' feelings is vital. Allowing them to express an array of emotions will help them cope during a very stressful time. It is difficult to accept the expression of feelings such as crying, stubbornness, playfulness, and periods of withdrawal. However, like adults, it is unavoidable. Encouraging siblings to talk about their brother or sister, draw pictures, write poetry, and attend memorial services is helpful. This process helps a child work through their grief and decreases isolation. Siblings want to be part of the grieving family. Allowing children to talk and ask questions can be painful for adults. However, children learn and obtain control through this process. When children ask about what happened to a brother or sister:

- Let the child direct the questions
- Keep it simple
- Explore and remove any issues of blame
- Listen
- Be honest

Help children honor their sibling:

- Create a memory book
- Plant a tree
- Light a candle
- Release a balloon
- Write a poem
- Draw a picture
- Acknowledge anniversaries of the sibling's birth and death

The bereavement community is beginning to see the results of a decade of "open grieving" related to infant and child death. Sisters and brothers, including the subsequent sibling, seem to be

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well-adjusted and consequently comfortable with issues of death and dying. They are loving and compassionate people. Parents and their children can grieve together and receive comfort and support from one another. A sibling allowed to integrate a deceased brother or sister into their lives seems to feel more complete. After all, the sibling relationship is unique and needs to be nurtured in life and death.

4.6c We're Not Really Alone: The Importance of SUDC Awareness

We're Not Really Alone: The Importance of SUDC Awareness

By Jordan Young, SUDC Sibling to Casey (09/01/09 - 06/03/11)

When my 21-month-old sister, Casey, died suddenly and unexpectedly in her sleep back in 2011, all of my emotions swallowed me whole — sadness, grief, anger, confusion, fear and so many others. But one other less obvious emotion also stuck out and took over my life: loneliness.



I couldn't help but feel like no one else in the world could possibly understand what my family or I was going through. None of the other third graders in my class could relate to me when I was pulled out of school for the week to attend the funeral proceedings, and when I went to my friends' houses after school, their siblings were still there — happy, playing and still alive.

I especially felt alone because of the way it happened. I was always hearing on the news of little kids dying in natural disasters, of long-term illnesses or because of other unspeakable tragedies. But before Casey, I had never heard of a seemingly healthy child just randomly dying in their sleep. No one in my life had.

We were told that there was no explanation. That it was a rare, unsolvable medical mystery. However, as I would eventually learn, just because an experience is rare, that does not necessarily mean you are alone in it.

In 2020 alone, 390 children in the U.S lost their lives to sudden unexplained death in childhood, or SUDC. The rate at which SUDC occurs could be even higher, as the way death investigations are conducted vary by region. Therefore, any count is an estimate. Currently, there is little knowledge about what causes SUDC, no way to predict or prevent it and no targeted federal funding to research it.

I have found that no one really knows what SUDC is outside of those it has affected, including medical professionals. Every time a new doctor asks for my family medical history, they are stunned. I cannot help but wonder how many cases of SUDC aren't being caught by medical examiners simply because there is so little awareness about what it is, and instead considered explained with a speculative diagnosis.

If my family had not learned about SUDC, our lives would have veered down a very different path. Because Casey's death was identified as SUDC, my family was given access to extensive medical testing for genetic diseases linked with sudden death. However, families can only access these possibly life saving tests if they know about SUDC. Awareness is integral, otherwise medical professionals are left unable to assess the risk of surviving relatives. Awareness also paves the way to more funding into research, that way deaths can be accurately counted, causes can be investigated



and maybe one day prevention strategies can be formed in order to ensure that this doesn't happen to another child ever again.

And of course, as cliché as it may sound, awareness is what ultimately brings us together — so that we don't feel alone anymore. I remember when I was about 14, my mom, my youngest sister and I went to an event with other SUDC families. All of the families were supposed to decorate candles with the name of the child they lost and then take turns bringing them up to a pedestal at the front of the room. We watched as the pedestal slowly turned into a rainbow of the names of children who had been lost in the same way that we lost Casey. There were almost too many to comprehend.

I was also asked to read a poem for the event. I remember standing at the front of the room seeing all of those families looking back at me, and it was then that it hit me just how many of them there were. So many of them were kids who had also lost their siblings, just like I had. I had spent so much of my childhood ruminating on the loneliness of my family's situation, yet here was a room filled to the brim with people who were all stuck in the same boat. I like to think that more awareness can help find the stragglers out there who are still lost at sea, thinking that they're alone and that there's no one in this world who could possibly understand what they have gone through.

It is absolutely heartbreaking knowing that all of these families have experienced the same trauma that mine has, but I now know that the idea that we are alone in that trauma is simply a fallacy.

4.6d How Children React to Emotional & Psychological Trauma

Regression. Many children return to an earlier stage when they felt safer and more cared for. Younger children may wet the bed or want a bottle; older children may fear being alone.

Feeling helpless. Being active in a campaign to prevent an event like this one from happening again, writing thank-you letters to people who have helped, and caring for others can bring a sense of hope and control to a family.

Thinking the event is their fault. Children younger than 7 or 8 tend to think that if something goes wrong, it must be their fault – no matter how irrational this may sound to an adult. Be sure your child understands that he did not cause the event.

Sleep disorders. Some children have difficulty falling asleep; others wake frequently or have troubling dreams. A stuffed animal, soft blanket, or flashlight in bed can help. Quiet activities in the evening can also soothe.

Health issues. They complain about aches and pains.

School and relationship issues. Difficulty concentrating in school, not wanting to do normal activities, anger and irritability, being withdrawn, and isolating themselves from family and friends can all be reactions to grief.

Helping a Child Recover from Trauma

- Communicate openly
- Maintain routine
- Reinforce safety
- Provide comfort
- Validate feelings
- Professional support



4.6e Additional Resources for Children

- The National Child Traumatic Stress Network – www.nctsn.org/trauma-types/traumatic-grief
- American Academy of Child and Adolescent Psychiatry – www.aacap.org
- Support Grieving Students – grievingstudents.org
- How to Help a Grieving Child in the Classroom – www.fernside.org
- A comprehensive list can be found on the SUDC Foundation website at www.sudc.org > Family Services > Grief Resources.
- Suggested books can be found on the SUDC Foundation website at www.sudc.org > Family Services > Grief Resources.



When a Student Loses a Sibling: A Toolkit for Schools

Download your toolkit at
www.sudc.org/siblingtoolkit



4.7 Supporting Grandparents in Grief

The grief of grandparents is sometimes described as double grief. They grieve the grandchild who has died, and they grieve for their own children, whose pain they cannot take away.

In addition to our overall family services, our online email group – just for registered grandparents – can be a helpful way to connect with others who understand. It is a large and supportive group and grandparents are welcome to join at any time. (See Section 4.1a)

4.7a Insights from a Grandmother's Grief Journey: Ronnie Was the JOY in Our Lives

Insights from a Grandmother's Grief Journey: Ronnie Was the JOY in Our Lives

By Rivka Guttman, SUDC Grandparent to Ronnie (09/27/17 - 01/13/20)

Ronnie Joy, our youngest grandchild at the time, brought so much joy, peace, and calm to my life. I had planned to retire in June of 2020 and was looking forward to playing with Ronnie and taking her to music classes. She had so much personality! She had an unusual love of animals, especially dogs and sheep, loved to sing songs and dance, play dress up, and carried her two bunny "luvies" everywhere. She especially loved imitating her big sister Lielle and watching her brother Ari play his video games.

My best memory of Ronnie is putting her to bed at night when I would babysit. We'd sit on the rocking chair in her room, and she would choose the books she wanted to read. Sometimes she would "read" them to me with her incredible memory. I'd hold her in my arms, and she would lay



her head on my shoulder. I'd sing her a lullaby, put her into her crib and then watch her on the monitor rolling in her bed and talking or singing to herself. My last memory was of her standing front and center as our family lit Hanukkah candles, waiting to blow them out as if they were birthday candles.

Ronnie died suddenly, and with no explanation, on January 13, 2020, at the age of 2 years and 3 months while playing at home. My husband and I were on vacation when it happened, and the time it took for us to get back to Montreal to hug our daughter Dahlia and son-in-law Michael was the worst 24 hours of our lives. We were in shock, hollow, and empty.



Of all the scenarios I could have imagined in my life, losing a grandchild never came to mind, let alone a death of unknown cause. Even though we are a family of healthcare professionals, we had never heard of SUDC, and it was shocking to learn that the pediatric doctors in a major university children's hospital were no more knowledgeable. It was a friend's internet search that led us to the SUDC Foundation.

My only experience with grief up until this point was the loss of my father, of cancer at 79 years. I miss him but not in the same way I miss Ronnie. The pain remains raw even after almost two years. I had so much to learn, and I felt so helpless.

My initial contact with the SUDC Foundation was with Laura Gould. It was comforting to talk to someone who had been there, and I immediately felt a sense of calm, even though I understood that the journey would be difficult. She sent me information which I shared with my daughter who subsequently contacted the SUDC Foundation herself and is now an SUDC Foundation Ambassador.

From the beginning, my focus was my daughter and her two other children. I didn't know what to do or what to say. My daughter could sit for hours scrolling through pictures of Ronnie on her phone or texting, while I sat next to her feeling lost. Not only had I lost my precious Ronnie, but I lost the daughter that I knew. As a parent, I could always help to make things better, whatever challenges my children would encounter, there was always a solution. I felt like a failure as a mother and that my daughter's life, our family, would never be normal again. It was, and still is, a roller coaster of emotions.

I participated in one of the Foundation's virtual Grandparent Support Hour events early on when I needed some guidance on how to best be there for my daughter. I appreciated the grandmother who joined five years after her loss; she gave me a perspective of what to expect and how I might navigate the ups and downs, especially future family gatherings. It was comforting to share and learn from someone who understood the loss of a grandchild, and the helplessness I felt. I also appreciate the SUDC Foundation Grandparent online community in the SUDC Foundation Network; the conversations are relatable, and I feel comfortable contributing when I think it might be helpful.

Through the Foundation's parent Facebook posts and SUDC resource articles, I gained an appreciation of how to navigate birthdays, holidays, and other events in a meaningful way, and how important it is to give meaning to Ronnie's life. I support Dahlia in her charitable endeavors through Ronnie's Joy Foundation and its mission to bring joy to sick children, support grieving families, and the SUDC Foundation.

There is not a day that goes by that I don't think about Ronnie, what she would look like, what we would be doing together as she would have turned three and, recently, four years old. She now has a baby sister and I hope to talk to her about Ronnie when the time comes, and tell her all about her loving, silly sister.



4.7b Sudden Unexplained Death in Childhood for Grandparents ... a “Double” Grief

From the moment you became a parent, you have sought to protect your child from the pain and sorrows in life. Mostly, you have been successful, you’ve had the ability to solve problems and the power to lessen hurts.



Suddenly, your adult child is facing a pain far deeper than any other pain in life. It may be deeper than anything that you have ever experienced, or perhaps you can understand this sorrow because you, too, have lost a child.

Either way, you are now experiencing a variety of emotions: helplessness, frustration, grief, guilt, and anger. You are suffering a “double grief.” You are grieving for your grandchild – all your hopes and dreams have been shattered. You had wondered if he or she would “favor” your side of the family, wondered what she/he would “become” and had perhaps even bought gifts for “later” (like that first tricycle or that special doll). Your grief may not even be recognized. You had a special relationship with your grandchild – one of unconditional love.

You may feel frustrated and helpless because this is one pain that you can’t “just kiss” away. All the little ways that you had to coax a smile from your child are useless now; all the magic words that used to solve the problems are empty. You can only sit by, offer support, and watch your child learn to live with the terrible loss.

Grandparents often think that “they should cope better, have all the answers, control the situation, and be an example. When all that they have offered – advice, financial aid, babysitting, experience, and help – is not accepted, asked for, or is even rejected, they often feel guilt, frustration, and anger.”

Guilt and anger. Often, the two are intermingled. It can be difficult to determine where one begins and the other ends. Grandparents sometimes experience “survival guilt.” It seems unnatural that a grandparent lives longer than a grandchild; grandparents often express the wish that they “could change places” with the beloved grandchild. You may be feeling guilty for things that you didn’t do. (Why didn’t I babysit every time I was asked? Why didn’t I spend more time with this grandchild?) Perhaps you aren’t well, or for some other reason, you were unable to see your grandchild as often as you might have wished.

You may be very angry. Angry at God for “taking” this grandchild, angry at the doctors, nurses, or paramedics for being unable to save your grandchild’s life, angry at your other adult children whose families are intact (though a common reaction, grandparents feel a great deal of guilt because of this anger). You might even find yourself angry at your own child, wondering if there was anything they could have done or should have seen. Finally, you might be angry at yourself as you wonder if your genes or chromosomes were “responsible” for your grandchild’s death.



Please know that grief is a highly individual process. People do not need to be urged to grieve in some predetermined way. There are tremendous cultural differences in how people grieve – even a husband and wife will seldom grieve in the same way. As parents move along in their grief, there will always be setbacks, some triggered by specific events related to the child (birthdays, anniversaries, etc.) and some seemingly unrelated. An SUDC death is uniquely difficult because of its very nature. Its suddenness and the lack of answers to important questions intensify the grief reactions.

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4.7c Locating Additional Local Resources

Every community has diverse grief resources. Keep in mind, you may need to make several phone calls before finding what works for you. The internet and your local library can be a helpful resource as well. Below are some ideas to help you get started, but remember that the SUDC Foundation's staff is always available to assist you in finding helpful resources.

Contact the funeral home that made your arrangements. Ask for a list of referrals.

Contact the medical examiner or coroner's office. Some have personnel who provide family support services.

In the U.S., contact 211.

Research online for local groups from the below:

- Hospice organizations
- Children's hospitals
- Compassionate Friends
- Bereaved Parents of the USA
- Catholic Family Services, Jewish Family Services or other faith-based groups
- Bereavement organizations
- Contact the social services department at a local hospital.
- Contact a hospice. Many hold support groups for various types of grief.
- Contact your medical insurance for referrals to therapy. When calling, ask if they have experience in grief, and if appropriate, trauma.
- Ask your personal physician, your child's pediatrician, or your obstetrician for referrals.
- Contact the police department. Many have access to counselors who work with trauma and grief.

Not every resource will be right for you. Try to think about what you want most from a group or counselor. Try to ask as many questions as you can when making local contacts.



Someone may have the right information to help you find the right support for you.

If the task seems overwhelming, ask a friend or family member to do the research for you or reach out to the SUDC Foundation for additional help and support.

4.7d Additional Resources for Grandparents

A comprehensive list can be found on the SUDC Foundation website at www.sudc.org > Family Services > Grief Resources.

Suggested books can be found on the SUDC Foundation website at www.sudc.org > Family Services > Grief Resources.

4.8 Remembering Your Child with an Event

The SUDC Foundation currently receives no public funding. At this time, the Foundation is solely supported through private donations, grant awards, and revenue generated by fundraising events organized in memory of SUDC children. Around the world, families are using their passion to create unique events in the memory of their children.

To continue our work and to help support the financial needs of the Foundation, we are grateful to families and their friends who have been able to channel grief through fundraising. Organizing a fundraiser in the memory of a child brings a sense of unity and motivation for others to support the SUDC Foundation's mission.

Fundraising takes many forms at the SUDC Foundation; some popular ideas are themed parties, golf outings, memorial 5k races, t-shirt fundraisers, and virtual and other community-based activities.

The SUDC Foundation maintains a library of planning resources and tools to provide extensive information on how to put together a fundraising event from start to finish. If and when you are ready to organize a fundraiser, please contact our development staff at development@sudc.org.



Soccer Tournament for Jax
(2021)



Paxton's PacMan Party
(2022)



Jackson Walsh Char-i-tee
(2021)



4.8a Finding Gratitude Through the Love of Strangers

Finding Gratitude Through the Love of Strangers

by Brianna Langerfeld, Mom of Keegan (10/10/20 - 10/16/21)

When Keegan passed away, our world came to an abrupt standstill, as I would imagine most families would feel. I will never be the same person, let alone the same mother, that I was before I opened that nursery door. A month before Keegan was gone, we found out that our family was growing. We were so excited and so happy. We instantly started talking to Keegan

about being a big brother, making plans for when we were in the hospital, and just picturing the two of them being the greatest siblings. Our hearts felt truly complete, but the second Keegan was gone, I couldn't even imagine bringing a new baby home. The anxiety that took over was crippling. My entire second pregnancy was a complete blur. I spent most of it drowning in sorrow and grief, feeling heartbroken not only for Keegan, but also his little brother. All I've ever wanted in life was to be a mom, and then I questioned if that was even possible. I dreamt of the day I had a home full of kids running around the house wreaking havoc. When Keegan was born, the love I felt for him completely took over, but when he was gone, I couldn't imagine feeling that same amount of love for anyone. I think my heart and mind were protecting me from feeling this pain again. However, when Kellen was born, six months after the horrific day, all that questioning went out the window. The love I had for Kellen was just as hard as it was for Keegan, and if anything, it felt stronger. While I was pregnant, during a SUDC support call, a mother shared that "you will love your future children so much harder because of the child you lost." That was exactly what I felt. Because of Keegan, Kellen is surrounded by the deepest, strongest love. He has been the biggest blessing, not only for me and Bobby, but for our families as well. He allowed us to feel joy again and for that we are so grateful. He may not get the same mother that Keegan had, but I will try my hardest to get there. The anxieties that I have around anything and everything to do with Kellen are only because I love him immensely and will not allow us to lose him. He gave us a purpose again.

"Keegan's Touch-A-Truck was the first time in those awful 12 months that I felt actual happiness. It was able to turn such a painful day into a day filled with children and families laughing and smiling."

—Brianna Langerfeld

Having a new baby during the hardest year of our lives was a challenge, but it forced us to get out of bed and move forward. We still have our dark days, but they were now surrounded with love. Because of Kellen, Bobby and I were able to put one foot in front of the other, but one thing we realized is how fast time goes by; we experienced this the hardest during Keegan's first year gone. It started with, "I can't believe he's been gone a week," to, "How has it been six months without him?" Some days it honestly felt like Keegan didn't even exist because of how fast he was here and then gone. The date of his birthday and anniversary were slowly creeping up and were constantly in our forethought; his birthday was what I was anticipating being the hardest, since such a celebratory day



is now a day full of sadness. Bobby and I talked long and hard about what to do – if anything at all. Do we acknowledge the day or just forget it even existed? After months of going back and forth, we decided not only to acknowledge it but to celebrate it, just like Keegan deserved.

Our hope was to give Keegan the birthday that every 2-year-old should have, as well as raise awareness of SUDC. And what does every little boy love? Trucks! Keegan's Touch-A-Truck came

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together quicker and smoother than we ever thought possible. The second we put the event out there it seemed everyone just wanted to help and be a part of the day somehow. We hoped for an event to show Keegan and the SUDC Foundation so much love, but we never expected what occurred. On the day of the event, we had over 900 people in attendance and raised over \$17,000, all for our sweet boy. Keegan's Touch-A-Truck was the first time in those awful 12 months that I felt actual happiness. It was able to turn such a painful day into a day filled with children and families laughing and smiling. During the event, a woman who I had never met before stopped me and said, "Thank you so much for bringing this event to our community and spreading awareness for SUDC. I had never heard of this awful tragedy but now I will make sure to share your son's story." My goal was accomplished, and I know Keegan was so proud.

4.9 Creating a Memorial Tribute Page for Your Child

4.9a Memorial Tribute Page

The SUDC Foundation will create a loving memorial tribute page for your precious son/daughter. Families work with a member of our staff to create a loving tribute page for their child, through which families can share pictures as well as their own personal story. Each page includes a personalized donation form for friends and family to easily donate to the SUDC Foundation in memory of your child and may also include information about your fundraising events if you are planning one. Scan below to visit sudc.org/sudc-memorial-tributes.

To request your memorial tribute page, log in to www.sudc.org > Member Services > Registered Families > Get Involved > Memorial Tribute Request. If at any time, you would like to add or make an update to the memorial tribute page, such as a special memory day, simply reach out to our support services staff at support@sudc.org.



4.9b Memorial Instagram Page

Our Instagram Memorial page is a loving tribute in memory of children affected by sudden unexpected or unexplained death in childhood. We collect from you, your child's story, which is best told by recalling early moments and milestones, personality traits, hobbies, favorite things, and other cherished memories that you'd like to share with others, along with special photographs of your child. We then create the post on the SUDC Foundation Instagram Memorial Page to be shared with loved ones and friends. Scan below to visit sudc.org/sudc-memorial-tributes.

To request your memorial tribute page, log in to www.sudc.org > Member Services > Registered Families > Get Involved > Instagram Memorial Request. If at any time you would like to add or make an update to the post, simply reach out to our support services staff at support@sudc.org.



★ Section 5

Reflections of Hope

We hope you find the poignant stories and poems below help you not feel alone and provide hope in your own resilience to cope with your loss. For more stories, please see our SUDC memorials at www.sudc.org.

5.1 Stories

5.1a Amy Was the Centre of Our Family, And Suddenly She Was No Longer Here

Amy Was the Centre of Our Family, And Suddenly She Was No Longer Here

By Beewan Atwal, Mother of Amy (06/12/08 - 12/06/20)

My daughter Amy was not expected to die. Amy had no illness or injury, there was no warning. She went to sleep one night and did not wake up. I found her, on a Sunday morning. She was 12 and a half. I thought she was sleeping a little longer than usual, as we'd had a few late nights that week. I went into her room to wake her and she was unnaturally cold. Death had taken hold during the night. There was a horror and panic, seeing a dead body, and because it was my little girl who was dead. She was nearly my height, just half a centimetre away. The day before she had been to her dance class, watched movies and been so very alive and full of joy. Her death is unexplained, nothing physically wrong with her body apart from the glaringly obvious fact that she died.



That is the place where we start our grief: the shock, the sudden unexpected death of our child. The horror, that our child has died. And the trauma of finding her and not knowing why she died.

In the days and weeks following my daughter's death, my body ached for hers. I felt a physical hole in my chest, a pain so real I was sure that if I was to be x-rayed that they would find a large piece of me had been carved away. My body reacted to the loss of my child; I felt like my breasts were full as though I had recently stopped breastfeeding. Everything was primal and raw, a mother without her child.

I cried a cry that I have never heard or felt before, one that comes from a place so deep within my body, with echoes of the past. The cry was animalistic and it moved through my body without permission or control.

For months I sat in my daughter's room, convinced that I would die too. Surely that would be the only fair thing to happen. I have paved the way for my children, experienced life before them. I should be dead too before them to guide my daughter in death. How could this happen? Death did not come to me, the cardiologist we were referred to couldn't find anything wrong with us. I was tested again and again, waiting for them to say we have found something and you will die too. Nothing was found, I have to admit I was disappointed.

I went to a bereaved parent group called SLOW. When my husband and I first attended, we joined via zoom as COVID had us in lockdown. One of the mothers said that it had been 20 years since she lost her daughter. It shocked me; how could anyone live that long without their child? I

continued...



remember thinking, "I don't want that, that would be too cruel." We carried on going to the group, and I heard of how other families have lost their children: it's all terrible, no matter how they die, simply because children should not die. I am struck by how much the parents find it hard to hold their grief and navigate in the "normal" world now. No one knows how to deal with grief in our society, and it seems that other people's behaviour contributes to the trauma of losing a child.

We are now a horror story that other people tell each other about. What can happen to a normal family on a normal day. Friends who are parents have distanced themselves, I suspect out of self-preservation. The knowledge that a child can die any moment and without apparent cause is too much for the parents we know. They are able to look away and throw a cloak over this tragedy. We have no choice, as this is our existence now.

I also had friends who just stepped up and helped. The best ones just witnessed and sympathised without trying to fix us. They walked with me as I told them the horror, and they held me as I cried. They didn't look away or expect me to "move on." These are my special friends now as they found a strength to help me. Therapy is ongoing but in the first year I found talking therapy as a couple helpful as we both grieved differently and we needed to understand each other as well as understand what we were individually going through. EMDR was horrific to do but it shifted the trauma and opened up so many other memories of Amy. I also did acupuncture for grief, which I really appreciated as I didn't have to talk, I could go and just cry in a room.

Slowly, I developed rituals to help me. I needed to get out of our house on Sundays as I found Amy on a Sunday. I struggled to find things to do; but one day, I went to the flower market, and I just kept going back each Sunday to buy flowers for Amy. We now know quite a few of the stall holders and feel part of the Sunday community at the market. Choosing flowers, arranging them, plus tending to them is something I do for Amy.

We also light a candle to Amy each day. So many religions and cultures have a fire ritual to connect this world to the spiritual world, which I like. The glow from the candle also makes our space feel more emotionally warmer.

Most importantly, for me, is that I write to Amy each day. This started three days after she died. I don't know what made me start to do it. I think I wanted to physically communicate with her and holding pen to paper felt connected. I write each day. It gives me a little space to be with my thoughts about Amy. I really value this time.

It is just over two years now since we lost Amy. I still want her every day, and I think I always will. I am a different person since Amy died. Death is very real, very random and cruel, and it walks beside us. I have deeper friendships and better boundaries. I have hope for the future and am determined to live a life that I can tell Amy about when I see her again. I would hate for her to think her legacy to us was sorrow and misery. She was a very bright, joyous, positive and loving person and in our first year of grief, we often asked what Amy would do in a situation. We try to live in a meaningful connected way.





5.1b Mom's Search for Meaning

Mom's Search for Meaning

You give my life meaning

I love you infinity

by Melissa Monroe, Mother of Alice (07/26/11- 08/06/13) and author of Mom's Search for Meaning

While home alone one day, it occurred to me we'd eventually have to divide the girls' things (after the divorce). I had the gutting realization I would have to divide Alice's ashes eventually.

The thought of this sent me spiraling into a pit of horror and anxiety. I knew anxiety could lead me to redevelop PTSD symptoms. I never, ever wanted to have to recover from PTSD symptoms again because it was the most difficult thing I'd ever done. So I took a deep breath and reminded myself I had some time and space to do it little by little. I reminded myself not to anticipate difficulties, to stay here and now, to do what I could when I could do it.

A few days later, I tried to go through Alice's clothes while Grace was at preschool. I thought I'd start with one thing at a time. Just her clothes.

It didn't go well. I found myself in a heap on the floor of the girls' tiny closet. I cried until I had nothing left and determined I was not quite ready to go through Alice's clothes.

Then I picked myself up, picked up Grace from school, and made dinner.

At dinner she said to me, "I'm going to be good for you, Mama. I am going to be calm. Because your baby died and I'm sorry for you and I want us to have fun!"

She somehow knew I was struggling that day though she wasn't home for the worst part. I didn't want her to have to comfort an adult, and I began to feel guilty about that. I was, however, relieved that my child possessed compassion. I smiled and hugged her and reminded her I loved her at all times, forever.

Three days later, I tried going through Alice's clothes again. I have no idea why I thought it would go better three days later. I think it speaks to how disconnected I was from time. Holding up everything she ever wore and deciding what to do with it was BRUTAL.

"KEEP THIS ONE? Donate it? What to do with the ones I keep? Make a quilt with them? Keep them in a box for Grace to have? I remember when she last wore this. I remember her sauntering into school with that hoodie over her head. She never grew into the shoes Aunt Mandy bought her. She had her first feeding in this onesie. She wore that on her first day to preschool. I remember the moment she created this stain; the stain is here but she is not."

AS THE YEARS PASSED, this is how I managed to release anything Alice may have touched – little by little over long periods of time, like radioactive decay of the heart.





5.1c Life After Tragic Loss

Life After Tragic Loss

By Kristen Worrell, Mother of Emy (05/30/17 - 02/17/19)

October 7, 2016, I found out I was pregnant with Emersyn ("Emy") Grace. I spent my entire pregnancy praying for her, wondering what she would look like, shopping for her, planning and decorating her nursery, and anticipating her arrival. On May 30, 2017, Emy was born, and I discovered a love I never knew existed. Becoming a mother was the best thing that ever happened to me. From the moment I laid eyes on Emy, I knew she was "My Sunshine."



The fall of 2018 I was preparing for the new year never knowing what really lay ahead. On December 31, 2018, my mom was diagnosed with a very rare cancer of the tailbone, called Chordoma. It is literally a 1:1,000,000 and belongs to the sarcoma family. January 2019 was full of many doctors' appointments and treatment plans for my mom. Our home state of Arkansas did not have the radiation needed to treat her cancer. Therefore, my mom, Emy, and I all temporarily moved to Shreveport, La., where she underwent twelve weeks of daily proton beam radiation.

Just five weeks into my mom's cancer treatment, the morning of February 17, 2019, at the age of 20 months old, I found my beautiful and completely healthy baby girl had died in her sleep. I immediately went into shock, screaming and crying. As a registered nurse for nine years at that time, I knew she was gone, but I could not comprehend it. All I wanted was to wake up from the nightmare. Just twelve hours before, she was full of life and joy. All the firsts, gone, and now left with the wonders of the memories we would have made together and what her future would have looked like.

Emy knew who Jesus was and she prayed to him often. She loved everyone and it radiated the love she carried in her heart for others. She rarely met a stranger, and she had a vivacious personality. She smiled with her whole face, and it would light up the room in an instant. She had such a contagious laugh that often ended with a snort. Her hugs and snuggles were the best, and she loved to give "shoogies" (kisses). As part of our nightly routine, I would hum or sing "You Are My Sunshine" while rocking her.

Emy loved life, and she lived it abundantly. Every day was a new adventure. She loved the outdoors, playing in her sandbox, swinging, riding the four-wheeler, helping her mammy water the flowers, splashing in the creek, playing at playgrounds, sliding, and anything that pertained to being outside. She loved her farm animals, and one of her favorite pets was her dog Hank. They both adored each other, and he was so gentle with her. They would lie together and watch TV. Emy loved to eat and would often steal bites of food from you or ask for "more." As her mommy, and one who loves to shop, of course, Emy did too! She had more clothes and shoes than you could imagine. She loved being a helper whether it was with laundry, sweeping, cleaning, paying bills, or helping her friends and family. She knew her colors, and her favorites were pink, purple, and yellow. She loved to play with Play-Doh, put on make-up and lip gloss, run, and jump. Before she could walk, she loved stroller rides on the farm. She often hummed during the stroller rides. She could count to ten and spell her name, "E-M-Y." She loved for us to read to her. We took her to church, and she loved her class of friends. She accomplished so much in her short time here. Emy's life changed me; her death rearranged me; and now my purpose is to walk by faith and share our story. Within the first few days of Emy passing away, I can remember questioning God. Yet, within those same words I would utter through tears, "If one person comes to know the Lord through this tragedy, this is my why."



I started a non-profit foundation in Emy's memory called the Emersyn Grace Rima Foundation. I had never heard of SUDC, and I had been a nurse for nine years at the time of her death. My why covers a multitude of reasons I started the foundation and to far greater depths than words can explain, but, my main reason is to give honor and glory to my Lord and Savior because without His promise of eternity in heaven with Him and my girl, I would not be where I am today. I would have no purpose. Yet, he has me here for a reason and someone needs to hear our story of redemption and healing. That it is still possible to have a heart full of faith, hope, and love in Him, all while grieving what life should have been and trying to pick up the broken pieces. Grief is a process where overtime becomes intertwined with your reality, and you learn how to embrace each day with grit anchored in grace. You learn to muster up the courage to get out of bed and put one foot in front of the other and face the world.



Although I believe it was Emy's appointed time to go home to heaven, and I have peace in that, it does not stop my mind from wondering what caused this. I have taken my grief journey and focused on honoring and glorifying the Lord while also advocating for more research into the cause and prevention of these "unexplained" deaths. We must be the voice for our children gone too soon. We must stop this category of death from happening to anyone else. We must make this topic a priority of conversation so others can learn more and come alongside us to raise more awareness. I will never stop honoring Emy's memory. I will let the love of Jesus shine in and through me to be the light in the darkness for others. Through our foundation, one of the programs we have initiated is Lunch & Learns. We go to pediatric clinics and share about SUDC by providing education, statistics, facts, and resources from the SUDC Foundation to help raise awareness. I have had several opportunities to speak to groups of professionals about SUDC, the SUDC Foundation, and our Foundation. We are expanding our efforts to reach a larger population as well. I have found that sharing my story and talking about Emy helps me keep her memory alive. Raising awareness, educating, advocating, and sharing have given me purpose after such a tragic loss in my life because one child gone is one child too many, and my precious sunshine was one of them. Mommy loves and misses you so much Emersyn Grace!

"You are my sunshine, my only sunshine.
You make me happy when skies are gray.
You'll never know dear, how much I love you.
Please don't take my sunshine away."



5.2 Poems

Support

By April Leffert, Mother of Madeline (born silent 09/12/03)

You sit there in the darkness
You feel so all alone.
You suffer in your sadness.
Your house is not a home.

You call out in the night
"Just let me see your face!"
Hold on to a memory in your mind
A very sacred place.

The darkness is surrounding you.
On both the inside and the out.
All alone in this darkness
You feel that you must shout:

"I'm here. I'm all alone."
"I need your help. I need a hug"
"I'm dying on the inside"
"The pain of a mother's love."

Most mother's take for granted
the precious gift they have
Wishing they weren't parents
Especially when their child is bad.

Above this group of parents
Is a different kind of crowd
Of moms and dads who've lost a child
and cannot shout out loud: "I need your help. I'm all alone"
"No memories to share
"I'm here. I'm reaching out to you."
"Please show me that you care."

It's your future that you lose
Your past and present too
Losing a child changes
Everything you say and do.

I feel much more compassion
Mostly for new angel friends.
People from all over Earth, who
Listen while I tell again.

The story of my angel
No matter how many times told
They listen and reply to me
My feelings never get old.

They are always here to help me
And stand right by my side.
They are always there to comfort me

In them my feelings I confide
Each day is a new journey in grief,
Never knowing what will come
Some days are happy,
Some painful, some horrible and then there are
some- Days when darkness surround you,
And you really must just shout:
"I lost my child, I can't help but cry,
And I must just GET IT OUT!!!"

Just post and look around you
For always we will be here
There is no need to be all alone
We'll be here for you, dear,

Although our names may change
And at times there may be few,
Know there is always someone out there
Willing to listen and share with you.

Through good days and all the bad
To my loving angel friends, I've met
For all the comfort, love, and hugs
Received and sent, thanks to the internet.



**"When someone you love becomes
a memory, the memory becomes
a treasure"
—Author Unknown**



5.3 Quotes

"The reality is that we don't forget, move on, and have closure, but rather we honor, we remember, and incorporate our deceased...into our lives in a new way. In fact, keeping memories of your loved one alive in your mind and heart is an important part of your healing journey."

—Harriet Schiff

"If you know someone who has lost a child or lost anybody who's important to them, and you're afraid to mention them because you think you might make them sad by reminding them that they died, they didn't forget they died. You're not reminding them. What you're reminding them of is that you remember that they lived, and that's a great, great gift."

—Elizabeth Edwards

"Sometimes," said Pooh, "the smallest things take up the most room in your heart."

—Winnie The Pooh

"There are no goodbyes for us. Wherever you are, you will always be in my heart."

—Gandhi

"Death leaves a heartache no one can heal, love leaves a memory no one can steal."

—Anonymous

"Those we love don't go away. They walk beside us every day. Unseen, unheard, but always near. Still loved, still missed, and very dear."

—Author Unknown

"A butterfly lights beside us like a sunbeam. And for a brief moment its glory and beauty belong to our world... But then it flies on again, and although we wish it could have stayed, we are so thankful to have seen it at all."

—Author unknown



WHAT IS NORMAL NOW?

NORMAL is trying to decide what to take to the cemetery for Christmas, birthdays, Valentine's Day, and Easter.

NORMAL is feeling like you know how to act and are more comfortable with a funeral than a wedding or a birthday party. Yet, feeling a stab of pain in your heart when you smell the flowers, see the casket, and all the crying people.

NORMAL is feeling like you can't sit through another minute without screaming because you just don't like to sit through church anymore. And yet at the same time feeling like you have more faith in God than you ever had before.

NORMAL is having tears waiting behind every smile when you realize someone important is missing from all the important events in your family's life.

NORMAL is not sleeping because a thousand "what ifs" go through your head constantly.

NORMAL is having the TV on the minute you walk into the house to have some "noise" because the silence is deafening.

NORMAL is telling the story of your child's death as if it were an everyday common event and then gasping in horror at how awful it sounds. And yet realizing it has become part of normal conversation.

NORMAL is each year coming up with the difficult task of how to honor your child's memory and their birthday and surviving those days. And trying to find a balloon or flag that fits the occasion. "Happy Birthday?" Not really!

NORMAL is a new friendship with another bereaved parent and meeting over coffee and talking and crying together over your children and worrying together over the surviving children.

NORMAL is being too tired to care if you paid your bills, cleaned your house, did the laundry, or if there is food in the house.

★ In Loving Memory...

A Page to Share Your Personal Reflections



"Grief is the last act of love we have to give to those we loved. Where there is deep grief, there is great love."
– Unknown



We sincerely hope that this family resource guide has provided you with valuable information and resources to help support your family's needs.

While we hope that this family resource guide has been helpful for you, we understand that there is no one-size-fits-all solution to coping with your loss. We encourage you to take the time you need to process your emotions and find what works best for you and your family.

The SUDC Foundation recognizes and respects that each family's journey is personal and different. We are committed to supporting you wherever you are in that journey.

If you find that you need additional support or have any questions, please do not hesitate to reach out to us. Our organization is dedicated to providing resources, support, and advocacy for families impacted by Sudden Unexplained Death in Childhood, and we are always available to lend a helping hand.

Remember to be gentle with yourself and know that you are not alone.

We are here to support you every step of the way.

The SUDC Foundation

www.sudc.org

support@sudc.org

