



# Sudden Infant Death Syndrome

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learning from stories about SIDS,  
motherhood and loss

DAWNE J GURBUTT

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*' . . . a cry of anguish is heard in Ramah – mourning and weeping unrestrained. Rachel weeps for her children, refusing to be comforted – for her children are dead.'*

Jeremiah 31.15

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For Jessica and Tom

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# Preface

Much has been written about sudden infant death syndrome (SIDS), sometimes known as 'cot death'; many research projects have studied potential causes and sought to identify risk factors. Yet still much remains unknown about what causes an apparently healthy baby to die suddenly, unexpectedly and without an ascertainable cause.

The research for this study formed part of a larger pathological study into sudden infant death syndrome. I met and interviewed women who had recently experienced SIDS, and professionals and volunteers (some of whom had also experienced SIDS) who sought to try and offer support to these newly bereaved mothers. I met members of support groups and reviewed the literature made available to mothers whose infants had died. Although I did meet some fathers and grandparents, I mainly met mothers and so this book reflects primarily conversations with mothers relatively soon after their babies had died. This is a book primarily about SIDS, but also about maternal grief – from ancient times when writers have sought to express the depth of grief they have alluded to maternal grief following the death of a child.

It is hard to know sometimes where to start, what to keep in and what to leave out. I have tried to order these comments in some way to give them structure, and in doing so, some element of selection occurs. I have tried to represent as accurately as I can the essence of what they told me and to be careful in conveying the meaning as well as just using actual words. I was particularly concerned about anonymity and confidentiality and this necessitated leaving some things out and altering some details where appropriate.

Although I had previously worked for a lengthy time in practice before engaging with this research, I found the space to reflect on

SIDS and the way practitioners respond to SIDS a learning experience. This book has been written primarily to enable others to reflect on some of the stories which circulate around SIDS. They are not always easy stories to write or easy stories to read – but they are stories that need to be told and heard so that we can increase understanding of SIDS.

Dawn Gurbutt  
*November 2006*



# Acknowledgements

I would like to thank all the women who allowed themselves to be interviewed for my research study and all those who supported me in and contributed in any way to my research. I would also like to thank friends and colleagues who encouraged me to write a text and especially Gill Nineham for encouraging me to write *this* book in this way – I hope the end product approaches what you envisaged.

I especially want to thank Russell – who always believes that I will be able to do the things that I find daunting – for his continual support, encouragement and practical help. We have made a good team. Thanks too to my children who constantly teach me so much about life and love – and are inspiring company. Finally, thanks to my mother-in-law Sheila, who many years ago shared her particular story of motherhood with me.

# About the author

Dawne Gurbutt has a keen interest in narratives and qualitative research. She has been engaged in a number of projects exploring different aspects of women's lives. Her career has included nursing, midwifery and health visiting. She worked in community practice for over a decade in the North of England, prior to working in the university sector. Her HEI work has included teaching, research, management and consultancy. She is married with two children.

# Abbreviations

BtoS	Back to Sleep campaign
CESDI	Confidential Enquiry into Sudden Deaths in Infancy
CONI	Care of Next Infant programme
GP	General practitioner
SIDS	Sudden infant death syndrome

# What's the story?

## Understanding narratives

### We are all storied

We all know about stories. Stories are part of every culture and part of all of our lives. We are surrounded by stories of one kind or another: newspapers, conversations, fiction and drama. We are all engaged in telling and listening to stories, weaving our experiences into words. Some of our earliest memories may be of listening to the stories our mothers told us. Those stories had a shape, a beginning, middle and an end. Through them we learned to shape our world – to look for beginnings and to recognise endings. We learned about characters and the importance of events. At primary school we learned to write our lives in stories – to select events out of all the things that were happening to us and to give them a shape and a form, to try to find a place to begin and to decide where to end. We learned to communicate something of ourselves in that form – to describe our lives as a series of episodes. We learned to orally put together our autobiography – events, thoughts and emotions – in a way that could be shared with other people. And then as we learned the art of telling our stories, of engaging other people in our lives, storytelling became a part of what we are, how we live and how we make sense of our complicated and confusing world.<sup>1</sup>

We constantly tell stories, from sharing the events of our day to

sharing the circumstances and contexts that we believe have shaped our human experience and personalities. We are encouraged to tell the story of who we are and what has happened to us in a variety of settings, from meeting people who have newly entered our lives, to sharing something of ourselves with strangers, to recounting how we developed our current skills in a job interview, to explaining our actions to our children and friends, or explaining events to ourselves in our diaries. We constantly tell stories; they are part of the fabric and currency of our lives. Some of the stories we only tell once, some we tell over and over again. Some stories are instantly forgotten in the plethora of new stories that are developing around us, and some are frequently revisited and often retold, and may be re-shaped by subsequent events, constant reminders of the integral themes of our lives. We choose our words and we select our audiences.

Some of our stories may not seem significant to other people, but they are highly significant to us and to those closest to us. My teenagers still like to hear particular stories about things they did as small children. The events I recount are incredibly familiar; they are tales that have been told and retold, but they still enjoy the story. Part of the appeal is in the telling; they are waiting for the elements that they are familiar with; the triggers to which they can respond. But part of their enjoyment in the story is the link with the past, with the people they were and are. These narratives locate them within a wider discourse, relate them to significant others in their lives, and remind them that they are part of a wider network. The stories tell of events that have shaped their identities. They are also stories about relationship. As a mother, when I tell them stories about their childhood, I am also telling stories about my mothering – about the things that I remember because they were funny, or touching or sad – but things which reaffirm our relationship. I am telling them ‘our’ history. Nor does it stop there – I tell them the stories my grandparents, parents and in-laws have told me. I am the repository of parts of a family history – and so we connect the past with the present – the living with the dead. Whilst I am alive, some of their stories of love, romance, bravery and adventure will persist, and we will all have a sense of the people they were and are; how their qualities, their lives and their legacy