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Chapter 1 : Helping a Family Whose Baby Has Died from Sudden Infant Death Syndrome : Infant Loss Res

The information provided here about Sudden Infant Death Syndrome (SIDS) and about useful roles for helpers is intended to assist those who are helping a family that has been impacted by the sudden death of an infant.

We will meet in the parish building on the second floor. Please call prior to attending the meeting so that the correct location can be verified. Once the renovations are complete, we will move back to St. Timothy Episcopal Church, Beechmont Ave. Contact Carol Terbrueggen at Contact Karen Pinsky at karenpinsky gmail. Rapp at mgrapp hotmail. Ignatius Church, North Bend Rd. Companions on a Journey Grief Support: Bereaved Parents Group This group is designed for any parent who has suffered the death of a child, no matter what age at the time of death. This group meets at St. Support Group Peer-led support group for parents who have lost a child through molar or ectopic pregnancy, miscarriage, premature birth, stillbirth, neonatal death, SIDS and birth defects. This group meets the second Monday of each month from 6: Healing Together Support Group For families who have experienced pregnancy loss or the loss of an infant or young child. Loss of an Adult Child Support Group Grief support group for parents who have experienced the death of adult children. For locations, please call Hospice of Dayton at POMC is a national organization dedicated solely to the aftermath and prevention of murder. Margaret of York Church, Columbia Rd. Reach out to Grieving Parents Peer support led by parents who have lost a child due to miscarriage, stillbirth or newborn death. For information, please contact James Ellis at or stars stelizabeth. The group meets from pm on the second Wednesday of each month at the Ft. Contact Kelly Schoen at for additional information.

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Chapter 2 : A Response to Parents After the Loss of a Baby : Infant Loss Resources

Experiencing the loss of a child to SIDS can be devastating, not just for the parents, but for everyone who loved the child. If you or someone you know has lost a baby to SIDS, we encourage you to reach out, seek help, and find a SIDS support group to get involved in.

There is no greater loss than the loss of a child. Sudden death is a contradiction to everything we know to be true; losing a child to sudden death is a disruption in the natural law and order of life. It is a heartbreak like no other. Parental grief is different from other lossesâ€"it is intensified, exaggerated, and lengthened. Children are not supposed to die; parents expect to see their children grow and mature, and one day to bury their own parents. Ultimately, parents expect to die and leave their children behind, as this is the natural course of life, our life cycle continuing as it should. The loss of a child is the loss of innocence, the death of the most vulnerable and dependent. The death of a child signifies the loss of the future, of hopes and dreams, of new strength, and of perfection. Grieving parents say that their grief is a lifelong process, a long and painful process by which they try to take and keep some meaning from the loss and life without the child. The hope and desire that healing will come eventually is an intense and persistent hope for grieving parents. Bereaved parents frequently live their lives more fully and generously due to this painful experience. SIDS is sometimes known as crib death because the infants often die in their cribs. These deaths occur among infants less than 1 year old and have no immediately obvious cause. The three commonly reported types of SUID include: Accidental suffocation and strangulation in bed. In , there were about 1, deaths due to SIDS, 1, deaths due to unknown causes, and about deaths due to accidental suffocation and strangulation in bed. Researchers have discovered some factors that might put babies at extra risk. Perhaps the most important is placing your baby on his or her back to sleep. The impact of Sudden Infant Death Syndrome SIDS presents unique grieving factors and raises painful psychological issues for the parents and family as well as those who love, care, and counsel them. In many cases, parents of SIDS babies are very young and are confronted with grief for the first time. SIDS often occurs at home, forcing parents and sometimes siblings or other children to witness a terrible tragedy and possibly scenes of intense confusion. In some cases, the parents themselves are the ones who find the child dead and they must always live with that memory. In other cases, the parents may feel overwhelming guilt or anger if the death occurred while the child was in child care. They may feel that the baby might not have died if they had been caring for the infant. They replay such thoughts as: Also, in some cases parents are required to explain SIDS to adults who are misinformed or know nothing about the syndrome. In some SIDS deaths, the autopsy findings may help answer questions. Parents are often anxious to consult with the pathologist after the autopsy. The pathologist reviews the autopsy results, explaining in terms the parents can understand how these findings point or do not point to a determination of cause of death. The pathologist should also take the time to answer any questions that arise. Friends and family members should try to do all they can to show their concern and help the parents in keeping memories of their baby alive. By extending these personal and sensitive gestures, loving and concerned relatives, friends, and caregivers can become a source of reassurance and comfort for the grieving parents. Some SIDS babies are so young when they die that family members and friends never had a chance to welcome them. Many individuals do not understand the depth of parental attachment to a very young child. Researchers are still looking to pinpoint an exact cause for SIDS, as it is a diagnosis of exclusion, meaning that when an autopsy is performed, no other cause for death can be found, it is called SIDS or SUID sudden unexplained infant death. Potential risk factors vary from child to child. Some infants are born with problems that make them more likely to die of SIDS. Many infants who died of SIDS had recently had a cold, which might contribute to breathing problems. Sleeping on the stomach or side. Babies placed in these positions to sleep might have more difficulty breathing than those placed on their backs. Sleeping on a soft surface. While the risk of SIDS is lowered if an infant sleeps in the same room as his or her parents, the risk increases if the baby sleeps in the same bed with parents, siblings or pets. Boys

are slightly more likely to die of SIDS. Infants are most vulnerable between the second and fourth months of life. Babies who live with smokers have a higher risk of SIDS. Is younger than

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Chapter 3 : Grandparent Grief

Being a mother that lost a child to SIDS, I rely on these types of devices, not only for peace of mind, but it could save my child's life. All parents should be CPR certified. In our home, these devices are a must.

The Tragic Loss of a Child Parents grief In our previous discussions about the different types of losses by death that may occur, we have made note of how difficult and trying most of them can be. Grief following sudden death, trauma, suicide or murder can be very hard to deal with due to the emotional overlay usually present. But no matter how one loses a child, whether by prolonged illness or sudden death, the loss of a child is perhaps the most profound, the most overwhelming, the most inconsolable of losses to deal with. There are many reasons for this: It violates the natural order of things your children are not supposed to die before you. Your love for your child is unconditional and pure perhaps the most profound of attachments you will ever have. You as a parent are responsible for the well-being of your children. No matter how random the accident was, you will probably feel like you let your baby down. You may feel responsible for the death, even if that blame is not justified. A woman may blame a miscarriage or stillbirth on something she did during pregnancy. The uncertain causes of a SIDS death brings a special kind of guilty hell for parents who think there was something they could have done to prevent the death. Guilt is almost always present in the death of a child. We are so very sorry for the loss of your child and wish you strength to make it through. You must take care, however, to avoid unfairly blaming other family members or your spouse. Following the loss of your child, you may find that some of your friends avoid you. The death will make them very uncomfortable. It may force them to contemplate the mortality of their own kids It could happen to them. If only they knew that all you wanted was for them to listen! Sadly, emotional and social support is often withdrawn when you need it the most. If they do show up later in your mourning, it will be to encourage you to get over the loss. Grief due to losing a child is so painful that they just want it to go away. If only it were that easy! It has been said that a major tragedy will either bind a couple together, or tear them apart. If your marriage or relationship was conflicted or on shaky ground before this tragedy happens, it may be difficult to save it. In lashing out at the injustice of the loss, you may well blame your partner for the death, which can be devastating. People also grieve in different ways, so try not to misunderstand motives, reactions and feelings that may be different from yours. Marriage counseling may help you two see what is happening to you, and perhaps help save the marriage. Hopefully, after the initial shock has worn off, you will reach for each other for support at this most difficult time. Try to share your feelings with your mate, and talk about it often. The Death of a Baby: Now, you know how absurd this is, but try to understand; that is the reason for their lack of empathy. They may not understand your intense grief, or not know what to say. In their efforts to comfort you, they may say something incredibly stupid or hurtful, like: Try to find it in your heart to forgive their ignorance. They surely do mean well. Tragedy can be awkward and foreign to them. Even in an early term miscarriage, it is important for you to affirm your great loss and mourn fully. It was not "just a miscarriage" to you Mothers and fathers begin emotional bonding long before they get to know a child on the outside. The fluttering of life inside you You have experienced the loss of a loved one, and you may grieve for a very long time. This is normal and should be encouraged. Often, abortion is a secret loss that you would rather forget. You may feel relieved on the surface, but loss by abortion must be mourned, too. Do not rob yourself of the much-needed period of grief to bring resolution to the experience. Due to circumstances, you may not have many physical "remembrances" of your lost child. Try to find some. Photos, hospital records, certificates, a baby blanket or knit cap, footprint, lock of hair, nursery bracelet, and sympathy cards can all help enforce the importance of your loss. Make a baby book or keep your mementos in a special box. Name the baby, no matter what age of gestation. Have a funeral or memorial service. Claim your right to grieve fully. Fathers need to grieve, too. Parents who have lost a child can feel alone and unsupported in their grief Support groups of other bereaved parents can be especially helpful to you, because those folks will understand better than anyone else the pain you feel. While

friends and acquaintances may feel uncomfortable listening to you express your grief, support groups will be much more apt to lend a sympathetic ear. Those who have "been there" can truly understand and accept your grief. You may find much-needed support here: American Childhood Cancer Organization -- for parents of very sick or dying children:

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Chapter 4 : Sudden Infant Death Syndrome (SIDS) Support Groups Online | DailyStrength

The Death of a Childâ€"The Grief of the Parents: A Lifetime Journey 1 going relationship with their child through their memories and mental life. a SIDS loss.

Other ways to help can be found here. From the moment you became a parent yourself, you have sought to protect your child from the pain and sorrows in life. Suddenly, your 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: You are suffering a "double grief. You had wondered if he or she would "favor" your side of the family, wondered what he would "become," and had perhaps even bought gifts for "later on" like that first tricycle or that special doll. Your grief may not even be recognized by your own child, but you are, most definitely, entitled to it. Grandparents are often referred to as "the forgotten grievers. You can only sit by, offer support, and watch your child learn to live with this loss. When all that they have offered: One often causes the other; soon the two are so intermingled that it is difficult to determine where one begins and the other ends. Grandparents experience "survival guilt" You may be very, very angry. We do not grieve according to the age of a baby. Some of the emotions that your child will have will sound strange to you, some will sound familiar because you will be having similar reactions. Helping your child to grieve will facilitate your own grief. Your child will be going through a grief "process. May appear stunned or dazed or may be continually crying. May experience intense panic, anger or distress. Usually denies death, feels that what is happening is "unreal. May experience restlessness, pronounced mood swings. May constantly search for cause of death through questioning and conjecturing e. May "hear" baby cry or "see" baby in shopping mall. May continue to check on baby. May be a period of great irritability and anger. May experience need to "do something. The bereaved parent, in the process of reorganizing his role May feel empty and helpless. May feel deeply depressed. May be weak and exhausted. May have very little interest in anything. May neglect basic needs may have large weight gain or loss. May experience somatic complaints headaches1 aching arms. May experience panic attacks, may be afraid to be alone, may be overly fearful for spouse or other children. May "pretend" to be happy. Is beginning to accept the reality of death. Will experience periods of normalcy. Enjoys renewed energy and interest. Has renewed ability to make decisions. Returns to normal eating and sleeping patterns. Is now able to remember the child as living--not only at the moment of loss. Grief is, however, 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 will grieve--even a husband and wife will seldom grieve in the same way. The resolution of grief takes a long time: As parents move ahead in resolving their grief, there will always be setbacks, some triggered by specific events related to the child birthdays, anniversaries, etc and some seemingly unrelated. Its suddenness and the lack of answers to important questions intensify the grief reactions. Occasionally, an older or younger child may die of SIDS. About 7, babies will die each year in the United States about two per 1, live births. SIDS will take more lives than cystic fibrosis, childhood cancer and heart disease, and child abuse, combined. A minor illness such as a cold may proceed the death but many victims display no observable symptoms. Death occurs within seconds, usually during sleep. The term Sudden Infant Death Syndrome came into general medical use after Your role is to guide and support--and that role will require great patience and understanding. Their suggestions, along with a few of our own, include: Let your genuine concern and caring show. 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. Allow them to talk as much and as often as they wish about their child. Help them let go of the questions and the guilt. 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 judgement 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. 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 they have lost. Make any comments that suggest that the care given their child at home, in the emergency room, etc. By grieving together, you reaffirm that grief is normal and that life will go on. Gerner, Margaret "To Bereaved Grandparents". For more information, please contact:

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Chapter 5 : BEREAVEMENT EXPERIENCES AFTER THE DEATH OF A CHILD - When Children Die - NC

The Center for Infant and Child Loss is not responsible for the availability or content of these sites. The Compassionate Friends Nationwide support group for parents who have lost children at any age, gives local support groups information & various grief related information.

While bereavement is stressful whenever it occurs, studies continue to provide evidence that the greatest stress, and often the most enduring one, occurs for parents who experience the death of a child [1 â€" 6]. Individuals and families have many capabilities and abilities that allow them to respond to interpersonal loss and to emerge from the experience changed but not broken. The few studies that have compared responses to different types of losses have found that the loss of a child is followed by a more intense grief than the death of a spouse or a parent [5]. This conclusion must be considered cautiously, however, since these studies have typically confounded sample differences in age and degree of forewarning [7]. Forewarning is important because according to the Centers for Disease Control and Prevention [8], about half of child deaths occur during infancy, most with limited preparation time. Unintended injuries are the leading cause of death in children age 1 to 14 and account for more than half of all deaths among young people 15 to 19 years of age. In addition, while the overall death rate for children aged 14 and younger has declined substantially since the s childhood homicide rates have tripled and suicide rates have quadrupled [9]. Recent findings suggest that parents of children who die from any cause are more likely to suffer symptoms of traumatic stress and experience more severe problems with emotional dysregulation than occurs with the death of a spouse [10]. Integrating the loss of a child into the life narrative, making sense and new meanings of such a wrenching event, presents a challenge to parents and family [11]. Although once common, deaths of children between the ages of 1 and 14 now account for less than 5 percent of all deaths in the United States; about 57, infants, children, and adolescents died in In contrast to the past when families might have had several children die, death in childhood is now rare. Children are expected to live to adulthood. Increases in the incidence of suicide and homicide in adolescents and random acts of violence in our society have increased the risk of traumatic stress responses for bereaved family members. Medical advances have prolonged the dying process for children as well as adults, making terminal illness in children longer and more complex, often requiring parents to make difficult decisions about end-of-life care. Also reviewed are interventions and research directions. It is widely recognized as a complex and dynamic process that does not necessarily proceed in an orderly, linear fashion [14 , 15]. Bereavement includes the internal adaptation of individual family members; their mourning processes, expressions, and experiences of grief; and changes in their external living arrangements, relationships, and circumstances. Grief is a term that refers to the more specific, complex set of cognitive, emotional, and social difficulties that follow the death of a loved one [16]. Individuals vary enormously in the type of grief they experience, its intensity, its duration, and their way of expressing it. Taken together, the grief and mourning processes are understood to be a normal and universal part of the natural healing process that enables individuals, families, and communities to live with the reality of loss while going on with living [17 , 18]. Complicated grief in adults refers to bereavement accompanied by symptoms of separation distress and trauma [19]. These symptoms must have lasted at least six months and led to significant functional impairment. Because parents of children who die are at greater risk for traumatic stress symptoms and emotional dysregulation, they are at greater risk of complicated grief [10]. Siblings of children who die have also been found to be at greater risk for externalizing and internalizing problems when compared to norms and controls [20 - 23] within 2 years of the death. Complicated bereavement has been less clearly defined for children but is also thought to include symptoms of PTSD, other psychological characteristics associated with this disorder, and grief. The Expanded Grief Screening Inventory is a item measure developed to assess complicated bereavement in children and adolescents. Factor analysis indicates three independent factors including positive reminiscing, intrusion of PTSD on the grieving process, and

existential loss [24 - 27]. This measure has shown strong psychometric properties and is currently being used to follow the clinical course of such complicated bereavement in children. The human experience of this process, however, adds many elements of psychological, social, and meaning construction. At various stages in the life cycle, men and women relate to child-conceiving and child-rearing roles as central to their existence. Of the bonds formed within the family, the parentâ€"child bond is not only particularly strong, it is also integral to the identity of many parents and children [4]. Parents of children and adolescents who die are found to suffer a broad range of difficult mental and physical symptoms. As with many losses, depressed feelings are accompanied by intense feelings of sadness, despair, helplessness, loneliness, abandonment, and a wish to die [28]. Parents often experience physical symptoms such as insomnia or loss of appetite as well as confusion, inability to concentrate, and obsessive thinking [17]. Extreme feelings of vulnerability, anxiety, panic, and hyper-vigilance can also accompany the sadness and despair. Grieving parents evidence anger as part of the normal reaction to the loss of their child [17 , 29 â€" 33]. This may be expressed as intense rage or as chronic irritation and frustration. It may be directed at the spouse, at other family members, at the professional staff, at God, at fate, or even at the dead child. Anger may also be directed at the self, creating feelings of self-hatred, shame and worthlessness [28 , 34 - 36]. While guilt and self-blame are common in bereavement, they are especially pronounced following the death of a child. For years I was prepared for the loss of my sons in war ; and now comes that of my daughter. Since I am profoundly irreligious there is no one I can accuse, and I know there is nowhere to which any complaint could be addressed. Quite deep down I can trace the feelings of a deep narcissistic hurt that is not to be healed [43 , p. They express the reality that even the successful mourning process results in a transformation in the person consequent to the death of a loved one [44]. Despite traditional assumptions that all bereaved individuals must mourn, prospective studies have shown that considerable numbers of bereaved individuals evidence no overt signs of grieving or of the reconstitutive processes associated with grieving for a review see [1]. The question these findings raise is to what extent this type of resilient pattern may also be found among those mourning the death of a child [27]. Equally apparent is the fact that the bereavement response is predominantly one of readjusting and recalibrating the often covert psychological attachment to, and preoccupation with, the person now deceased. In a recent study of parents of infants who died of SIDS sudden infant death syndrome , the phenomena associated with the bereavement response had a very different time frame and trajectory when the continuing investment in the relationship with the deceased was assessed [4]. The Two-Track Model of Bereavement [41 , 42] combines the perspective of both the symptomatic bio-psychosocial response to bereavement and the relationship with the deceased. The bereavement response is understood to unfold along two multidimensional axes or tracks that are generally significant to understanding human adaptation to life demands. The first track focuses on how people function generally, and in the case of loss, it focuses on how functioning is affected following death. The second track focuses on how people are involved in maintaining and changing their relationships with significant others. Thus, the human bereavement response is not only triggered by the death of a significant person, but also initiates a degree of a continuing, albeit quite varied and modified, relationship to that person across the life cycle. The implications of the Two-Track Model of Bereavement are relevant to theory, research, social support, and clinical and counseling interventions. It is important to consider not only the degree of overt function and dysfunction following loss, but also the ways in which memories and thoughts about the deceased are discussed, thought about, and serve an active role in the emotional and mental life of the bereaved. This ongoing connection is most vividly and consistently reported, indeed insisted on, by many bereaved parents in relation to the death of a child. The two-track model proposes 10 domains for assessment on each of these axes following loss. On Track II, the nature of the relationship to the deceased is assessed on 10 other dimensions. These include 1 the degree of preoccupation with memories and thoughts of the deceased; 2 the extent to which the description of the deceased is characterized by an inability or unwillingness to express the personal feelings brought about by the death; 3 the degree of idealization of the deceased; 4 the report of psychological conflict or contradictions in the relationship; 5 the degree and type of

positive affect and emotion; 6 the degree and type of negative emotion toward the deceased; 7 the degree of closeness or distance from the relationship and experience of the deceased; 8 the affective experience when discussing the deceased e. The individual with complicated grief is at greater risk for a variety of psychopathologies and physical illnesses. Compared to parents who were informed later, parents informed closer to the time the physician documented the terminal nature of the illness were able to reflect on the death with greater feeling of their own effectiveness in providing their child a peaceful death. With the longer terminal illness period made possible by medical advances, it is important for physicians to recognize and inform families when there is no realistic possibility of significant extension of life so that they can make informed decisions about palliative care or other concurrent model of care rather than curative treatments. Wolfe also found that families may be helped during this highly stressful period by mental health interventions. Trauma theories and grief theories developed in separate literatures, and only recently has research begun to integrate the findings, concepts, and responses related to these overlapping but distinct conditions [45 â€” 48]. There is some evidence to suggest that those bereaved by traumatic deaths may benefit from initial interventions focused on reducing terror, fear, and anxiety about the circumstances of the deathâ€”that is, by interventions similar to those typically used for PTSD. Grief therapies have also been found effective in situations of complicated grief, of which traumatic grief is one example [47]. For example, cognitive behavioral interventions suggested for trauma symptoms in a treatment manual by one research team include stress inoculation therapy, gradual exposure, and cognitive processing. Gradual exposure aims to separate overwhelming negative emotions such as terror, horror, extreme helplessness or rage from thoughts, reminders, or discussions of the death of the loved one. In contrast, bereavement interventions focus on understanding the mourning process including feelings of loss and anticipation of reminders; resolving ambivalent feelings about the deceased, preserving positive memories of the deceased, accepting that the relationship is one of memory and recommitting to present relationships [48]. Nader describes convincingly how trauma prevents reminiscence necessary to grieve by evoking feelings of terror [25 , 49]. Conversely, grief can also act as a traumatic reminder to the individual who may be experiencing a sub-clinical response to trauma or meet criteria for a formal diagnosis of PTSD, increasing anxiety in either situation. Those bereaved by deaths seen as nontraumatic are more apt to focus on their relationship to the deceased as an important feature of the experience of loss [44 , 50]. Many aspects of parental grief reactions in response to the death of a child have been viewed as overlapping with traumatic symptoms, and indeed even parents whose children have cancer have been assessed to experience high levels of traumatic stress [51]. Even when offered, families affected by homicide have seldom participated in follow-up bereavement services [52 , 53]. Management of the final moments of an intentional or unintentional sudden death of a child continues to challenge professionals. Trauma research consistently supports the benefit of early intervention with traumatized individuals or families close to the time of the death in order to prevent later adverse reactions [54]. However, which interventions are most effective in which situations continues to be debated and awaits further research. For example, a summary of studies of critical stress debriefing in a review of the effectiveness of psychological debriefing concludes that though debriefing holds potential as a screening procedure, it does not prevent psychiatric disorders or mitigate the effects of traumatic stress. Still, people generally find the intervention of debriefing helpful in the process of recovery [55]. They involve large numbers of deaths and unusual situations that present unique coping challenges during bereavement. Each catastrophic event has important commonalities with other catastrophes, but also important differences. It is these similarities and differences that need to be identified and studied in order to sharpen the ability not only to treat grief reactions, but also to prevent the development of PTSD as well as other forms of complicated bereavement The World Trade Center attacks involved an attack from an outside hostile enemy that mobilized patriotism and national anger and gave rise to an ongoing war on terrorists throughout the world. Victims, especially firemen, policemen, and rescue workers were hailed as heroes in a war, killed in the act of protecting or saving others. Victims were mostly adults. Particular stresses for survivors include the ongoing

search for bodies or body parts and the many continuing reminders related to the ensuing war as well as the many public memorials. For some, finding no remains hinders progress with the mourning process. Early reminders included frequently announced threats of other impending terrorist attacks and other purported enemy acts, such as sending anthrax in letters. Bereaved individuals discuss their experience of having changed as a result of the loss, of learning to value anew what is really important to them, and of reviewing priorities. Some relationships with families and friends are strengthened, others are found wanting. Perhaps the most important relationship affected by child loss is that of the parents. The majority of studies on this issue have focused on divorce as an indicator of stress upon the parents. A recent review of these studies concluded that some writers give overly high estimates of divorce for which there is no empirical support [32]. On the other hand a substantial minority of couples do seem to experience severe marital distress. In her study, about 30 percent of husbands and wives reported having more negative feelings toward their spouse since the death; 19 percent of husbands and 14 percent of wives felt their marriages had deteriorated since the death. About the same proportion had considered divorce after the death of their child. A major difficulty in doing such research is that the frequency of divorce in the U. To address this issue Compassionate Friends, a self-help organization for bereaved parents, recently completed a survey of 14, parents who had lost a child. When a Child Dies: Its concern was how troubled newly bereaved parents frequently feel when they read or hear about high divorce rates among couples following the death of a child percent by some estimates.

Chapter 6 : Sudden Infant Death Syndrome (SIDS) - American Pregnancy Association

This non-profit group doesn't necessarily deal specifically with SIDS cases, but welcomes any parent who has lost a child, regardless of circumstances. Today there are local partners of the First Candle (formerly known as SIDS Alliance) in Greensboro, Charlotte and Raleigh.

These days infant and child mortality is so much lower than it used to be in the past. Advances in health mean that in most western countries infant mortality, death of a baby less than one year old is less than 5 in births. Compare that to around 20 â€" 30 per in Europe and the USA 60 years ago, and over deaths per in most African countries today. Because it is less common and death is, in general, more hidden in our western societies, cot deaths or crib death seem so much more shocking today. In the past families would have 10 or more children, knowing that they might lose half of them. The death of a baby was no less painful then, but people were more prepared for it, and society and the extended family were there to support families. Today a baby might be the only child a couple plan to have. It might be the only chance if the parents are older, having put their careers first. Perhaps it was a last chance to conceive by IVF. Coping with Child Mortality as a Professional When a baby is born in the UK, the midwife visits and monitors the baby and mother for the first 10 days. Then the health visitor will visit and let the family have her phone number and clinic times. Parents always feel they have support. The health visitor will see the baby at home or in the clinic for the next 6 weeks, then regularly 6 monthly or yearly for developmental checks until the child starts school. When I worked as a health visitor for 10 years, we got to know the children and families well. Many children then went on to the school the health visitor was attached to. With around families on your books, you became involved in the community and became very well known. I was privileged to meet many wonderful families and share in their happiness, but also in times of great sadness. When the death of a baby occurs it affects the whole family, the neighbours, the community, the doctors, nurses and health visitors. But it is also very isolating. A Story of the Death of a Baby and How to Cope In this website I am trying to encourage everyone to think positively about the gift of life even if it is a short one, and I am mentioning a few examples of such sad events to help people realise that they are not alone. One of the saddest experiences I encountered was when a grandmother caring for 2 toddlers and a lovely baby went shopping. The baby was in the pram and the toddlers walking. When she got home, she unpacked the shopping, gave the toddlers some snack lunch and went to get the baby to feed her. The horror, guilt, grief is just unimaginable. Friends had even peeped into the pram to see the baby while they were out and all had seemed well. It turned out that the families recent colds had been more than baby snuffles in this case. Keeping busy is the only way. One day the pain and grief become bearable and you start to remember the baby with pleasure again. My family had extended family and friends, but it was their own courage which pulled them through. She wrote a book as her way of coping with the devastating experience. Her book shows her great courage and strength in going on with life after a cot death. She talks about the experience with incredible honesty and describes as no-one else could the day to day challenges of coping with such a difficult loss. However, she never wallows in self-pity, or feels sorry for herself, but gets on with life, day by painful day, until she learns how to live again. I would recommend her book to anyone who has had to go through this experience as a moving and uplifting story which will give hope again. I have mentioned elsewhere that some babies are just not viable with life. Some are overcome by infections, some are born with genetic disorders or heart defects. I do not claim to be an expert. There have been many studies done into what causes SIDS, and parents these days are advised to lay babies on their backs in cots and prams. But many causes are never identified. Here is a link which will take you to some of the latest scientific research. The general pages on how to deal with grief will give you lots of advice on how to cope on a daily basis. We hope you will use this as a resource if you are a professional helping parents cope with their grief.

Chapter 7 : Support Groups | Pastoral Care

It seems like I have spoken a lot lately with grieving moms who are wrestling with the desire to have another baby after losing a child to SIDS. I've spoken with some moms who are already pregnant and overwhelmed with fear at the thought of losing another baby.

Jefferson City Springfield When you call, ask for advice and request free pamphlets both for yourself and to pass on to other interested friends or family members. Accurate information about SIDS for those close to them can ease many burdens on the parents. Offer to help notify family, friends, co-workers, and groups to which the parent might belong. Be the telephone operator: Allow the family to decide to whom they wish to speak. Just be there for the family and for yourself to share sorrow and offer support. Offer to cancel scheduled appointments, classes, etc. Let the family talk about the baby. Provide complete meals in disposable containers along with paper napkins and disposable utensils. Leave written instructions about how to prepare the food. Offer to help care for the surviving children. Read age-appropriate books with the children and offer to take them on outings our scheduled activities. Support the family in its own ways of grieving. Support parents in their decisions about funeral arrangements. Comments of this sort only hurt and tend to discount the loss. Keep your faith, beliefs, and cliches to yourself. If those beliefs help you, use them for your own comfort, but do not expect the family to appreciate or find solace in them. Avoid trivial conversation; the weather, work, and gossip are of little interest to the bereaved family at this time. Remember that silence and mere presence can be helpful. Offer to accompany you friend to appointments, and offer to drive so that parking will not be a hassle. Offer to notify service providers with whom the family has frequent contact, e. Offer to notify others involved with activities of siblings, e. Offer to pick up pictures that were left for developing, call the photographer if the portraits were recently done and ask if the negatives might be given to the family. Offer to order an enlargement of a favorite picture of the baby. If portraits were done by a large company that specializes in inexpensive picture packages call ahead to explain the death. Ask the company to donate the picture set to the family. If you have a baby, ask the family if they want your baby to be present or not at funeral services and other activities. Everyone is different in this respect and their desires may change from one visit to another. Offer a gift certificate for a therapeutic massage. Memorial Suggestions Design a commemorative activity in memory of the baby, such as planting a tree or garden. Make a donation to a food pantry or child care center. Give presents you would have bought the baby to a needy child. If you have questions or issues, ask an authority. Do not approach the family with your theories and research questions. In that way, you may unwittingly be implying that had they been aware of your information, their child might still be alive. Remember that the pain and hurt are present months later. Expect and accept bad days, crying jags, and anger. Accept and validate the feelings of anger, the comments of unfairness, the frustration expressed because of a lack of control. Remember the holidays-all of them! Holidays, which do not have much significance for some, may be very difficult for families to face. Be aware of places where you might see many babies when planning outings with the bereaved family. They can be painful. Visit the cemetery and offer to accompany the bereaved parents on visits to the cemetery if they wish to go. Take flowers to the parents when they are taking flowers to the grave. Stop by the cemetery yourself and leave flowers or dust the markers. Tell the family that you were there. Offer to include the family in special parties, but allow them to decide if they wish to attend. Baby showers may be especially difficult for bereaved mothers to attend. Do not be surprised if the grief seems magnified. Fears of another loss may overshadow the positive feelings, even though the pregnancy was planned. With the arrival of a new baby, anticipate that the family will still need to speak of the deceased infant, will still need recognition of anniversary dates, will compare this infant to the one who died, and will still have some very sad times in their lives. And when you make a mistake, do something wrong, or do not do as well as you would have liked, keep in mind that we are all human. Apologize if that is appropriate or share your feelings with the family. Ask what they need. Be prepared to

help if you offer. Do not stay away! Avoid statements such as: Suggestions for Co-Workers Most employers will initially be understanding of a family whose infant has died from SIDS, but eventually they are faced with a business or organization that must continue to operate. Co-workers are also faced with these dual issues surrounding the aftermath of a SIDS death. Their compassion for the family may be complicated by the need for the bereaved co-worker to carry his or her share of the work. Behaviors, which might be exhibited by a bereaved employee, include difficulty in making decisions, inability to concentrate, disinterest in job-related details, excessive work hours, frustration and irritability, depression and mood swings, or marital and family problems. It may take a long time to overcome such behaviors. The following may provide some assistance for co-workers in coping with the work situation and being supportive to the bereaved person: Encourage co-workers to be comfortable with conversations related to the infant and the death. Remind co-workers to allow the family to make their own decisions about participating in work-related special functions, such as holiday parties or summer picnics. SIDS is a centuries old, worldwide enigma and remains as one of the last great unsolved childhood catastrophes. Even though research is ongoing locally, nationally, and internationally, there is currently no detection, treatment, or prevention for SIDS. Although we cannot predict or prevent SIDS, we do know that babies die primarily in the first year of life. Most of these deaths occur during the period from two to four months of age, and during a period of sleep. SIDS deaths occur more commonly, but not exclusively, during the cold weather months. SIDS is neither contagious nor hereditary. It is not caused by choking, abuse, or neglect. SIDS can strike a family of any race, religion or ethnic group. Frequently parents have shared their feelings of hurt and anger about things that well-meaning but misinformed people have said to them. It may be helpful for you to be aware of some of the following insensitive comments so that you will be prepared to support the SIDS family, as well as to help combat misinformation.

Chapter 8 : Have You Lost a Child to SIDS? - Mamapediaâ„¢

Certainly, a child's death is a challenge to a relationship, and seeking support groups, counseling, or a link with others who have been through a similar experience can be very helpful. Please contact SIDS Resources for more information on available services in your area.

But most SIDS diagnoses come only after all other possible causes of death have been ruled out. This review helps tell true SIDS deaths from those due to accidents, abuse, and previously undiagnosed conditions, such as cardiac or metabolic disorders. Why Is Stomach Sleeping Dangerous? SIDS is more likely among babies placed on their stomachs to sleep than among those sleeping on their backs. Babies also should not be placed on their sides to sleep. A baby can easily roll from a side position onto the belly during sleep. Some researchers believe that stomach sleeping may block the airway and hurt breathing. Stomach sleeping can increase "rebreathing" â€” when a baby breathes in his or her own exhaled air â€” particularly if the infant is sleeping on a soft mattress or with bedding, stuffed toys, or a pillow near the face. As the baby rebreathes exhaled air, the oxygen level in the body drops and the level of carbon dioxide rises. Infants who die from SIDS may have a problem with the part of the brain that helps control breathing and waking during sleep. If a baby is breathing stale air and not getting enough oxygen, the brain usually triggers the baby to wake up and cry to get more oxygen. If the brain is not picking up this signal, oxygen levels will continue to fall. What Is "Back to Sleep"? In response to evidence that stomach sleeping might contribute to SIDS, the American Academy of Pediatrics AAP created its "Back to Sleep" campaign, which recommended that all healthy infants younger than 1 year of age be placed on their backs to sleep. Babies should be placed on their backs until 12 months of age. Common Concerns Some parents might worry about " flat head syndrome " positional plagiocephaly. This is when babies develop a flat spot on the back of their heads from spending too much time lying on their backs. Many parents fear that babies put to sleep on their backs could choke on spit-up or vomit. However, only babies with certain uncommon upper airway malformations may need to sleep on their stomachs. What Is "Safe to Sleep"? Still, SIDS remains the leading cause of death in young infants. The "Safe to Sleep" campaign builds on "Back to Sleep," reminding parents and caregivers to put infants to sleep on their backs and provide a safe sleep environment. Get early and regular prenatal care. Place your baby on a firm mattress to sleep, never on a pillow, waterbed, sheepskin, couch, chair, or other soft surface. Cover the mattress with a fitted sheet and no other bedding. Keep soft objects and loose bedding out of the sleep area. Do not use bumper pads in cribs. Bumper pads can be a suffocation or strangulation hazard. Practice room-sharing without bed-sharing. Breastfeed , if possible. Exclusive breastfeeding or feeding with expressed milk is most protective, but any breastfeeding has been shown to reduce the risk of SIDS. Put your baby to sleep with a pacifier during the first year of life. Make sure your baby does not get too warm while sleeping. Watch for signs of overheating, such as sweating or feeling hot to the touch. Do not use alcohol or drugs during pregnancy or after birth. Parents who drink or use drugs should not share a bed with their infant. Make sure your baby gets all recommended immunizations. For parents and families who have experienced a SIDS death, many groups, including First Candle, can provide grief counseling, support, and referrals.

Chapter 9 : SIDS Helpful Links â€“ Serving Baltimore, Maryland

provide specific services and outreach for neglected sub-groups of parents and family members: e.g., parents who have lost an only child, parents who have lost multiple children, parents whose child died from accident, suicide or homicide, grandparents of children who die.

There are many ways in which the death may have occurred; it may be a miscarriage which occurred without warning, a baby who was born but was unable to survive, a fetal death from medical causes, a newborn who struggled but was never able to leave the hospital, or a baby that died from unexpected complications during the process of pregnancy, delivery, and neo-natal care. Some babies may have died during the first year of life from a medical problem, or even from sudden and unexpected causes like accidents or SIDS. The list is endless, and often the questions and feelings, which accompany these losses, are endless as well. In this guide, you will find information about the grief process, which many new parents experience when a baby dies and when that expectation of parenting that child has ended. While every situation is different, this may help to understand some of the common emotions that accompany grief and the process which parents go through in learning to cope with this loss. Recognizing the Reality Months of planning and preparation accompany the births of a new baby. Expectations begin immediatelyâ€¦Will it be a boy or a girl? These expectations go on, and new parents have an endless stream of thoughts about what the future will bring. Therefore, when a baby dies, so do our expectations. Oftentimes, parents experience a feeling of shock, because these losses are so overwhelming to the mind. The reality of death seems too much to handle. Shock is often a common reaction at an early stage of the grief process. But, they are signs that the mind and the body are trying to make sense out of an overwhelmingly difficult situation. Shock, and the feelings of confusion that go along with it, will slowly go away over time as the reality of the death is recognized. Remember that even if you logically KNOW what has happened, it takes much longer for your emotions to accept the reality of the loss of your baby. Reactions to Grief After the initial shock and numbness begin to wear off, you may find that you are left with prolonged sadness. At these low points, it can be very helpful for you to talk to another parent who has had a similar experience or a health care professional who has helped others in similar situations. You may find it difficult to concentrate for any length of time. Your mind may wander, making it difficult to read, write or to make decisions. These feelings are a very normal part of the grief process. Sleep may be difficult, or it may be all that you want to do. Either way you probably will feel exhausted. Grieving takes a lot of energy. If you have a family to care for or a job to get back to and lack of sleep is a persistent problem, you may want to discuss this with your Physician. You may experience muscular problems or other physical symptoms centering around your heart and stomach. You may not have an appetite or you may eat all the time. You may feel an irresistible urge to get away, a fear or dread of being alone or unreasonable fears of danger. If you have other children, you may fear for their safety and may not want to let them out of sight, but at the same time may be afraid of or shun the responsibility of caring for the other children. Your feelings are there because you get strong enough to admit it was real and you have to deal with that. However, these are not the same emotions that were there before the death. These are the emotions that no one likes to feel: The initial temptation may be to do something that STOPS you from feeling, Sometimes people who have experienced an intense loss try to stop feeling and become involved in unhealthy behavior like drinking too much, taking drugs, or over-using prescription or non-prescription medication. But, feelings are a part of every person. So, the healthy way through this part of grief is to actually FEEL the emotion of the loss, and learn ways to take care of yourself and support yourself during times of intense emotion. This anger can be from actual events that you experienced, such as events at the hospital or with other people. At other times, anger is more general, like at the injustice of the loss of a baby or the ways in which life seems unfair. People may become angry with themselves, other friends and family, people associated with the death, even at God. Understanding that anger is an intense, but normal, emotion can help to keep anger from controlling you. Often, it can help to find

an outlet for some of the anger, such as writing a letter whether or not you send it! Be open to your partner or other members of your family and try not to take hurtful comments to heart. This is a time of great pain. As you work through your emotions you will begin to see that there is no one to blame, just a great sadness that the whole family is struggling to live with. Because parents feel such a great degree of responsibility for their children, the loss of a baby almost always carries with it some feelings of guilt. It is difficult to cope with events over which we have no control â€" such as death itself. Although it is natural to want to place the blame somewhere, often there really is no one to blame. The hard task is then to try to come to terms with the reality of the loss. You may have felt withdrawn from other people, detached from enjoyment of life, and may have had a change in your sleep and appetitie since the lost. These normal feelings of depression are commonly experienced during grief, but there is a difference between these feelings and Major Depression, which is a separate mental health problem. Even when you feel down and withdrawn, you should still be able to eat enough to keep you body healthy, to get enough sleep so that you are not exhausted, and to be able to take care of the important things in life such as going to work and caring for your family. If you feel a depression that never lifts or overwhelms you for days on end, this may be a sign that you need to consider doing something more for yourself to work through this depression. This may include talking to a professional, such as a counselor. It is important to know that, as alone as you may feel during depression, you are still capable of reaching out for the help needed to cope with this intense emotion. Every time the phone rang, I thought it was to tell me something terrible had happened. When you have been forced to deal with this fear, it is only natural that the world can seem to be a very scary place. You and other family members can become very fearful that something else is going to happen. You may become over protective with your other children. Your other children may cling to you or they may be afraid of being separated from you. At times, fears and anxieties may make it difficult to try new experiences. Sometimes holidays, anniversary dates of the loss, or large social gatherings may be events that produce anxiety. At the end of an experience, even a difficult day, you may find it was not nearly as bad as you were worried it would be. Keeping anxiety in check by focusing on what things can and cannot be controlled is also helpful. Be patient with yourself, as it will take time to be able to trust again. Different Ways of Grieving Everyone grieves differently. Since everyone has different feelings surrounding the anticipated birth of a child, everyone will have different feelings surrounding the loss of the baby as well. Mothers and Fathers often express their grief in different ways. Fathers may find it more difficult to ask for help and support from others and may seek diversion through their work; they may even take on extra work to escape being preoccupied with the loss of the baby. Grief may make you very irritable. Small differences between you and your partner may now be very hard to take. You each have to grieve in your own way. At times you may be able to reach out to comfort each other. At other times you may need comfort and find no one there to hold on to. It is important that mothers and fathers share their feelings. For example, one may feel an intense need for the comfort of sex, while the other partner cannot imagine ever enjoying sex again. You need to talk, which often helps in understanding each other. You are both normal, and just expressing your sadness in different ways. The loss of your baby may be the first grief situation you have ever experienced. Grief is such an extreme condition that you might find yourselves searching for ways to relate to each other as well as to your friends and relatives. In order to prevent misunderstandings, most families find it helpful to maintain an atmosphere where feelings can be discussed. For single parents, the death of a baby is a unique challenge and can be a very lonely experience. Parents for whom this was the first child to be born may also feel a sense of isolation and struggle with this loss of being a parent. These are important feelings to talk through with friends and family, and specific resources to help meet this challenge can also be arranged through SIDS Resources. Couples may read or hear stories about an increased divorce rate among parents who have lost a child. More recent studies show that the divorce rate is actually lower for parents who have lost a child than those in the general population. The quality of the relationship prior to the death is a significant factor in the healing process. Surviving Siblings Children will definitely be affected by the loss of a baby. They may have questions about whether they will die, or fear that

something bad may happen to people they love and care about. Provide honest and direct answers to their questions, even if it is to tell them that you are uncertain of some things yourself. It is OK for adults to express grief around children, and in fact, it can be quite healthy as a way to teach children that feelings are OK and open, honest communication is best. Additional resources for talking with children about death and helping children cope with grief are available by contacting SIDS Resources. The initial shock and pain of loss will get less intense over time as you learn to cope in a way that is positive and meaningful for you. People who have lost a baby have found that it can be helpful to talk with someone who has gone through a similar experience. For a list of resources available to you, call us at