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## “It’s the Hardest Thing We Ever Had to Go Through”

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MY FIRST GRANDSON, Eli, died when he was two. He was sick beyond repair within an hour of being born. All the days he struggled to stay alive, I ached for him. I ached for my son and daughter-in-law. They loved Eli enormously and were locked in a grinding around-the-clock vigil to keep him breathing and as healthy as he could be. After Eli died I hurt, much more for my son and daughter-in-law than for Eli or myself.

As things turned out, my son and daughter-in-law had wonderful resources in themselves, in their relationship, and in their community to help them cope, but Eli’s death got me wondering about couples who have a more difficult time of it. I knew from the research literature and my own previous work that many bereaved parents struggle for a lifetime with personal and marital issues related to a child’s dying. Where can they go for help with their couple relationship? When I looked in bookstores and libraries for books that could help couples deal with marital problems connected to a child’s death, I knew this book was necessary.

I found lots of books on individual parent grief, and some books had a few pages or even a chapter on the couple rela-

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tionship, but I could find no book that spoke in depth about the many challenging and complex problems couples can have when a child dies. No book examined in much detail what might go on in a couple relationship following a child's death. No book offered much advice on what to do when things seem to be going wrong in a couple's marriage. This book attempts to fill that void.

For many years before I started writing this book, I had been teaching about family relationships at the University of Minnesota and had been researching, writing about, and teaching about grief. I knew the research literature, and it certainly gave me many ideas about what belonged in this book, but I needed to know more. So I set out to interview couples who had had a child die. The twenty-nine couples whose stories of their child's death, their grieving, and their marriage are central to this work all volunteered after learning about my project.

Imagine going with me to do the interview. The setting might be a well cared-for middle-class suburban home, an old farmhouse, a small apartment in an older part of the city, or an expensive home with a long driveway and a kitchen bigger than most living rooms. We sit down with the couple in the kitchen, the living room, or the family room. They offer us coffee or something else to drink. They are obviously tense and eager to start. I turn on the tape recorder and begin asking for background information, questions that help us to know who they are and help them to relax. When we finish with those questions, I ask about the child who died and the story of the death. Most couples start out with an almost objective neutrality, a report of facts, but their story always becomes emotional and personal. It is obviously a story they have thought about many times. And even decades after the death, it brings up strong feelings.

Typically the interview lasts two to four hours. The couple talks a lot about grief, about their relationship with each other, and their relationship with others. There are almost always tears. There is almost always laughter, **too**. As we get ready to leave, I thank the couple, and often they thank me and say that they had rarely **or** never had the opportunity to tell the full story.

For me, each interview is a powerful spiritual experience. Each couple tells **so** much about how they have faced and wrestled with deep and demanding questions about death and life, their struggles to communicate with, understand, and be a partner with each other, the meaning of their child’s life and death, and the meaning of life. What they talk about and their accompanying passion could stir up deep feelings in anyone. The emotions their words stir up can penetrate to the core of anyone’s heart and soul. I wish you had been there, but I hope this book will give you a strong sense of what you would have learned by sitting in on those interviews.

The children who died ranged in age from three days **to** thirty-three years. Some of the children had been born so prematurely that they could not survive. There were children who died from genetic disorders, birth defects, accidents, sudden infant death syndrome, suicide, cerebral aneurysm, cancer, and causes nobody could be sure of. Some couples had lost more than one child. Some also talked about children who died of miscarriage **or** stillbirth, and what they had to say about those losses is included in this book. The time between a couple’s most recent child death and the interview ranged from a few months to thirty-five years. (At the end of this book is an appendix with a brief description of the couples and the deaths they talked about, which may help you to keep track of the couples as I quote them throughout the book.)

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One of the twenty-nine couples had divorced, one was separated and divorcing, one was separated but not planning to divorce, and two had been separated for months but were together again. Except for the divorced couple and the couple that was divorcing, all couples were interviewed together. The people who were interviewed ranged in age from thirty-three to sixty-eight and in formal education from eighth grade to Ph.D. Maybe what is most important to say about them, however, is that these are people who know what it is like for a child to die. If you have had a child die, they can empathize with you.

Nothing I write here is intended to say, “This is how you should be,” or “this is guaranteed to solve your problems.” The ideas are suggestions, possibilities, things to think about, ways to look at where you and your spouse have been, are, and may be going. I hope this book will help you to be patient with the long and difficult grief process, to find greater mutual understanding and a shared sense of the enormous range of what can occur in a grieving couple’s relationship, to communicate better, and to find ideas that will help you on your shared journey.

### **A Child’s Death Changes Everything**

The death of a child not only changes a parent forever, it also permanently alters a couple’s marriage. As individuals you must each deal with the awesome, confusing, and painful thoughts and hard and often agonizing and overwhelming feelings that come with a child’s death. As a couple you must deal with how each of you has changed. In a sense, you each have become something of a stranger to yourself and each other. And in the process, your marriage cannot be what it was before. It is the marriage of two peo-

ple who have shared a very heavy loss, of two people who have seen each other grieving, of two people who have gone through the relationship struggles couples experience when a child dies.

You become new people, with no sense of whether you can or should return to being your old selves. You are likely to be beginners at dealing with the kind of grief parents feel and beginners at coming to terms, as a couple, with whatever is going on in you as individuals and as a couple. For quite a while, grief is likely to sap you and your partner of energy to solve problems, to talk about things, to think things through well, and to come to terms with what has happened. For weeks, months, or even years, you may feel that you are in some kind of holding pattern, just trying to do the bare minimum to get along.

Also, your child’s death makes you different from most people you know. Although several million American couples have lost a child, you may not know anyone whose experiences can be a resource to you. In fact, your friends, relatives, neighbors, coworkers, and the people in your religious congregation, if you belong to one, may not be able or willing to help beyond the first outpouring of sympathy. Most will never have had a similar experience and most, even if they care for you deeply, will not be very comfortable with you.

Added to all this, grieving can make your couple relationship difficult. Being down so much, being needy and looking at everything in new ways after a child dies, it is easy for you and your spouse to see many negatives in each other and in your marriage that may have been ignored or were not present in the past. So in addition to dealing with the loss of a child, you may have to deal with whether and how to change your marital relationship or even with the possible loss of your marriage.

**Hannah:** You do a lot of searching. Things come to the surface that you wouldn't think about, unless something happened. Our marital problems have always been there, but they're more on the surface because of what we've been through. I don't know what's gonna happen. It's kind of a shame to throw away thirty years. The problems that we are having have always (**Fred:** [quietly] Yeah) been there. We just never dealt with them before.

Your child's death also may open you as individuals and as a couple to examine and change values, perspectives, and what counts the most for you. You may be moving toward new perspectives on the meaning of life and on what is important.

**Elaine:** Things that were so important the week before Kyle died were not important at all anymore. Our oldest daughter got pregnant before she was married. At one point in my life that would have been the most devastating thing that could have ever happened. But it was like, what is that in comparison to losing? I'd rather have her that way than not have her at all. Sure, you wished it didn't happen, but how could we not think that this little girl isn't the be all and end all?

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**Ted:** Any experience like that is going to make you appreciate life that much more. That, for us, was a big hit about we've got to live for each moment.

Changes in your basic values and perspectives may seem necessary and desirable, but they also can challenge you individually and as a couple. You and your spouse may not change in the same way, and you may not have the same idea of what a change implies. For example, what if Ted and his

wife had different ideas about how to live for each moment? Also, those changes, like the death and your grieving, will make you different from many people around you. That may mean you pull away from relatives and friends or they pull away from you. That throws you and your spouse together more than in the past, just at a time when you are not likely to be at your best in relating to each other.

## **Will We Divorce?**

Many grieving parents are aware of the old research studies that say the divorce rate is much higher for couples who have had a child die, but few parents have heard that those studies are widely criticized by experts or know about other studies that suggest the divorce rate is no higher if a child dies. Although I believe divorce is not necessarily more likely after a child’s death, I also understand why couples find it easy to believe that they are more likely to divorce. After a child’s death, many couples feel how fragile their marital relationship is, that it is so shaky they could divorce.

Many couples go through very difficult times in their relationship after a child dies, often dealing with difficult marital problems connected to the death for years afterward. There are couples living together like strangers, perhaps even less courteously than strangers. There are couples who stay married despite enormous amounts of anger because one blames the other for the death or cannot forgive the other for grieving the way she or he grieves. Some couples who remain together grow so distant from their partner that it is like an emotional divorce.

**Lisa:** I can live in the same house with him and not talk to him for a week. Not look at him. It’s like a wall

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between us. And as many times I'm sure *he* thought of just, "Let's get out of this." (*Nick*: I'd thought about it hundreds of times.)

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Karl: When Ruth died, we withdrew from everyone, and it was like when Joel died we almost withdrew from each other. It was that little bit deeper, and I love Kathy as much now as I did then, but sometimes I find (crying) that (she's crying too) I just back away. We both go our separate lives.

Kathy: I remember getting into my car every day, crying all the way to work, then getting to work and working, getting in my car and crying all the way home, and taking care of our surviving child, and when I was alone crying again *for* I don't know how long. And I don't remember Karl in the picture at all.

*Karl*: And that was obvious. (*Kathy*: Yeah) That's the way I felt, that I wasn't in the picture.

The psychological distance between bereaved partners still together can continue for years. Karl and Kathy still were struggling 12 years after the more recent death.

Karl: You're almost like a roommate now. (*Kathy*: Yeah) That's been pretty much the way our life is now. She'll be sitting at the table, and I'll walk in the door, and unless it's a very, very special occasion it's just, "Hi."

Even if statistics now convince the experts that divorce is not more common for couples who have a child die, some couples who divorce will believe that the death led to the divorce. And many couples who stay together will experience months or years of emotional distance, sexual distance,



anger, blaming, and limited communication related to the child dying.

This book is written to help you find ways to head off, minimize, live with, or get past the hard times that you may have together. I have to tell you that I am not against divorce. I think it can be the right choice for one or both partners. But I am also not for divorce. I know that people who think they will or should divorce often can be helped to get to a relationship that is comfortable, affirming, understanding, and loving. Divorce is **a** way to solve some problems, but often those problems can be solved in other ways.

## **Grieving Is a Shared Journey**

Most of what has been written about grief has focused on individuals, and grief is usually understood and explained as an individual experience. Grieving parents are pushed to think that dealing with a death is basically an individual matter. Yet **a** grieving couple is so mutually entangled that each is crucial to how the other deals with the death. Grief for **a** couple whose child has died is very much **a** couple thing.

Most bereaved parents who are married work out together how to think about the death, how to talk about it, what to believe about it, and how to grieve it. If you are like most married parents, it is your spouse—not somebody else—who most often sees you grieve, who has the most opportunity to understand what you are thinking and feeling in your grief, and who most influences when and how you express and deal with your sorrow. It is with your spouse that you are most likely to figure things out and organize to move ahead.

When **a** child dies, partners share the loss. You and your spouse had similar relationships to the child, and each of you witnessed the other’s relationship with the child. Each of

you is likely to be the adult who best knows the other. You probably made many joint decisions concerning the child—including medical treatment, the funeral, and what to do with the child's things. And those decisions will show up in what you think and feel as you grieve. If you are a couple who might have another child, you must decide together whether to do so. In terms of hours per day, each of you may be the adult the other spends the most time with. If you **do** not deal with your couple issues well enough, your relationship will be in jeopardy, and the end of the marriage can be another devastating loss.

Dealing wisely with your relationship will help head off or minimize difficulties. If you can work together on your relationship, you may have success at backing away from bickering, blaming, and hurt feelings. You may have success dealing with communication difficulties, disappointments, and other issues that can undermine your relationship. And you may be able to offer support, help, and understanding for each other.

Parenting together is a shared journey, and dealing with a child's death is as well. In bereavement, the couple journey will be hard. But it does not have to end in disaster. This book is filled with stories and insights that can help you and your spouse find your way together through the difficulties. It addresses many of the hard issues that come up for bereaved couples, including communication, sexuality, blaming, and whether to use counseling or a support group. This book is not a guide to the one best path; you two have to find your own way. But the information here can encourage, support, and inspire as you together find your way.

If you want to understand your own or your partner's individual grief, this book will help, but there are many other books that focus much more on individual grieving. This

book focuses on couples. It does not have to be read by a couple to be helpful, though if you both are on the same page and thinking the same things, that might make the book more useful. I know, however, that one spouse typically will read more than the other and that one tries harder than the other to make use **of** what is read. **So** do not be surprised if this book is primarily yours **or** primarily your partner’s and not a fully shared resource. But regardless of whether both of you closely read this work, it can still be a couple resource.