WOMEN SHARING FROM THE HEART

Women Sharing from the Heart

Marie Allen, Ph.D. Shelly Marks, M.S.



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Library of Congress Cataloging-in-Publication Data

Allen, Marie, 1954-

Miscarriage, women sharing from the heart / by Marie Allen & Shelly Marks.

p. cm.

Includes index.

ISBN 0-471-54834-0 (acid-free paper)

- Miscarriage—Psychological aspects.
 Miscarriage—Psychological aspects—Case studies.
 Bereavement—Psychological aspects.
- Bereavement—Psychological aspects—Case studies.
- I. Marks, Shelly. II. Title.

RG648.A56 1993

155.9'37—dc20

92-22852

I wrote this book in honor of Baby Andy. I dedicate it to my children here on earth. Thank you for sharing your lives with me. You are my Greatest Blessings . . .

Terese Noël,
Jordan Taylor,
& Grace Lorelei
I love you with all my heart,
Mom

To my grandma, Leah, whose spirit guided me through the writing of this book and to Jamie, whose life was the gift that began the journey.

Shelly

To Chris Dunne, Anne Nickel, and very especially Peggy Macy (Empty Cradle support group) for providing the acceptance, security, and guidance that enabled us to journey through grief and return to life.

To Gary Winters for assisting us in the process of defining our dream. To Betsy Wheeler for publicizing our invitation to potential participants throughout Los Angeles, opening her home there to us, and finding us space in which to conduct interviews. To Honolulu University for providing us space, too. To Teri Brown for her referral of many of the San Diego participants.

To Tom Diamond and Josh Shade for their statistical expertise. To Kathy McCoy for marketing guidance. To Bill Durbin for overseeing our contract. To Sue Cramer, L.C.S.W., and Antoinette Thomas, Ph.D., for help with our Additional Reading List. To Judy Davis, L.C.S.W., for sharing her personally compiled list of children's literature.

To fathers who sent us personal writings or gave interviews to help others, including Lyall Kitson, Richard Rudiger, Tim Riley, and James Kenneth Watson.

To Martha Durbin, R.N./M.S.N., Peggy Macy, L.C.S.W., Kurt Benirschke, M.D., Harlen Alcorn, Ph.D., Michael Graves, Sharon Calagna, Jody O'Konski, Steven R. Drosman, M.D., Barbara Drosman, Bleema Moss, M.F.C.C., Judy Davis, L.C.S.W., Susan Cracroft, Reta Shulman, and Gerald Spector, M.D., for support and guidance on our manuscript.

To Robin Rue at Anita Diamant Literary Agency for believing in and selling a book on this subject. To Ted Scheffler at John Wiley & Sons, Inc., for the vision to recognize its importance and persuading Wiley to publish it. To our editor, Judith McCarthy, for her careful and astute suggestions and for coming through on promises.

To Michael Graves and Mike Marois for their skill as photographers.

To Richard F. Jones, III, M.D., and National President of American College of Obstetricians and Gynecologists, for acknowledging the importance of miscarriage as a loss and supporting this effort by writing our foreword.

To Gregory Allen for his belief in me, help with the computer, and countless hours of love and care for our children over the two years and nine months since the origin of this project. To Reta Shulman, for terrific ideas and emotional boosts. To James Isaacson for allowing me to witness

the beauty of his journey in grief and the privilege of touching his heart. To Patti Aretz for warm arms, deep compassion, and howling laughter. To Martha Durbin, R.N./M.S.N., for love and an incredibly bright mind. To my parents, Thomas Lanny Gipson and Geraldine Dazey Gipson, for life and love.

To Tinette Thomas for being my personal cheerleader. To my mother, Gloria Marks, for her supportive phone calls throughout the writing process and especially for her prayers. To my husband, Gary Winters, who gave me love and support from the moment I met him and whose continual unfolding and belief in us encourage me to grow and to be all that I am. To my daughters, Lorien, Lyndsey, and Hallie, who gave up their mother for the time it took to write this book and who are my most precious teachers of love and joy.

In the quarter century that I have been a practicing obstetrician/gynecologist, I have seen countless women stricken by the loss of their babies, both born and unborn. The tiny life they carried flickered out; they were left to grieve alone.

Although medical art and practice has become increasingly sophisticated in treating women whose full-term babies are stillborn, there has been little emphasis on dealing with the loss experienced by women who lose their babies earlier on. This is no doubt due, in part, to the controversy surrounding the definition of life—when the miraculous division of cells can be regarded as first embryo, then fetus, then unborn child. Regardless, women who are pregnant, at whatever stage, know themselves to be hosts of more than merely potential life. Often even before conception they change their life-style—they quit drinking and smoking, they take vitamins and improve their diets and exercise habits—they make plans, they dare to dream, they feel different. They become mothers.

And it is this emotional dimension that gives women who miscarry the right and the need for support, validation, and compassion. We who are involved with these women must be sensitive to the devastation that miscarriage inflicts on their psyches. We must understand that bonding between mothers and their unborn babies takes place long before others can see that they are pregnant, long before ultrasound can prove that life exists, long before the father and other loved ones can feel the stirrings of young life as the baby kicks and moves within its mother.

We must be acutely aware of other dynamics as well. Domestic violence, substance abuse, and untreated disease can and do result in miscarriage and leave a woman shattered. Underlying treatable and physical problems can result in the loss of a pregnancy. And there is the pregnancy that ends for unknown reasons.

Whether or not there is an explanation, there is a loss. Women take these losses very personally and are certain, somehow, that they are at fault.

The unique focus of this book lies in its emphasis that women who miscarry must not and need not be left in emotional isolation.

I am pleased that this timely and sensitive reflection on miscarriage is now available to grieving women and to those who are involved in their lives. Grief, unless expressed and validated, will persist. It is my hope, xii FOREWORD

therefore, that the personal insights expressed within will provide some comfort and direction and will contribute to the catharsis vital for the resolution of grief.

My congratulations to the authors.

-Richard F. Jones, III, M.D., FACOG President, The American College of Obstetricians and Gynecologists

OPENING NOTE TO THE MOTHER

Dear Mother,

Regardless of the length of time you were pregnant, you carried a real, living being in your womb. That little being, your baby, died. What you are feeling is grief, a complex, yet normal, response to loss. We will give you information about the feelings you may experience in response to your loss. Although the future appears dark, you will survive. You will find your strength along the way. You will see the light of day again. Together we'll hold steadfast through the tears.

Shelly and Marie

Foreword xi

Opening Note to the Mother xiii

PART ONE MISCARRIAGE 1

- 1. A Beginning 3
- 2. The Mother Who Has Miscarried 12
- 3. Shelly's Story 21

PART TWO MATERNAL LOVE AND ATTACHMENT 31

- 4. Our Pregnancies, Our Babies 33
- 5. Julianna's Story 40

PART THREE ECHOES OF MOURNING 45

- 6. A Death 47
- 7. Grieving 52
- 8. Jessi's Story 67
- 9. The Hardest Part 69
- 10. Insights and Reflections 75
- 11. Leah's Story 81

PART FOUR RELATIONSHIPS 85

- 12. Our Partners 87
- 13. Our Partners' Grief 93
- 14. Our Living Children 107
- 15. Our Families and Friends 117
- 16. Professionals 122

PART FIVE FACETS OF GRIEF 127

- 17. Understanding Grief 129
- 18. Respecting and Honoring Our Grief 132

19.	Emotional	and Physical	Dimensions	135

- 20. Eve's Story 144
- 21. Understanding Our Emotions 148

PART SIX BELIEFS THAT GET IN THE WAY 159

- 22. Childhood Lessons 161
- 23. Societal Myths 165
- 24. Hannah's Story 171

PART SEVEN THE JOURNEY 175

- 25. Passage Through Grief 177
- 26. Elizabeth's Story 185

PART EIGHT UNFOLDING 189

- 27. A Common Grief 191
- 28. Marie's Story 193
- 29. Opening to Life 205
- 30. Gifts 211

Parting Note to the Mother 217

In Appreciation 218

Appendix A: Taking Care 220

Appendix B: Additional Reading 244

Appendix C: Statistical Findings 247

Glossary of Medical Terms 249

Index 251



A Beginning

In 1987, our unborn babies died. The months to follow contained the darkest hours we have ever known.

We had both always been under the impression that miscarriage was no more than a brief disappointment, and people treated ours accordingly. By all indications, miscarriage was not a serious loss—especially at only 10 and 14 weeks of pregnancy. But we were devastated.

Separately, each of us believed herself to be the only woman in the world who felt profound grief over the loss of a miscarried baby. Both of us feared that we were crazy to be feeling as we did, torn apart by an event that the world minimized. After all, it was "only" a miscarriage. We didn't trust that we had a right to grieve. Weeks went by and still we did not feel better. We were stuck and couldn't heal.

We sought books on the subject. Our public libraries and bookstores had no books concentrating on the emotional experience of miscarriage, which seemed to validate that the emotional experience was not a big deal.

What we did find helped us in many ways. But in other ways, what we found also fortified our previous impressions that we should not have felt so bad over "mere" miscarriages. Miscarriage as a loss was merely touched on in some books. Others clumped miscarriage with the loss of full-term babies. Stillbirth* was referred to as the "death of a baby." Miscarriage, on the other hand, was referred to as the "loss of a dream." What did that say about our babies? Were they hallucinations? We felt that our babies and our losses were not valid and our grief was not justified next to babies and losses that were verifiable as "real." Suggestions for healing, such as holding our babies and obtaining footprints and photographs, were not options we would ever have. Our needs went unattended; the nuances of our invisible tragedy went quietly unrecognized. Some books emphasized diet, nutrition, and exercise. But in the face of the death of our babies, we were looking for a meaning in living.

^{*}You can refer to a glossary in the back of this book for definitions of this and other medical terms used throughout the book.

The two of us met later that year and forged a friendship. With caution and growing trust, we risked exposing to each other the pages of our private journals. What we discovered amazed us. Some of the words and expressions on our pages were identical. Marie asked, "Now do you know you're not crazy?" Shelly answered, "No, now I know we're both crazy!"

We wondered if other women also experienced deep grief over their miscarriages. And if they did, was deep grief over miscarriage rare, commonplace, or something in between? We knew that if other women felt as we did, there was a great need for the education of society on the emotional impact of miscarriage. Someone needed to delve into the secret places in the hearts and minds of these women and make it known that they are suffering and in need of care.

Our self-doubt, our suspicion that other women experienced miscarriage as a profound loss, and our care about their presumed suffering placed us on the road to this book. We embarked on a descriptive study of the emotional impact of miscarriage (pregnancy loss before 20 weeks gestation).

GATHERING THE DATA

With the goal of eliciting the in-depth emotional experience of women from the time of their miscarriages to the present, we conducted interviews with 100 women ranging in age from 20 to 62 years whose miscarriages occurred 9 days to 39 years prior to their interviews. The miscarriages ranged from 4 weeks to 20 weeks (4½ months) gestation and included blighted ova, ectopic (or "tubal") pregnancies, miscarriages that occurred when women were not yet aware that they had even been pregnant, when one twin survivied, when elective abortion already had been scheduled, and others.

There was a wide range in the study group in terms of cultural, religious, and educational background, and socioeconomic status, age, and race.

About half the women came to us from word-of-mouth referrals. Whereas there is a range in women's emotional responses to miscarriage, these self-referred women who stepped forward to participate in a study on the emotional experience of miscarriage may have been more aware of their grief than the general population of women who have miscarried and/or may have been from the end of the spectrum in which grief was more profound. Also, the fact that they wanted to talk about their losses

suggests the possibilities of insufficient attention received at the time of their losses or afterward, that they wanted to help other women, or both.

The same applies to another approximated quarter of the women who were referred to the study by support groups for pregnancy loss in San Diego and Los Angeles. Also, perhaps the women referred by support groups were more aware of their need for social support or of the option of social support than the general population of women who have miscarried. These can be seen as limitations of the study.

Another quarter of those interviewed were women we knew directly or indirectly and whom we asked to participate. In all but a couple of these cases, their miscarriages had occurred prior to our knowing them and had not been discussed with us prior to their interviews, so we had no inkling how they would respond to the questions. This was of particular interest to us in that we had known them over a period of time only in social or career contexts. It is unclear what effect, if any, this method of acquiring participants may have had on our findings.

Although each woman was told that interviews would take approximately an hour and would involve personal and probing questions, we found women highly motivated to participate. Many expressed a desire to be interviewed not only to help other women but also to contribute to a book that they themselves would find helpful.

The interviews averaged 80 minutes and consisted of 85 questions soliciting the range of each woman's feelings about her miscarriage. Because some women had experienced multiple miscarriages, some questions solicited separate responses for each of their miscarriages. Most questions required anecdotal as opposed to single-word responses (e.g., "What happened in you spiritually in the time to follow?"). Descriptions or explanations were requested following positive responses to yes/no questions (e.g., "Did your sex drive change following the loss? If so, how?").

All the interviews were tape recorded as well as transcribed by hand at the time of the conversations. Some of the interviews were conducted in person and some by telephone. The latter method had the advantage of efficiency and provided women maximum privacy and anonymity. Actually, we found it both significant and fascinating that many women who granted their interviews over the telephone mentioned that they were in their beds with their bedroom doors closed as we spoke—some with a cup of coffee in hand—well reflecting the incredible intimacy associated with discussing the matter of their miscarriages with another woman who had had a miscarriage, who wanted to listen, and who probably would be accepting of their feelings.