



VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

Pregnancy Loss:

A Teaching Guide for Loss Parents

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The stories referenced in this study guide can be downloaded for free. Please see the "Pregnancy Loss" volume of VOICES <https://nibjournal.org/voices/>

Art Frank has written a short reflection piece on learning from narratives for NIB. Please see the Narratives Page under the Education tab on the NIB website to download the piece.

General Questions:

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1. Several of the stories talk about healthcare professionals, friends, and family discounting the suffering and grief of pregnancy loss. Why do you think individuals tend to diminish the grief of pregnancy loss?
2. The idea of "bodily failure" and experiences of guilt come up in several stories. How do clinicians or communities support patients who feel their bodies have failed them? Why do women feel this sense of bodily failure after experiencing pregnancy loss?
3. How did experiencing pregnancy loss change your relationships with those around you? In what ways were relationships strengthened or how were they made more challenging?
4. Should the role of healthcare professionals extend beyond purely "physical" medical support of families dealing with pregnancy loss to emotional support as well? If so, how can that emotional support and care best be given?
5. How will you think of or respond to pregnancy loss differently after reading these stories? Has your own experience of pregnancy loss affected the way you support or respond to individuals who may have revealed that they too have experienced pregnancy loss? In what ways?

Story Questions:

You Can Do Hard Things

Christina Mulé

1. Christina speaks to feeling a lack of control amidst her pregnancy losses and the difficulty around a successful pregnancy not being something she could “achieve” or “work hard” to get. How (if at all) did needing to “relinquish” control play a role in your pregnancy loss experience?
2. Christina discusses the impact of COVID-19 on her experience of receiving care during pregnancy loss. For example, she describes not being able to have a support person with her, delays to ultrasound appointments, and confusion around where to go for her appointment. How did COVID-19 affect your experiences receiving healthcare?

The Mountain is the Valley

Reverend Shaina Rose Ciaccio

1. Reverend Shaina speaks both to how she offered comfort to the patient who had had a stillbirth and the comfort given to her when she herself was a patient in the hospital. What did healthcare professionals do for you that was comforting? Is there a specific memory of a provider who was particularly helpful to you?
2. The COVID-19 pandemic impacted how care was delivered in many ways, and one way that Reverend Shaina discusses is physical touch. She embraces the patient, despite it being against the distance protocol and says, “but it feels like a sin not to provide the comfort that sometimes only touch can give.” She also describes what it meant to her to have a nurse embrace her and her child when she feared her son may be sick. In what ways did distance protocols and protective gear change your relationship with your clinicians?

What Joan Marie Taught Me About Life, Loss, and Love

Rose Bendas

1. Rose speaks to what she learned through her own pregnancy loss about how to help those around her process their own grief and suffering. Was there a time in which your own experience with grief surrounding pregnancy loss changed how you related to or interacted with others who were going through their own losses or challenges? Additionally, Rose speaks to how challenging it was to hear about birth and pregnancy announcements from those around her while she was dealing with her own pregnancy loss. What was the process like of managing your own grief while also dealing with happy news from others?
2. Rose discusses the pain and mourning process and how she and her husband received comments from those around them that weren’t particularly comforting. What was it like interacting with friends and family after pregnancy loss? In what ways was it comforting, or in what ways was it painful, and why?

Helping Loss Parents Heal After Miscarriage: The Critical Role of Medical Professionals

Monica Snyder

1. Monica speaks to how several healthcare professionals discounted the grief she felt over the loss of one of her twins. People who are pregnant with multiples or who already have living children may have their grief discounted further because they already have a “healthy child” or are “still pregnant.” In your experience, in what ways did already being a parent or remaining pregnant with one child impact how

others interacted with you or spoke with you about your grief? What impact did this have on your own experience of grief?

2. Monica writes that after the loss of Scout she “craves ritual and acknowledgment” but is unsure how to fill that need. She chooses a name and buys an engraved memory box, but she writes she doesn’t have much to fill it with. She also seeks grief counseling but finds that the psychiatrist who is assessing her seems to act as if she does not have a need to go to counseling. She also joins pregnancy loss groups online which she says “help significantly.” What steps did you take to make your grief shorter-lived and less intense?

Primigravida

Jessica Bratt Carle

1. Jessica writes, “I still perceived that an earlier loss like mine just wasn’t that substantial; not quite as deserving of as much sympathy compared to the kinds of later pregnancy losses and infant losses, I had all too often witnessed in hospital chaplaincy.” Why do you think individuals discount the grief of pregnancy loss, particularly those that may be early on? Did anyone try to “talk you out” of your grief? How did you respond?
2. Jessica recounts a painful encounter with her physician when finding out she had miscarried as well as office staff when she was asked if she needed to schedule another appointment. Their attitudes make her feel as if she shouldn’t be devastated over her loss and that the miscarriage, “isn’t a big deal.” How could Jessica’s physician have offered her better care and acknowledged her loss?

I Adore You

Angela Yvonne Dahm

1. The on-call physician suggested using a Foley bulb catheter to move Angela’s labor along, assuming she and her husband just wanted the nightmare of delivering her baby who has died in utero to be over. In contrast, Angela speaks about nurses who are “angels” and a hospital chaplain who mourns with and supports her. In what ways do these healthcare professionals support and care for Angela that the on-call physician does not? What do you wish all healthcare professionals would do for patients dealing with pregnancy loss?
2. While dealing with grief, Angela says she learned that “social connection can foster healing.” What helped you to manage your grief after pregnancy loss? How did you find support and comfort?

The Value of a Life

Monika Jaquier

1. Monika felt many individuals around her believed the value of baby Anouk’s life was lessened or practically nonexistent when they learned of Anouk’s anencephaly diagnosis and that she would die shortly after birth. Monika’s doctor recommends that she terminate her pregnancy and start again with “another baby that is worth it.” How would you have responded if you were in Monika’s shoes? In what ways did Monika’s new doctor support and care for her and Anouk?
2. Monika’s midwife helps her create a “bubble of normality” during her pregnancy though she is aware of Anouk’s fate. She participates in water aerobics with other pregnant moms and gets to “chat about normal things of pregnancy,” In what ways would living in a “bubble of normality” be helpful for a parent who is anticipating a pregnancy loss? Do you see any potential drawbacks? If so, what are they?

Losing Desiree

Sirena Washington

1. Sirena talks about how the loss of Desiree affects her relationships, in particular, with her partner when he goes back to work. In what ways were your relationships affected by pregnancy loss?
2. For those who are religious or spiritual, in what ways, if at all, did your pregnancy loss affect your own feelings around faith or God?

Caleb's Stillbirth, 5 Years Later

Jill Wieber Lens

1. Jill writes of her feelings of guilt after losing Caleb and how she saw losing Caleb as “bodily failure.” Why do you think Jill felt guilt over losing Caleb? How do you think the healthcare community could help in combating that guilt? If you also experienced this feeling, how long did it take for it to go away, if it did at all? What did you find helpful, or what do you think would have been helpful?
2. Jill writes that “The happiness does not cancel or balance out the sadness. It doesn’t work like that. Instead, the happiness and sadness coexist; I am both very sad and very happy at the same time.” Do you relate to this sentiment? Describe a time when you felt the co-existence of both happiness and sadness in your life.

I Am a Mother of Three Little Angels

Indrè Razbadauskaitė Venskė

1. Indrè talks about how due to COVID-19 restrictions, she was initially unable to see her husband after the delivery and death of her twins. What was the impact of COVID-19 (if any) on your experience with pregnancy loss?
2. Indrè states that after experiencing infertility for many years, she finally became pregnant with twins through IVF. Unfortunately, Indrè’s twins die before she is 23 weeks along. After another round of IVF, she becomes pregnant again, but that baby is miscarried after 14 weeks. How does pregnancy loss impact parents who require reproductive assistance differently? Are there any special considerations that healthcare providers should take into account when caring for these pregnancy loss parents? If so, what are they?

Finding Peace Through Recurrent Loss

L. Emily Cotter

1. Emily talks about nurses and physicians not understanding her lived experience. What do you think it means for clinicians to try to understand a patient’s lived experience, and how might they better do this?
2. “I had been candid with friends and loved ones discussing life after our first miscarriage,” Emily writes, “I hoped to break the trend of carrying these losses silently.” Describe a time in which you shared your experience and how you felt it was received. Why do you think that many parents feel they have to carry their “losses silently”?

Reproductive Trauma: Grief, Acceptance, and a Plea for Grace among Female Physicians

Giulia Faison

1. Giulia talks about how two clinicians used language that was hurtful—including a resident who used the term “schmutz” to describe Giulia’s embryo and a clinician who Giulia felt didn’t say anything helpful about her loss. Was there a time your healthcare provider used language that you felt was more hurtful than helpful? What do you wish they would have said instead?
2. Giulia talks about her experience managing pregnancy loss while also working as a physician. What was it like for you to manage a job or other family responsibilities and also grieve and care for yourself?

A “Good” Patient

Erica C. Kaye

1. Erica says she wanted to be a “good” patient so that someone in the system would see her and care. Does this thought resonate with you? In what ways? How could trying to be a “good” patient hinder a patient’s ability to receive adequate care? In what ways could it facilitate receiving better care?
2. Erica talks about how the partners in the fertility clinic where she underwent IVF decided to fire her as a patient. Describe a time when you felt blindsided by news from a clinician or felt you had been abandoned by a healthcare provider.

Thrice the Pain

Taylor McIntyre

1. At 16 weeks along, Taylor goes to the ER and learns that, due to an anembryonic pregnancy where the gestational sac develops without an embryo, she will miscarry. The ER nurse says to her, “At least it wasn’t a real baby.” But Taylor painfully relays, “The baby was beyond real to me.” Describe a time when you felt hurt or angry at a provider who was supposed to be caring for you. How did you handle it?
2. Taylor discusses her several attempts to get pregnant and sustain a pregnancy. How did pregnancy loss affect subsequent pregnancies or your desire to try to get pregnant again? Did you have a number like Taylor did, where you decided you could no longer continue to try?

Gravida Plus One

Anita Kumar Chang

1. Anita writes that “it’s strange how, at times like this, the smallest show of compassion makes its way deep into one’s memory.” Was there a time that you were shown deep compassion amidst pregnancy loss by a healthcare provider or someone in your community?
2. Anita talks about not knowing how much she was “allowed” to grieve the loss of her pregnancy. Can you relate to this feeling? How did you handle it? What brought you comfort?

My Three Pregnancy Losses: A Story Told from an OBGYN Physician Working in Japan

Shizuko Takahashi

1. Shizuko, a practicing Obstetrician, says that after experiencing miscarriage herself she learned “How little comfort the scientific explanations provided patients who were struggling to fulfill the soci-cultural norms that accompany carrying a pregnancy to term.” Was there comfort for you in knowing medical reasons for why a pregnancy loss occurred? Did you feel societal pressure to be able to carry a pregnancy to term?
2. Shizuko describes the differences between how she handled her pregnancy losses and how her partner did. Did you ever feel in conflict between how you and your partner wanted to grieve or heal from loss?

Baby Judah and the Lessons We Take with Us

Daniel J. Hurst & Rachel N. Hurst

1. Daniel assigns Eric Cassel's article to his class, which says that "A goal of medicine must be relief of suffering (not just pain) and that failure to understand suffering can become the source of additional suffering for the patient." What does it mean for a physician to attend to the suffering of a patient and not just their pain?
2. Daniel contrasts the physician and ultrasound tech's reactions, one as supportive and comforting and the other as cold and hurtful. What do you think makes statements from a physician comforting versus harmful?

The Thin Clear Drape

Elise C. Tarbi

1. Elise writes, "Pregnancy and parenthood are so often met with phrases that feel hollow and one-dimensional, such as "Congratulations!" and "Enjoy every minute!" Elise wishes pregnancy and parenthood were talked about with deeper vocabulary and different questions such as, "Do you want to talk about what scares you now?". How does Elise's wish resonate with you? Were there questions that you wish you had been asked when you were pregnant or experiencing loss?
2. Having already experienced pregnancy loss before, Elise says that when she went to her midwife's office after becoming pregnant again, she told the midwife that she was "preparing for the worst." Were there times you also were "preparing for the worst"? How did you manage these feelings?

Clinicians' Unintentional Lack of Support through Pregnancy Loss

Katarina Lepinski

1. Katarina writes "There's a fine line between what's medically necessary and what's emotionally necessary." After her miscarriages, some of what Katarina wanted was "emotionally necessary." As a patient, was there ever a time you desired something emotionally necessary though not physically necessary? What was it that you desired? How could receiving what was emotionally necessary have made a difference in your situation?
2. Katarina discusses a time when, after a miscarriage, an appointment she had scheduled with her OB/GYN was mistakenly canceled by the clinic staff at her OB/GYN's office—an incident that left Katarina feeling the office lacked compassion. What are some ways that healthcare providers can show compassion? Did you receive the emotional support and compassion that was lacking in Katarina's story? If so, from whom and how did the person's actions make a difference to you emotionally?

Sacrifices

Efrat Lelkes

1. Efrat talks of sacrifices in her narrative and how her career altered her timeline for becoming a parent. Do you feel, if at all, that you have made sacrifices during your journey to becoming a parent? If so, in what ways? How do you feel about those sacrifices now?
2. At the end of her narrative, Efrat writes that "this system broke me." What does that mean to you? In what ways does the system fail people trying to conceive or who experience pregnancy loss?