



# VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

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## **Pregnancy Loss:**

### A Teaching Guide for Healthcare Professionals

By Taylor Abboushi

Edited by Heidi A. Walsh

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:**

General Questions:

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. All of the stories in VOICES: Pregnancy Loss happened to be from parents who experienced the loss of a wanted baby—all were distraught by the loss—and most were shocked. However, some people who experience pregnancy loss may feel relieved or conflicted. As a healthcare provider, how do you ensure that your response meets each individual’s needs?
3. 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?
4. Should the role of healthcare professionals extend beyond providing purely “physical” medical support for families dealing with pregnancy loss to offering 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. What is it like to work your hardest to care for patients, all the while knowing that some outcomes are out of your control? Describe a time when you were not able to “work hard” to achieve an outcome you wanted for a patient (for either medical or social reasons)?
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 providing 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 experienced a stillbirth and the comfort given to her when she herself was a patient in the hospital. As a healthcare professional, in what ways do you try to offer comfort to your patients? Is there a specific memory of caring for a patient where you felt you were able to offer comfort particularly effectively?
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, saying, “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 might be sick. In what ways did distance protocols and protective gear change your relationship with your patients?

### 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 experience as a healthcare professional who had experienced some kind of grief or loss changed how you related to or interacted with patients or others who were going through their own losses or challenges?
2. Rose discusses some of the comments she and her husband received during the mourning process that weren't particularly comforting. In thinking about your interactions with patients who have experienced pregnancy loss and are grieving, have you ever responded in a way you now regret? What could have gone better?

## **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, how did you view patients who experienced pregnancy loss while already being a parent or remaining pregnant with at least one child? Do you think this had any impact on how you interacted with or spoke with such patients?
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 have you taken to help cope with the challenging emotions of seeing patients grieve or deal with great sadness or loss?

## **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? Have you seen individuals (healthcare professionals or family and friends) try to talk a patient out of their grief? How did you respond?
2. Jessica recounts a painful encounter with her physician when finding out she had miscarried as well as with 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? How can office staff be better prepared to interact with patients experiencing 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 had 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? Why do you think there is variety in response to patients dealing with pregnancy loss?
2. While dealing with grief, Angela says she learned that “social connection can foster healing.” What is it like to deal with your own emotions and grief over a patient’s situation while also providing care for them? 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." Why do you think Monika's doctor phrased this to her in this way? What language would you have used? In what ways did Monika's new doctor support and care for her and Anouk?
2. Monika, who was also cared for by a 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," Do you think it is helpful for a parent who is anticipating pregnancy loss to be in a "bubble of normality"? 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. Have you witnessed scenarios in which pregnancy loss has affected a couple's relationship negatively? How so? What advice would you have for parents of pregnancy loss to help safeguard their relationship after a pregnancy loss?
2. How may your response to or the support you give to parents who are religious or spiritual differ from the ways you respond to or support parents who are not particularly religious or spiritual? In what ways, if at all, does watching patients deal with pregnancy loss affect your own feelings around faith, spirituality, 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 a "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? Was there a time when you felt guilt while watching a patient in pain or suffering, even if you had done everything in your control to help? How do you manage this?
2. Jill writes, "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 coexistence 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 their twins. What was it like to have to enforce COVID-19 restrictions while caring for patients who were experiencing grief surrounding pregnancy loss? How did enforcing the restrictions change your relationships with your patients? What strategies did you use to circumvent any negative ramifications?
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. Are there differences in how you work with pregnancy loss parents who have required reproductive assistance? 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 own experience of loss or grief with someone. How was it received? How did you feel afterward? Do healthcare professionals often feel they must "carry their losses silently?" If so, why do you think this is the case?

## **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 ever a time when you said something to a patient that you later felt was more hurtful than helpful? Was there something you wish you had said instead?
2. Giulia talks about her experience managing pregnancy loss while working as a perinatologist. Recognizing the changes in her body, she drives herself to the hospital, confident she is experiencing a pregnancy loss, which is confirmed by an ultrasound that she can interpret along with the OB resident providing her care. As a healthcare provider, have you had the experience of diagnosing your own ailment or condition? How has this ability been a comfort to you? How has it been a burden?

## **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. Do you think of some of your patients as “good” or “bad”? 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 had to stop working with a patient. Why and what was that experience like for you?

## **Thrice the Pain**

*Taylor McIntyre*

1. At 16 weeks along, Taylor goes to the ER and learns that, due to an embryonic 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.” Patients may feel hurt or angry at healthcare professionals for the ways they relay difficult information. What communication strategies do you use when you have to discuss difficult topics with patients or families to ensure you don’t damage their trust or cause them additional distress?
2. Taylor discusses her several attempts to get pregnant and sustain a pregnancy. How has witnessing or caring for patients who experience pregnancy loss impacted your personal views or fears regarding pregnancy and childbearing?

## **Gravida Plus One**

*Anita Kumar Chang*

1. Anita writes, “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 when you were shown deep compassion amidst a difficult experience? Describe that experience, the compassion you received, and what it meant to you. How can you apply what you learned to the way you show compassion to parents who have experienced pregnancy loss?
2. Anita talks about not knowing how much she was “allowed” to grieve the loss of her pregnancy. Has there been a time when you wondered about the extent to which you are “allowed” to grieve over your own personal loss? How did you handle the loss? 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 sociocultural norms that accompany carrying a pregnancy to term.” Do you relate to this sentiment? How so? Describe an experience where, as a patient, what you heard from your healthcare provider wasn’t helpful or what you wanted to know. In what ways are you a “different” patient because you are also a healthcare professional?

2. Shizuko describes the differences between how she handled her pregnancy losses and how her partner did. As a healthcare professional, how have you responded or what have you recommended when a patient and their partner or other close person have had differing opinions or reactions to a diagnosis, treatment, or therapy?

### **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. It states 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 a patient's suffering and not just their pain?
2. Daniel's story is the only one in this issue written from the perspective of the non-gestational parent who experiences pregnancy loss. Why do you think less non-gestational parents chose to write stories about their experiences? What do you think are the unique challenges to being the non-gestational parent who experiences pregnancy loss and how can healthcare professionals better recognize these individual's needs?

### **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?" Do you think it is the role of the healthcare professional to ask patients questions like this? Why or why not?
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." How do you work with patients who are "preparing for the worst?" In what ways do you feel your job is different when working with a family who is expected to carry a pregnancy to term versus working with one who is concerned about experiencing pregnancy loss?

### **Clinicians' Unintentional Lack of Support through Pregnancy Loss**

*Katarina Lepinski*

1. Katarina is told by her PCP that not until she has a third miscarriage can she undergo any testing that may provide answers as to why she has been experiencing recurring miscarriages. Katarina writes, "There's a fine line between what's medically necessary and what's emotionally necessary. Being told that we had to go through the emotional trauma of a third loss before being encouraged to find answers was isolating." What other considerations, such as insurance company policies, or industry guidelines, do you think about when deciding whether to offer something to a patient that may not be indicated by their symptoms or situation? Is offering patients things that are not medically necessary but that they strongly desire, part of the role of the healthcare professional?

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—an incident that left Katarina feeling that the office lacked compassion. What went wrong in this encounter, and how could it have been circumvented? What protocols or training are in place at your clinic or hospital that prevent unnecessary harm like Katarina experienced? Are these protocols effective? What could be improved?

## **Sacrifices**

### *Efrat Lelkes*

1. Losing a pregnancy can have long-lasting—and far-reaching—effects. After experiencing a miscarriage, Efrat's relationship with her partner ends. She writes, "I am alone—without a partner, without a child. I am now on the excruciating IVF journey. I think constantly of my pregnancy, however short it was. It pained me for months when friends would tell me that they were pregnant. I try not to cry at work, surrounded by children. I fail often." What can healthcare providers do to make sure pregnancy loss parents have long-term support and strategies to cope with what may ensue after a pregnancy loss?
2. Efrat, a physician, talks of sacrifices in her narrative and how her career altered her timeline for becoming a parent. "I was furious. I gave my reproductive years to this career and this institution." Do you feel that there are specific sacrifices that healthcare professionals make regarding becoming parents that may not be applicable to other careers? If so, what could be done to support trainees and physicians so they can better achieve their personal goals along with their professional ones?