



motherhood

A devastating personal experience drove Linda Layne to devote two decades to studying issues surrounding pregnancy loss.

Today she is a leading national advocate for reform.

Lost

A WOMAN WAKES UP WITH A START in the middle of the night. In pain and unfamiliar with her surroundings, she stumbles in the dark to the bathroom. Sitting alone on the cold floor, she tries to recall the advice a nurse had given her a few days before about how to know if she were bleeding to death. Lacking medical assistance and adequate information about what is happening to her body, she is frightened and alone. | That was Linda Layne's experience during her seventh and final miscarriage. The devastating loss occurred while she was staying the night at a stranger's home in Oregon where she was conducting field research. | At that time Layne, the Alma and H. Erwin Hale '30 Professor of Humanities and Social Sciences, had been dealing with pregnancy loss for 10 years and had received various medical treatments after suffering miscarriages in the emergency room, her doctor's office, an abortion clinic, and her own home. Although each loss differed in the level of care she received, every experience shared the common thread of confusion. | "I was physically or emotionally unprepared for each of my losses, which made the already distressing experiences overwhelming," says Layne. "Our society makes sure that pregnant women know what to expect during labor and what their options are if difficulties arise—such advances have not occurred regarding pregnancy loss. We keep women in the dark about the possibility of miscarriage. Then, when a loss is imminent, caregivers begin to discuss a woman's options with her. A crisis is not the right time to give people information." | **Nearly 1 million women suffer miscarriages annually in the United States alone. For the last 20 years Layne has been fighting for the rights of each of them.** BY AMBER CLEVELAND

Fifteen to 20 percent of all pregnancies end in loss, according to the American College of Obstetricians and Gynecologists. Nearly 1 million women suffer miscarriages annually in the United States alone. Layne calls miscarriage “an utterly common medical event.” So why doesn’t anyone talk about it?

FROM ANGUISH TO ACTION

After her first loss in 1986, which she calls “the worst and most confusing experience of my life,” Layne, an anthropologist, dedicated herself to ending the silence that shrouds pregnancy loss.

When she became pregnant with her first child at age 30, she says she wasn’t even aware that it was possible for her to miscarry.

“Miscarriage never came up during any of my prenatal visits. And I devoured pregnancy books, eager to learn about the minute details of my baby’s development—but they, too, failed to mention the topic of pregnancy loss.”

When she began to show signs of a possible miscarriage at 13 weeks, Layne was told by her midwives to go to the emergency room. They did not go with her, although they would have if she was in labor and something went awry. Afraid, she hoped the doctors in the hospital could explain what was happening. What she got, however, was a gruff physician who announced that the loss was imminent and then left the room. Nurses prepped her for a medical procedure to remove the materials from her womb and wheeled her away. Before she knew it, the pregnancy she pined for was over.

Furious about the lack of information she was given about the potential for pregnancy loss, Layne began to ask questions.

Why had women worked so hard to reclaim control of their pregnancies—fighting for their rights to decide where they could give birth, who could be with them, and for adequate information about the process—but such advances had not occurred regarding pregnancy loss?

In the 64-page booklet her clinic gave to all patients during their first prenatal visit, why was miscarriage not discussed until page 49, and then why were only four lines devoted to the topic?

Why had Layne’s midwives informed her of their protocol in case of emergency cesarean section, but not discussed what would happen in the case of miscarriage during the first three months of pregnancy when pregnancy loss occurs in one in five women?

Why is the comfort and quality of the birth

experience given a great deal of attention, but no such concern is offered to women who miscarry?

Why don’t we expect family members to grieve for the loss of a wished-for pregnancy, the way we grieve for so many other losses in our lives?

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Trying to answer these questions, Layne realized that anthropology could help shed light on the factors that made the devastating experience of pregnancy loss even worse. She joined a local support group and began investigating the experience of loss among the group’s members using an anthropological research method known as participant observation. Using the technique, researchers immerse themselves in the subject being studied to gain deeper understanding. Dealing with her own losses, Layne studied the topic as both an observer and a participant.

SHATTERING THE SILENCE

For nearly 15 years Layne gathered information and tried to determine the causes of society’s silence surrounding pregnancy loss. She found that middle-class American women who suffered miscarriages in the late 20th century dealt with two contradictory forces. Factors like new reproductive technologies, smaller family sizes, and abortion politics, for example, led many to think of the fetus as a “baby” much earlier in a pregnancy than had previously been the case.

Layne presented her findings in the book *Motherhood Lost: A Feminist Account of Pregnancy Loss in America* (Routledge, 2003). The book was immediately endorsed by UNITE and SHARE, two prominent pregnancy loss support groups in the United States. Finally giving voice to a subject shrouded in silence for so long, Layne became an expert in the emerging field of research and was asked to discuss her findings with *The New York Times*, *Boston Globe*, *Newsday*, *Chicago Tribune*, and

other major media outlets.

In the book Layne explored the fact that pregnancy losses in this country are rarely acknowledged or discussed. “Grief for a dead loved one may be both inevitable and necessary, but the additional hurt that bereaved parents feel when their losses are dismissed and diminished by others is needless and cruel,” she says. “It is high time we recognize pregnancy loss and offer our support.”

In the final chapter, “Breaking the Silence: A Feminist Agenda for Pregnancy Loss,” Layne called for four changes that she believed would create a “woman-centered approach” to pregnancy loss: increased information about pregnancy loss, the right to choose how to handle an imminent loss, the option of a caregiver to assist with a loss, and increased social support from the medical community and society. She based her proposals on several principles of the women’s health movement of the 1970s, which empowered women to take charge of all aspects of the birth experience.

“First-person accounts indicate that middle-class American women feel supremely unprepared for pregnancy loss,” says Layne. “First and foremost, women must be informed—knowledge is power. I’d like to see information about pregnancy loss provided to women by their doctors at the earliest possible time, since most losses occur in the early weeks of pregnancy. Many women receive care even before they conceive when they are contemplating starting a family—that would be the correct time to approach the subject.”

Pregnancy loss discussed face to face, supplemented with printed information that women could keep in their homes and refer to in the event that they experience a home loss similar to her own, is the key to allowing women to take control of their situation, says Layne. She also found in her research that many healthcare providers are hesitant to inform women of the risk of pregnancy loss because they fear scaring them, and because it’s an unpleasant topic to discuss during what’s likely to be a happy time in a woman’s life.

“There’s no excuse for not educating a woman—pregnant or not—about the possibility and probability of miscarriage,” says



Layne. “As a society we need to stop being paternalistic and sheltering people from unhappy things. There used to be a time when we didn’t tell cancer patients that they had cancer or that they could die, because it was difficult for us to say, and for them to hear. We don’t do that anymore—it’s considered demeaning to withhold information from the person to whom it directly relates.”

Advances in the management of pregnancies have led to increased early diagnoses of miscarriages. Layne argues that doctors should use this added time to explain to women their care options, allowing them to select a setting that will work best for them. Unlike births—all but 1 percent of which take place in hospitals in the United States—pregnancy losses occur in a wide variety of settings: hospitals, homes, obstetricians’ offices, and clinics.

“Women need to be instructed in the pros and cons of each of these venues so that they may choose the location that best suits them, and so that they will know what to expect during and after a loss in that setting,” says Layne.

She also believes that women who choose to have a surgical procedure should be treated with the same dignity as a woman giving birth. Although women who give birth in medical venues do so in a comfortable room often decorated like a bedroom at home, such courtesies are not extended to women who are miscarrying.

“Women who miscarry are essentially viewed no differently than patients who are having routine surgery,” says Layne. “They receive the necessary medical attention and they are sent on their way, without any concern for their emotional state.”

Home miscarriages are becoming increasingly common with efforts to manage health care costs, and in many ways they can be more traumatic than a medically managed loss, according to Layne. She notes that women who miscarry naturally typically do so alone or with an equally unprepared partner—something that would never happen during a full-term birth.

“The option of a caregiver should be extended to all women who are experiencing a pregnancy loss,” Layne says. She also recommends making available pregnancy loss kits, which could include disposable bed pads, sanitary napkins, pain medication, and instructions.

“Although there are elements of distress over the loss of a wished-for baby that no one can relieve, the presence of a trained caregiver, who



Social support is crucial for women who have experienced loss. Women who miscarry are often caught in “a private space of shame,” left alone to grieve because family and friends can’t comprehend their pain. “The cultural silence is profoundly real,” says Layne.

knows what to expect, who is familiar with what’s taking place physically, and who can reassure a woman during the process, would greatly reduce the fear that accompanies handling this experience in isolation,” says Layne.

Social support also is crucial for women who have experienced loss, says Layne, stressing that women who miscarry are often caught in “a private space of shame,” as she calls it in her book—left to grieve alone because family and friends can’t comprehend their pain.

“The cultural silence is profoundly real,” says Layne. “Many times the remains of a miscarriage are disposed of, and everyone acts as though nothing has happened. The taboo around pregnancy loss in this country stifles a woman’s ability to grieve and to heal.” Layne contends one way to end the silence is by

broaching the subject in popular culture, with more frequent, honest, and detailed depictions of loss on television and in books and magazines.

While Layne was working in Jordan in the 1980s, a pregnant co-worker miscarried. Days later she invited Layne and some other friends over for a ritual meal. Each of the guests brought the grieving woman a gift, acknowledging that she had the loss and more importantly, that she had their support.

“Support rituals that focus on the woman and not on the lost child can help reduce the trauma felt by the would-be mother,” says Layne.

NATIONAL ADVOCACY

Today, nearly two decades into her research,

Real life in the Classroom

Layne's focus has shifted. Not content with simply bringing the subject of pregnancy loss to light, she has become an active advocate for the reforms she detailed in her book.

"The same issues I discussed in my book—the lack of information, the lack of support for grieving women—are still issues women are facing every day," she says. "And I realized that if I really wanted to see changes take place I couldn't just sit around and wait for someone else to pick up where I left off."

Layne has spent the last several years speaking out on the need for pregnancy loss health-care policy reform and lecturing at universities, hospitals, and conferences across the country on society's shortcomings when it comes to educating, caring for, and supporting women who have suffered losses.

Layne delivered one of those lectures at the University of Virginia's medical school. One of the multiple replays of the talk on a regional television network was caught by Susan Kehoe, general manager and executive producer of George Mason University's television station. Kehoe was so impressed she immediately contacted Layne and offered to tape and produce a series of television programs about the topic of pregnancy loss.

"When I suffered my loss, my doctor told me that I wasn't alone, and that a number of my friends, family, and acquaintances had [probably] been through similar experiences but hadn't talked about it. That stuck with me," says Kehoe. "When I saw Linda's talk on television I felt compelled to thank her for voicing the thoughts and concerns of so many women who've suffered miscarriages, and for giving others the freedom to share their experiences. I am pleased to have the opportunity to help her spread her message and to promote understanding and healing."

Layne came up with a list of artists, midwives, novelists, doctors, nurses, lawyers, religious leaders, product designers, environmental activists, and advocates who all, in their own way, were using their expertise to encourage pregnancy loss reform.

From that list evolved a television program called *Motherhood Lost: Conversations*. The first episode, which premiered last year, already has received acclaim from the television and film community, garnering Layne a prestigious Gracie Award for "outstanding talk show," a Silver Davey award, and a 2006 Bronze Telly Award.

Layne has committed to taping 10 episodes

of the show, which will run on the George Mason University station and other educational channels. Each episode is officially premiered at a conference or event at which Layne is speaking. In October, which is nationally recognized as Pregnancy Loss Awareness month, the third episode was premiered at the National Perinatal Bereavement Conference in Chicago.

Layne has even bigger plans for the programs.

"I'd like to see the shows become educational resources on television, and available in public libraries, as well as medical school and nursing school libraries. And because I'm a university professor, I can envision their use in college classrooms and as resources for continuing education programs." [See sidebar.]

Lynn Paltrow, executive director of the National Advocates for Pregnant Women—a New York-based organization committed to protecting and advancing women's reproductive rights by connecting local activism with national advocacy and policy work—praises Layne's work, calling her "a great ally."

"In the highly politicized world of reproductive health, the pain felt by so many women who've experienced a loss is too often ignored," says Paltrow. "Linda's work reminds us of the support and services that so many pregnant women are denied, and points toward significant ways that pregnancy and pregnancy loss healthcare can be improved and humanized."

Layne sees indicators that society is moving toward a positive change in a variety of places, from the recently formed Pregnancy Loss and Infant Death Alliance support group issuing policy statements, to the allocation of \$3 million by the National Institutes of Health (NIH) for research surrounding the causes of stillbirths, to the designation of October as Pregnancy Loss Awareness Month.

"There's a national movement finally happening," she says. "We're moving toward a new stage and becoming more proactive."

Once a lone voice speaking out on what she found was a cultural taboo surrounding pregnancy loss, Layne today is finding more allies and greater hope for her efforts to bring about understanding and policy reform.

"Twenty years ago I was one of the first to advocate for pregnancy loss awareness and policy reform," she says. "Now there are lots of people out there advocating, and I hope more will join me in this endeavor. Together, we can—and will—make things better."

LAYNE IS BRINGING HER RESEARCH ON pregnancy loss to Rensselaer students by developing curricula in conjunction with several episodes of her television program and working with colleagues to pilot them in classes this year.

Steve Breyman, associate professor of science and technology studies (STS), plans to pilot the episode "Linking Environmental Protection and Pregnancy Loss Prevention: A Conversation with Lois Gibbs, Executive Director of the Center for Health, Environment, and Justice," in his *Environment and Society* class.

Breyman praises Layne for putting pregnancy loss on the agendas of both the women's movement and the environmental health movement, calling her work "truly inspiring."

Layne is working with STS colleague Nancy Campbell to design a mock trial as the companion curriculum for the episode "Combating the Criminalization of Stillbirth and Miscarriage: A Conversation with Lynn Paltrow, Esq., Executive Director of National Advocates for Pregnant Women." Four lawyers from the Capital Region have volunteered to come to campus and participate in the trial.

"Linda's work is just the kind of publicly engaged scholarship that students benefit from seeing enacted. The mock trial will literally re-enact some of the hardest-held and most difficult positions involved in debates over reproductive rights," says Campbell. "For students to come to terms with these requires deep thinking and knowledge of the politics of pregnancy, which involve the translation of deeply held values into public policy."

Layne and Lois Peters, associate professor in the Lally School of Management and Technology, have recently decided to develop a companion curriculum for the episode "Preparing for Home Pregnancy Loss: A Conversation with Sandy Maclean of WomenCare." The program will be shown as part of Peters' entrepreneurship course this spring.