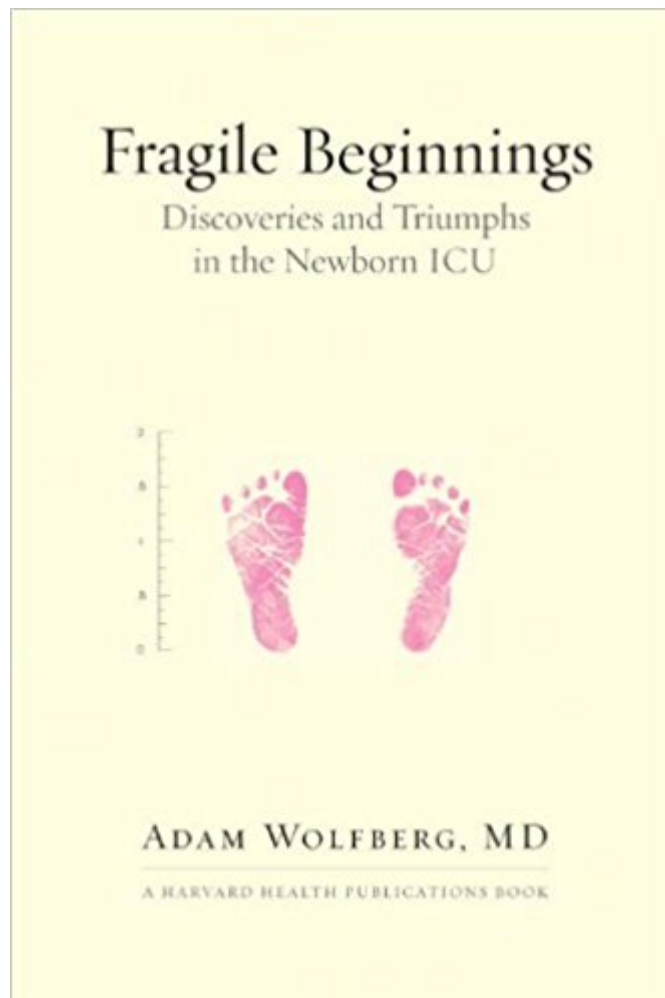




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Fragile Beginnings: Discoveries And Triumphs In The Newborn ICU (Harvard Health Publications)



Synopsis

Half a million babies are born prematurely in the United States every year. In this gripping medical narrative, Dr. Adam Wolfberg brings readers into the complex world of newborn intensive care, where brilliant but imperfect doctors do all they can to coax life into their tiny, injured patients. As a specialist in high-risk obstetrics and the father of a child born prematurely, Wolfberg explores the profound questions raised by such fragile beginnings, both from the front lines of the NICU and from his daughter's bedside. His daughter Larissa was born weighing under two pounds, and he describes the precipitous birth at six months that left her tenuously hanging on to life in an incubator. Ultrasound had diagnosed a devastating hemorrhage in her brain that doctors reasoned would give her only a 50 percent chance of having a normal IQ. Through Larissa's early hospital course, Wolfberg examines the limitations of newborn intensive care medicine, the science of "neuroplasticity," and the dilemmas that surround decision making at the beginning of life. Wolfberg also takes us into the lab where researchers are working to improve the futures of children born too soon. He follows a young scientist, Jason Carmel, who was inspired to study how the brain adapts to injury when his twin brother was paralyzed in an accident. Through lucid medical reporting, Wolfberg details current scientific practices and discoveries, and explores the profound emotional and ethical issues raised by the advancing technology that allows us to save the lives of increasingly undeveloped preemies. As they make decisions about life-saving care in the first hours of a premature infant's life, doctors and parents must grapple with profound moral and medical questions: How aggressively should doctors try to save the life of a premature baby, who will be severely neurologically and physically impaired? What might that child's quality of life be like after millions of dollars are spent on her care? Wolfberg traces the fits and starts of the physicians, government policy makers, and lawyers who have struggled over the years to find the best way to make these wrenching decisions. Written from Adam Wolfberg's unique experience as a reporter, as a medical specialist and researcher, and as the father of a prematurely born daughter, *Fragile Beginnings* lays bare the struggles, discoveries, and triumphs of the newborn intensive care unit.

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Customer Reviews

"A page-turner for any parent of a premature infant." — Boston Globe — "Midway through Dr. Adam Wolfberg's internship, his daughter is born severely premature. Suddenly he finds himself on the other side of the medical curtain, navigating the terrifying maze of life-threatening illness. From his unique vantage point as physician and parent, Wolfberg brings us inside neonatology and intensive care units, on a journey that is both heart-wrenching and eye-opening. Honest, perceptive, engaging." — Danielle Ofri, MD, PhD, author of *Medicine in Translation* and *Singular Intimacies* [An] honest, heart-wrenching yet hopeful account. — Isis Parenting — "Writing with a physician's acuity and a father's compassion, Adam Wolfberg presents a clear-eyed view of the challenges facing premature infants and their families, as well as the harrowing world of newborn intensive care. His honesty will be welcomed by anyone who has navigated this treacherous course." — Elizabeth Mehren, Professor of Journalism, Boston University, and author of *Born Too Soon* — "Adam Wolfberg is uniquely qualified to write this powerful, illuminating, and much-needed book. By blending the fears and hopes of his personal story with the knowledge and insight of his professional experience, he takes readers through every aspect of the newborn intensive care unit. Truth, unsweetened by sentimentality, informs every page. I learned far more than I imagined there was to learn while being so caught up in his daughter's journey that I couldn't put the book down." — Rachel Simon, author of *The Story of a Beautiful Girl*

Adam Wolfberg, MD, MPH, is a specialist in high-risk obstetrics at Tufts Medical Center and an assistant professor at Tufts University School of Medicine. He was formerly a research fellow and

faculty member in the Department of Neurology at Harvard Medical School. His research into fetal brain injury is supported by grants from the National Institutes of Health and private foundations. Wolfberg has been a contributor to Newsweek, the Chicago Tribune, Slate, WSJOnline, and the Boston Globe Sunday Magazine. He is a physician spokesperson for the March of Dimes.

I had high hopes for this book, being written by an obstetrician who also had a daughter born at 26 weeks. Being a NICU parent, I hoped for something that would balance the NICU experience from a parent's perspective with medical knowledge. Unfortunately, Adam Wolfberg seems to write more from the perspective of a doctor than a parent. That's fine, really, just not the book I was looking for. Here is what you can expect from this book:1) If you have a micropreemie born before 26 weeks, you may not like this book, especially at the beginning. In stressing the fragility of his 26 week-old's life, he writes off babies born before that. That was not something that I, as the parent of a barely 23 week baby, wanted to hear. You also have to keep in mind, though, that his story started nearly a decade ago possibly? Which is forever in the world of neonatology, and a lot has improved even since then.2) The book skips around a lot confusingly. One minute you're reading about Wolfberg's experience, then we're reading the life story of the head of the NICU. Oh, now we're reading about some random guys doing research on rats. I'd like to say he pulls it all together, but while it does become a little more apparent why these things are relevant, they never really come together in a meaningful way. It's like watching a disjointed film looking at very loosely connected people living different lives.3)It's very technical at times - possibly beyond the capability of many NICU parents, especially during the stressful time actually spent in the NICU.4) As his daughter had a Grade 4 IVH (intraventricular hemorrhage of the brain), Wolfberg focuses on IVH, brain development research, and neuroplasticity. I found it extremely interesting, but not at all relevant to our particular case, as our daughter had no significant IVH.5) Related to #2 and #3 is the fact that this book is not really very cheerful. Although his daughter does survive and does remarkably well, and although her parents are models of being active in the continuing care of a child with disabilities, I wouldn't say that it's a happy story meant to encourage parents of micropreemies. If you're looking for encouraging stories of perseverance with happy endings (although technically, this book is that), you may want to steer clear. If you want something more realistic about the challenges you'll face, this may be for you (even though, as I mentioned, Wolfberg spends little time actually discussing their particular experiences).6) Not sure if this should be separate from #4 or not. There were a lot of really quite disturbing parts of this book. Lots of animal testing - I never really thought I was that sensitive to animal testing, recognizing it as an important and necessary evil, but there were times I

had to put the book away when reading about some of the tests done on rats and kittens during neurological research. I also found it disturbing to read about the conditions in their NICU, which was supposed to have been modern and cutting edge. They seem to have allowed things that would have made me very upset as a parent, things that never would have been allowed in our NICU. There was also at least one anecdote about a woman who chose a very late-term abortion that upset me a lot at that time, given that her baby was already a few weeks older than mine was when she was born. Just to warn you about some of these things, in case you are sensitive to these things, as I was, especially in the first few weeks my daughter spent in the NICU. Overall, I'd say this book is for you if you are interested in brain development, neural research, neuroplasticity, or IVH. I found it very interesting and informative on those subjects. This book is not for you if you're looking for a feel-good depiction of life in the NICU with a happy ending (although it does have a happy ending).

Adam Wolfberg was an OB-GYN intern at Harvard's Brigham and Women's Hospital when his wife, Kelly, was pregnant with their third child, a girl who would be named Larissa. Her previous two pregnancies were uneventful, and all indicators pointed to another straightforward one. However, Kelly suddenly developed contractions when Larissa reached 26 weeks of gestation, 14 weeks before her due date. Despite the Wolfbergs' proximity to one of the leading obstetric and neonatal centers in the world, Kelly's labor could not be reversed, and Larissa was born after a very traumatic and stressful delivery. She was stabilized in the delivery room, placed on a mechanical ventilator due to her inability to breathe on her own, and whisked away to the NICU (or neonatal ICU; a neonate is a baby 0-28 days of age) at Brigham and Women's. Her birth weight was 1 lb 15 oz, making her tiny enough to fit into the palm of her father's hand. From his training, Adam knew that a baby as premature as Larissa faced serious complications, including cerebral palsy; epilepsy; severe developmental delay that could prevent her from being able to walk, talk, eat by mouth or function independently; and death. One of his greatest fears was realized within days of Larissa's birth, when she developed a severe intracranial hemorrhage, or brain bleed, within the first week of life, due to the trauma of her labor. This injury is always associated with some degree of impairment; however, the extent of the damage is often not known for a year or more, once the baby begins to sit, crawl, walk and perform routine activities of daily living. Thus, the neonatologists and neurologists caring for Larissa could not give the Wolfbergs a definite answer on her future prognosis, leaving them with the difficult decision to withdraw care, or to continue to do everything possible for her. In "Fragile Beginnings", Dr. Wolfberg discusses his daughter's early years and how

her premature birth has affected her and his family, while discussing the history, politics and ethics of the care of severely (less than 32 weeks of gestation) and extremely (less than 28 weeks) premature infants born in the United States. Normal gestational age is 37-42 weeks, dating from the first day of the last menstrual period. These babies normally don't have any complications during or after birth. Babies born at 32-36 weeks of gestation generally do well, although a small percentage have minor complications, particularly infant respiratory distress syndrome or chronic lung disease, due to the immaturity of the lungs and the relative lack of surfactant, a substance that keeps the alveoli (air sacs) in the deepest parts of the lungs from collapsing. Many of you will remember that John F. and Jacqueline Kennedy's last child, Patrick Bouvier Kennedy, born 5½ weeks premature (or 34½ weeks of gestation), died on his second day of life in 1963 due to hyaline membrane disease, the old name for respiratory distress syndrome, due to a lack of surfactant in his lungs. In 2012, the mother of a baby born at this age would receive a corticosteroid injection to increase the production of surfactant in her baby's lungs, and he would likely survive his premature birth with few if any complications. The author discusses the discovery of surfactant, along with the major developments that have allowed thousands of babies similar to and much worse off than Patrick survive and have meaningful and healthy lives. Needless to say, the more premature a neonate is at the time of birth, the greater is the chance of significant morbidity or mortality. However, as mentioned above, it is impossible to determine which extremely premature infants will do relatively well, and which will suffer severe complications. Doctors generally consider 22-23 weeks of gestational age or those who weigh 400 grams to be the limits of viability, and those who are less than this age or weight are normally delivered and handed to the mother by the pediatrician to die naturally in her arms. The obstetrician, pediatrician and parents can find themselves in an extremely difficult position in the case of infants who are at these limits, as they must decide which infant should live and which should be allowed to die. In most cases the doctors follow the wishes of the parents, once they are provided with information about the medical possibilities and probabilities for their child. However, there are times in which the parents and medical staff do not agree with each other; some families wish to do everything possible for a babies that the doctors believe are nonviable, and other families wish to withdraw or withhold care for babies that the doctors expect will have a relatively good outcome. Dr. Wolfberg discusses several famous cases and subsequent government laws passed in the 1980s and 1990s that have affected how obstetricians and neonatologists manage the extremely premature infant on the edge of viability. Finally but most significantly, Dr. Wolfberg discusses new developments in the field of neuroplasticity, in which the central nervous system makes new connections in order to overcome

injury. The highly educated and motivated--and financially stable--Wolfbergs were able to travel to get the best and most advanced therapies for Larissa, and work with her for several hours every day to maximize her physical and intellectual development."Fragile Beginnings" is a superb book about severely and extremely premature infants, their care, and the challenges they, their families, and their caregivers face. The author's own experience as a father of an extremely premature infant and as an obstetrician who provides care to mothers of high risk pregnancies greatly enhances and humanizes this important topic. Although designed for the lay reader, there is a good amount of medicine and neuroanatomy that may challenge the average reader without a strong science background at certain points in the book. However, I would still highly recommend this book to all readers, as the story of Larissa and her family is both riveting and highly inspirational.

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