I Carry You in My Heart:
Facing an Incurable Prenatal Diagnosis

by

Emma Sconyers

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Signature of Author: Signature redacted
Graduate Program in Science Writing
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Certified by: Signature redacted
Corby Kummer
Thesis Advisor

Accepted by: Signature redacted
Tom Levenson
Professor of Science Writing
Director, Graduate Program in Science Writing

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ABSTRACT

Prenatal diagnosis has given doctors the ability to predict problems before a child is even born. But what happens when the information gleaned from these tests is that the child is fatally sick? Doctors call these "futile" pregnancies. The increasing sophistication and prevalence of prenatal diagnostic tests means that prospective parents and their doctors are grappling with ethical questions unheard of just half a century ago. Legislators try to demarcate what choices are "good" and "bad". However, there is no good choice when it comes to a fatally ill infant. While archival research is used to frame modern perspectives, this thesis aims to explore the different choices women make and the difficulties they must grapple with in this day and age.

Thesis Supervisor: Corby Kummer

This was written for the women who face the most
difficult decision of their lives.

Thank you for telling me your stories.

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By Emma Sconyers

Janet steps onto the elevator, her hand resting on her stomach. A doctor standing in the back corner offhandedly says, "Watch out for that pregnant belly!" Janet's stomach turns. She's just come from a procedure to insert laminaria strips, thin rectangles of seaweed used to soften the cervix. This is not a happy moment. She's not thinking about whether or not she'll be buying blue onesies or pink ones, she's not thinking of the nursery's theme or even about a name. Janet is thinking about the papers she'll soon have to sign, the ones authorizing the death of her baby.

She changes into a hospital gown, fighting the tears wedged in the back of her throat like a fist. Her husband is right at her side. And in her hand she grasps an E. E. Cummings poem, carefully copied—sweaty and crumpled, like a high school note written with heartache.

> i carry your heart with me(i carry it in
> my heart)i am never without it(anywhere
> i go you go,my dear;and whatever is done
> by only me is your doing,my darling)

The words are for her child, the one with fluid under its skin, in and around the collapsed lungs; the one with kidney malformation, and under-developed heart ventricles. The words are for the child she desperately wanted but couldn't bear to bring into this world; a decision that didn't even feel like a decision.

When Janet sets the poem on the side table to heave her heavy, awkward body up onto the exam chair the nurse unknowingly tosses the poem in the trash. Janet's sad, pale, loving husband rummages through the red bin to find it, ignoring the "biohazardous waste" symbol. When the doctor finally arrives Janet hands her the pathetic scrap of rescued paper. "Can you put this with her?" she asks and the doctor obliges. Janet says goodbye to her husband and walks down the hall alone. She lies on the operating table, her entire body shaking with grief. It's only once the anesthesiologist says, "Here comes a big glass of wine," that Janet's mind quiets, numbly fading into the blackness.

Not all abortions are unwanted pregnancies. Sometimes they are the tragic conclusion to the answers provided by prenatal testing. Since the 1950's doctors have been able to look at a baby before it is brought into the world. With advancing technology, we're getting a clearer and clearer image of the baby before it is even born, right down to its DNA. For most, the only meaningful thing gleaned from the tests is the gender of the baby. But sometimes doctors present mothers with quite a different picture. Commonly, the ultrasound tech will go quiet and exit the room, leaving a very worried woman with cold gel all over her abdomen to wonder what is going on. When the doctor finally returns and utters the fateful words "something's not quite right," any hope for normality flies out the window. All that remains are questions:

What does that medical jargon mean? What is the doctor's opinion? Can you get a second opinion? Will there be complications during delivery? What is the life expectancy? Will you have to watch your baby die? What if by some miracle the child survives past infancy? What then? How will you care for this child? This *adult*? How is this going to affect your spouse, your family, your life? What if the child is going to suffer? What if you don't want to bring a child into the world without a chance at meaningful life? If you want to terminate, can you do it in a hospital or do you have to go to a clinic? Is abortion legal in the state you are in? Will you have to travel? Is this covered by your insurance?

It used to be that women and their partners didn't have to confront any of these questions. Those choices were left until that little life came sliding out into the world. The increasing sophistication and prevalence of prenatal diagnostic tests means that prospective parents and their doctors are grappling with ethical questions unheard of just half a century ago. Legislators try to draw lines in the dirt and bioethicists argue until they are out of breath. But what it comes down to is this: a mother's decision based on a doctor's assumption. A premonition about a life unlived. It is a question about a mother's love for their child, even if that means letting go.

"Futile" abnormalities are characterized as medical conditions where the child has no hope for survival. The prognosis is death. The causes are vast and varied: chromosomal mistakes, genetic glitches, environmental toxins, a faulty step in the body's intricate assembly into a fetus. Doctors have assigned hundreds of names to all the specific syndromes, but the end results start to sound sadly similar—malformed or missing body parts, severe mental retardation, organ failure, trouble breathing, trouble eating. Many fetuses simply don't survive a full term pregnancy and are stillborn.

Hundreds of years ago, doctors took this as an act of providence. It was a sign that these children were not meant to exist among the living. In a 1660's medical text Francois Mariceau, a French obstetrician, explained the miscarriage of an abnormal fetus, "[W]hen they are Monstrous, because they do not then follow the rule of Nature…they oblige the womb to expel them, not being able to endure the pains they cause."[i]

If children like this were born alive, prior to advanced technologies like tracheotomies, heart transplants, and feeding tubes, they were regarded not just as a lost cause but as something evil. Something to be feared. They were not even considered humans. Thus infanticide, otherwise punishable, was often deemed moral and even necessary. Religious leader Martin Luther, founder of Lutheranism in the 16th century, endorsed the practice of killing "monsters."

Even as intellectuals moved toward the age of Enlightenment, in the 17th and 18th centuries, the idea that disabled infants were corrupt persisted. Physicians and moral leaders claimed disabled infants were physical products of their parents' sins. Dr. Samuel Gridley Howe, one of the first advocates of state-funded insane asylums in Massachusetts in the early 19th century, explained in a medical paper the accepted cause of mental retardation and disability:

> *The moral to be drawn from the prevalent existence of idiocy in society is, that a very large class of persons ignore the conditions upon which alone health and reason are given to men, and thus they sin in various ways...and thus bring down the awful consequences of their own ignorance and sin upon the heads of their unoffending children.*[ii]

During the same period, some physicians advocated simply watching these infants die. Dr. Charles T. Hildreth published a case in 1834 of a "monstrosity" born without a spinal cord and with extensive brain damage. The child had two membranes over his face that prevented breathing. Dr. Hildreth decided not to intervene, and let the child suffocate rather than remove the membranes. The baby's inability to take its first breath without assistance allowed Hildreth to deem it a stillbirth, leaving the case unblemished as an infanticide.[iii] Difficult cases that toed the line of morality were discussed with hushed reverence by physicians. Then one doctor decided to step out into the open.

Depending on your view, he could be a savage or a saint. Although his controversial practices caused a public outcry in periodicals across the country, he also received support from intellectuals, religious figures, doctors, and mothers. Even Helen Keller, an outspoken disabilities advocate far ahead of her time, faithfully defended his methods. His name was Dr. Harry Haiselden; a man who believed and zealously promoted that disabled infants should be euthanized.

It started out with private cases. Parents from his Chicago practice who bore infants with multiple physical abnormalities were urged to let them die. Deaf and blind, hydrocephalic, blocked intestines, paralyzed, missing limbs—these were not fixable problems but severe, lifelong impairments. Within a few years the cases started entering the press and eventually he was dragged into court to account for his actions. In 1915 Haiselden delivered an infant boy with a malformed intestinal tract, fused kidneys, paralysis on his right side, one testicle, no neck, absence of a right ear and

"I can see no difference in permitting the infant's death and killing a person in any other way."

malformation of the other, blindness, and little to no reflexive response. An operation to fix his blocked intestines would have allowed him to live, but Haiselden insisted it would not be a life worth living. Without any intervention he watched the Bollinger baby die. Newspapers in every corner of the United States grabbed hold of the Baby Bollinger case and soon Dr. Haiselden's methods were publicized in black and white across the country.

The Watertown Re-Union, a New York newspaper, reported after the conclusion of the trial, "Dr. Haiselden's decree of death for Baby Bollinger created comment all over the civilized world. The Illinois Board of Health and Illinois Medical Society were asked to revoke the doctor's license to practice and the humanitarians and the moralists engaged in a battle which was waged for months."[iv]

Dr. George Lipschulch, a Chicago member of the Illinois state legislature, sought charges of manslaughter in addition to revoking Haiselden's license. Lipschulch told reporters before the trial, "I intend to go the limit in whatever can be done in this matter. I can see no difference in permitting the infant's death and killing a person in any other way."[v]

The opposition called Dr. Haiselden a murderer—yet parents of handicapped children wrote from all over the country asking Haiselden to help in any way he could that would allow their disabled children to die. Mrs. Bollinger herself said, "Now that the time has come and the baby has gone to rest forever, I feel I have done the greatest thing a mother could have done. Have I not allowed it to be taken from me so that it might not suffer?"[vi] Eventually, Haiselden was acquitted of all charges.

Following the press produced by the Bollinger case, Haiselden appeared on newsreels, wrote articles and gave public lectures. He started to argue that severely disabled infants should be given morphine or have their umbilical cords untied for a quicker, more humane death. He even produced a widely distributed motion picture called *The Black Stork* dramatizing the Bollinger case which circulated in movie theaters from 1916 till as late as 1942. He became the public face for euthanizing the disabled.

He was revered; he was reviled. Like most things it's problematic to label Dr. Haiselden's ideas as black or white, good or bad. His opinions were an amalgamation of popular medical practice, social theories, advancing technology and his own experiences—and the new science of eugenics, which he embraced. It was a moment in history that obsessed over exemplar bodies and minds. Most are familiar with Hitler's obsession with a "master race." It is less known that America influenced Hitler with our rigorous investigations on improving genetic quality of the population. "Eugenics" was a scientific subset of biology that was studied as one would now research neuroscience or immunology. Sexual depravity, morality, intelligence, idiocy, physical fitness, and disease were all traits scientists assumed could be genetically inherited like green eyes or curly hair.

As a doctor, Haiselden he thought he could stop the suffering of society. Disability was not what it is today. It was either a death sentence or a miserable existence of social isolation and distress. Haiselden had been deeply disturbed after reading the muckraking exposé of a psychiatric institution. So much so that he investigated for himself. Using the alias Henry Jones, Haiselden spent two days observing the patients at the Illinois State Institute for the Feebleminded. He went on to publish his own account in the *Chicago Herald* in 1915. The experience affected him profoundly, and he often cited his two days at the institute as a reason why he chose to let disabled children die.

Disability of any kind was obviously a very troubling thing for eugenicists to grapple with. What if the disabled grew up and had children of their own? Would eugenicists be allowing the nation to slowly turn into a population of "defective" citizens? In their mind, they were doing a public service by encouraging women not to let disabled children live longer than they otherwise would, and discouraging the disabled from having children themselves. It should be said, though, that not all eugenics is inherently evil or even archaic. Nowadays there is a question of individuals with fatal genetic diseases like Huntington's. If a mother or father with Huntington's chooses not to have children, so as not to pass on the defective gene, they are participating in eugenic philosophy. Those that decide to genetically screen embryos for abnormalities prior to in-vitro fertilization are also engaging in a more technologically advanced form of eugenics.

There was also the matter that Haiselden's practices weren't entirely unique. These issues went largely unspoken of by the public, but remained a closed, resigned practice for doctors unlucky enough to encounter "defective" babies. The only difference, really, was that Haiselden publicized his opinions and allowed a standard medical practice to be scrutinized by anyone who picked up a newspaper.

It is also inaccurate to assume he was uncaring or cold towards the children. An *Associated Press* article on the Bollinger case describes Dr. Haiselden as the only person in the room who would touch or look at the child. He stroked the child's head and pat his cheeks as he died.[vii] He himself was a father. He had adopted a little girl from a New York orphanage and later took in an infant abandoned at his hospital.

It is too easy to simply write off Haiselden as a monster. Both doctors and mothers supported his philosophies and medical practices; the controversy lay in the exposure of hazy, ethical choices conducted up until that point behind closed doors. Haiselden personifies a strongly debated question: should doctors and mothers try to predict a life unlived? Are their opinions about an unknown future enough to support the death of a disabled child? The facilitated death of a child after it has been born feels wrong. It has the uncomfortable undertones of neglect, even murder. So what if researchers came up with a way to find abnormalities before they presented themselves in a living, breathing baby? Would aborting an abnormal fetus negate the ethical dilemmas of killing an abnormal baby?

Diagnosing infants inside their mother's bellies has been around since the 1950's; but it has really been widely available only since the 1970's. The most favored test, because of its accuracy, is known as an amniocentesis. A doctor inserts a needle into the amniotic sac to collect a small amount of fluid. The doctor is mostly sucking up water and electrolytes but also bits of proteins, fats, and other chemicals the baby uses for development, along with a slurry of sloughed off cells from the fetus. These cells contain the fetus's DNA.

In 1960, a boy in Copenhagen was the first fetus to be aborted from information obtained through an amniocentesis. Researchers had finally figured out an accurate way to test a fetus's gender from a DNA sample. The boy's parents, a carrier and a sufferer from the sex-linked disease hemophilia, weighed the risks and felt they were too high (for hemophiliacs are almost exclusively male). Within a few years, doctors were able to test for other chromosomal abnormalities like Down's syndrome and Edward's syndrome, as well as neural tube defects like anencephaly and spina bifida.[viii]

Most women were offered amniocentesis only if they had a history of a disorder in the family. That all changed in 1978 when Dolores Becker, 37, gave birth to a child with Down's syndrome. It was a known fact that women over 35 had much higher risks for genetic abnormalities; but despite her age she hadn't been offered amniocentesis. She felt she could have prevented the pregnancy had she known ahead of time.[ix][x] When she sued her doctor for negligence, and won, Becker inadvertently created an immense population in need of amniocentesis. Amniocentesis became, and still is, the standard protocol for expectant mothers over 35.[xi]

A CVS, which stands for chorionic villus sampling, is different from an amniocentesis. Rather than go straight into the amniotic sac from the outside, a very thin tube is threaded through the vagina and the cervix to pluck a tiny piece of the placenta. It is done earlier than an amniocentesis, at 10-12 weeks rather than 15 weeks or later. Since the placenta emerges from the same cells as the developing fetus, it contains the same DNA. The procedure was developed around the same time as amniocentesis, gaining wide usage in the 1980's.

The most common prenatal diagnostic technique, the ultrasound machine, is nowhere near as invasive as an amniocentesis or a CVS, but it was developed over the same period, from the 1950's through the 1970's. Some may understand it only in a vague sense (there's cold gel and some sort of camera) but it is a highly advanced piece of equipment. The machine shoots sound waves, which are little more than vibrations, into the amniotic sac and the waves bounce back, revealing structures inside the mother's abdomen. It's the same way sonar on submarines can create an image of the sea floor by sending out a series of click and beeps.

Ultrasounds became widely available in the 1970's, when microprocessors were developed. When user-friendly, affordable PC's hit the market, so did user-friendly, affordable ultrasound machines. "Level II Ultrasounds" or "Targeted Ultrasounds" are newer breakthroughs that use 3D imaging. In 1993, the first 3D ultrasound image ever produced shows a baby with a cleft palate, a hand pressed up against its cheek. These hauntingly clear images drew attention to the usability of 3D scans.[xii]

Now doctors are using all these techniques, plus many more precursory tests, to gather as much information as they can before their patient's baby is born. When a woman is pregnant, she will have a first trimester screening to check her health. A blood test tells doctors whether she is anemic, if she has infectious diseases like syphilis, hepatitis or HIV, and whether she is a carrier for common but serious genetic problems like cystic fibrosis. Expectant mothers are offered genetic screening but it is not required like the infectious disease tests.

If there is cause for concern, doctors will give their patients a calculated risk factor before submitting them to an invasive test like an amniocentesis or a CVS. These statistical calculations take into account a measurement of the fetus's neck taken via ultrasound (called a nuchal translucency screening or an NT), the woman's age, and the amount of a certain type of protein found in her blood (called a PAPP-A test). These are mixed together mathematically, enabling the doctors to tell patients the chance that they are carrying a child with a chromosomal abnormality. Depending on whether a pregnant patient has a high or low risk, doctors will recommend the invasive but more accurate CVS or amniocentesis. An amniocentesis can correctly diagnose an abnormality 99.9% of the time.

New technologies have given doctors previously unimaginable ways of diagnosing a baby before it's even born, giving them a head start on pediatric or even in-utero treatment. But these tests often reveal problems that have no treatment, problems that are fatal. After that the mother has three choices. She can choose to abort the baby. Or, she can carry the baby to term and plan for "comfort care," a kind of infant hospice. Or lastly, she can ask that lifesaving measures be performed in the neonatal intensive care unit. Doctors counsel their patients about all the options, explaining all of the steps. There are often second opinions (or third or fourth or fifth opinions) with geneticists, other obstetricians or a subset of specialists like neurologists.

Dr. Christian Pettker is one of these doctors. He is young, about 40 years old, with curly blond hair and a penchant for bowties. He is very tall but not intimidating, and has an easy, casual air about him. It is easier to imagine him on a California beach with a surfboard rather than the sleek, glass and chrome filled lobby of Yale-New Haven Hospital where he is sitting in his white lab coat. He is an Obstetrician/Gynecologist but his specialty is high-risk pregnancies, called a Maternal Fetal Medicine Specialist or MFM for short. He is particularly careful with his words and makes sure his listener understands all the facts before moving on.

Dr. Pettker explains the difficulties in relying on the vague, cursory tests like the nuchal translucency screening. People look at risk factors very differently. “I can have three patients and I can tell them they each have a risk of 1 in 1000 for Down’s syndrome,” he says, “and one woman will say that’s a really low risk, I feel really good about it. Another woman will say that’s a really high risk, I don’t feel good about it. And then the third woman will just be plain confused and not know what to do.” Since CVS and amniocentesis have a small chance of causing miscarriage, doctors like Pettker hesitate to recommend either test to a woman who has a high risk factor. It’s more important to gauge what it would mean to each individual woman were she to have a severe diagnosis. If a woman planz to do nothing at all and have the baby as-is, then there seems little point in subjecting her to an invasive test. Some women would keep the baby regardless, but still want to know.

“We don’t always do the screening tests just so somebody can terminate pregnancy,” he says. “Helping a family know about what problem might exist or a risk that a certain problem might exist helps families deal with that issue before the birth so they don’t have to worry about those things after the baby is born.”

Dr. Ashley Zink, also a Maternal Fetal Medicine specialist, has similar views on patient consultation both before and after an amniocentesis or CVS. "When I start talking to them I just try to get a feel for sort of who they are and what they want and what their goals are," she says. Dr. Zink has a soft southern twang and a friendly cadence. She practices in Texas, thousands of miles from Dr. Pettker. People often cite the state as the most conservative when it comes to women's medical care. But Dr. Zink and Dr. Pettker are not that different when it comes to their opinions on care. Her straight, shoulder-length blond hair is neatly coiffed and falls just above her shoulders. She is the image of a perfect southern housewife, with a proclivity for pearls and pink, but the lady can rattle off complicated medical jargon without batting an eye. She is blunt in her explanations of prenatal testing, laying them out in a matter-of-fact way.

But her tone changes when she talks about her patients. She stops saying "fetus" and starts using the term "little one." Below her frank exterior lies a layer of intense empathy. She explains that when she confirms a severe abnormality, she is wary to bring up termination directly; not because she doesn't believe in it, but because she doesn't want to offend her patients. "That can be very hurtful to people who already see this as their child," she says. She assumes families are aware of that option and will bring it up themselves if they want to go in that direction.

This light-handed approach is sensible, but it's hard to ignore trends. An overwhelming number of women do decide to terminate once doctors have confirmed severe abnormalities. Ninety percent of women in the U.S. decide to abort after a prenatal diagnosis of anencephaly, a disorder in which the child is missing a significant portion of its brain. And ninety percent choose to abort after a diagnosis of Down's syndrome, the most common genetic abnormality. Down's syndrome is considered one of the most complicated diagnoses since there is such a spectrum of outcomes—there is simply no way to predict what kind of life the child will have.

Dr. Pettker says, "Down's syndrome isn't…it's a severe abnormality but it's not a lethal thing. Those kids have meaningful lives," he says. But he also understands that women can come from vastly different backgrounds. "If you have a family that has limited resources then that's a crazy thing to put on a family."

Stephen Latham is a bioethicist from Yale-New Haven hospital, the same hospital as Dr. Pettker. Latham has close cropped, graying hair and wears square glasses without frames. He tends to fiddle with paperclips and pens while he talks but rarely breaks eye contact. You wouldn't notice while he's speaking, but when he smiles you can see a small gap between his front teeth.

He explains how often Down's cases are debated among his colleagues on the topic of prenatal testing: "On the one hand kids with Down's can lead—I mean there's a range—but they can lead very fulfilling lives. And they can add fulfillment to the lives of their families," he says. "On the other hand, it's an intensely private decision about what parents feel they have the ability to handle."

In the early 1960's, Down's syndrome was essentially a death sentence. The lifespan was only 20-30 years and most individuals suffering from the disorder were placed in psychiatric institutions. But now with more knowledge, doctors are better able to treat children and adults with the syndrome and anticipate problems that may arise, like certain types of cancers or heart defects.

Dr. Zink is particularly uncomfortable with parents who choose to abort a fetus with Down's syndrome. "There's plenty of extremely happy children with Down's syndrome," she says. She speaks from experience volunteering for a Down's syndrome support group. "Maybe it's not what they have planned or expected but that baby brings a lot of joy to the family."

Prenatal testing has given doctors the ability to diagnose an infant before it's born; but doctors still can't tell parents what the child's life will be like, not fully. There is a spectrum of uncertain outcomes riddled with doubt. Yet whether it is a totally futile pregnancy, a non-lethal but severe abnormality like Down's, or something in between, more often than not a woman decides to terminate. If a woman opts for an abortion, she is not the odd one out. Whether it is for a child with Down's syndrome or something much worse.

When it comes to an abortion, it's not always as straightforward as deciding yes or no. State laws are shifting everyday. Women find themselves straddling the line of whether or not their abortion will be legal—even if their child has an incurable disorder. The anatomy scan, given at 20 weeks to determine the gender of the baby, is often the time when abnormalities come to light. It also happens to be the cutoff for legal abortions in much of the South and Midwest, and falls dangerously close to 24-week limitations in the rest of the United States.

The day before Dawn went to her 20-week appointment she was frantically cleaning the house. She found herself increasingly agitated and every other word out of her mouth was a snap at her husband. She didn't know why, but she felt like something wasn't right. The next day, still on edge, Dawn dropped her three-year-old daughter off at daycare before driving to the ultrasound appointment with her husband. She turned to him and said, "I think something is really wrong." Her husband assured her everything would be fine. But just a few weeks prior, the morning news had announced that Georgia had introduced a 20-week abortion ban. She kept turning that number over and over in her mind. What they would do if the baby was really sick?

They proceeded into the examining room, as any expectant couple would do. Dawn lay back on the table as her stomach was coated with cold gel, like cool globs of aloe vera smeared on a sunburn. The ultrasound technician brushed the plastic wand back and forth and stared at the fuzzy black and white screen. The room hummed with electricity and equipment cooling fans. The technician said it was a girl and then went silent. Dawn asked, "What's wrong?" The technician didn't explain. She said she would get the doctor as she dashed out of the room. Hot tears welled in Dawn's eyes and she started to sob. "Something's really wrong," she said, "I was right. Something is wrong." Her husband collapsed into a chair, lightheaded, nauseous, his vision black. His sudden fainting spell startled his wife. Dawn, tears streaming down her face and still covered with the sticky gel, tottered to her husband's side to hold his hand. Huddled together in the corner of the room, totally overcome by panic, they waited for the doctor.

The physician explained that the baby was missing most of her brain. Specifically, the large outer region called the cerebral cortex. We use the lumpy squiggles of brain tissue in this area for voluntary movement, like wiggling your toes or grasping a cup. It holds our memories, processes the images we see, allows us to use and understand language. Our cerebral cortex gives us our personality; it is the center of consciousness.

A future with a child that sick seemed insurmountable.

Without it, the baby would only have her brain stem, which some call the "reptilian brain." The infant would be blind, deaf, and totally unaware of her surroundings.

The condition, called *anencephaly,* is a severe form of spina bifida caused by a malformed neural tube. The delicately orchestrated formation of the spine and brain begins with an open tube, much like a single piece of PVC piping. Between the third and fourth weeks of pregnancy this hollow tube seals itself off at both ends. Spina bifida results when lower portions of the tube fail to close properly. But if the top part of the tube, the "cerebral end," doesn't close, then the child becomes anencephalic. Because the upper region is left open, the child also fails to develop any sort of protective covering for the brain, namely a skull, skin and hair. The tiny portion of the brainstem is usually veiled by only a thin, translucent membrane, like a flimsy piece of cellophane. From the nose down, anencephalic babies look indistinguishable from healthy ones, but oftentimes the missing portion of the skull makes the eye sockets grow either too large or too small. For this reason, babies can have frog-like eyes that bulge out of their tiny, misshapen heads. Cases of anencephaly are always fatal, since the brain stem cannot support extended physiological functioning. A handful of infants survive into their toddler years but these are exceedingly rare and a poor example of an infant's outcome. Those that are not stillborn usually live a few minutes to a few weeks.

Dawn's doctor gave her a grim prognosis, without any guarantee the baby would be born alive. Even if by some small chance the baby was not stillborn, she would face constant medical care: diabetes, an inability to maintain her temperature, endocrine issues, and kidney issues. The list seemed endless.

Although Dawn supports pro-choice for other women, she had always been pro-life when it came to her own pregnancies. Her entire opinion shifted after the diagnosis. She didn't know if she and her husband could handle that kind of care. A future with a child that sick seemed insurmountable.

Dawn's doctor didn't perform abortions, so she sent Dawn to a specialized clinic. The abortion clinic only saw women that far along in their pregnancies, past the first trimester, on Fridays and Saturdays. It was five days before she went in to have an abortion. "I guess some people treasure those times, whatever time you have with your child," Dawn says in an interview about a year after her termination. "But it felt cruel and like torture to me because I knew what the end was." She starts to cry, "I knew what we were going to do and I didn't want to prolong her suffering anymore than I had to." She had trouble sleeping the week before her appointment and started developing panic attacks. She changed her mind one way or the other every night before bed, worrying herself sick. Her husband kept her grounded. "He was 100 percent sure we were making the right choice and if you ask him today he would say he's 105 percent. He just knew," she says.

The type of procedure a doctor can do to perform an abortion is entirely dependent on the size of the fetus and how far along, in weeks, the pregnancy is. The first trimester extends from 0-13 weeks, the second from 14-26 weeks and the third from 27-40 weeks. Only 1.2% of abortions are performed after 20 weeks, and almost all of them are due to severe fetal abnormalities discovered during the anatomy scan.[xiii]

LD's (labor and delivery, sometimes called an induction) are used for very late term abortions in the second and third trimester. The baby's heart is stopped with an injected pharmaceutical solution before the mother delivers the child fully intact. These are often mislabeled "partial birth abortions"; in fact there is never a chance the child will be born alive. Only five doctors in the entire United States openly advertise and provide third term abortions; the procedures are exceedingly rare. There are two much more common methods.

A dilation and cuterage procedure (almost always referred to as a D&C) is used only on pregnancies prior to 16 weeks, but usually even earlier than that. The doctor opens the woman's cervix with a metal tube and scrapes out the lining of her uterus with a metal instrument. The process used more often in cases like Dawn's is dilation and extraction (D&E).

A D&E starts the same way as a D&C (with the dilation of the cervix) but since the fetus is about the size of a mango at 20 weeks, a doctor can't simply scoop it out of the uterus. If the baby is particularly far along, the woman will come into the clinic or doctor's office the day before to soften her cervix with the tiny, hard strips of seaweed called laminaria. They are described as extremely uncomfortable or even painful as they slowly widen the cervix. The procedure is usually done in a clinic or a surgical center. After dilation a vacuum is inserted to pull out the fetus and the same scraping tool used for a D&C is employed to make sure no fetal tissue is left behind. Women can get dangerous infections if any fetal tissue is present after the termination. For these later D&Es women are almost always given a general anesthetic or heavy sedation, the same way you're knocked out when your wisdom teeth are removed.

Nine states currently have laws banning abortion at 20 weeks, almost entirely in the South and the Midwest. Georgia, the state Dawn was in, could have been one of them—if not for a judicial injunction against Georgia's 20-week ban about a month before Dawn's termination date. The injunction threw the bill in limbo for a while.

In addition to the 20-week line, there was an added stipulation that medically futile pregnancies could be aborted after the 20-week limit. This would potentially allow women like Dawn to have abortions after 20 weeks if their baby was diagnosed as terminal. This too, is complicated, because any child that can be saved with surgical intervention, even if severely incapacitated, is not considered terminal. The stipulation is not perfect but it is a step in the right direction. If the law ever gets out of its judicial hold-up, Georgia has a small safeguard in place for women with dying babies.

Other states banning abortion at 20 weeks do not have such provisions for futile pregnancies. The only stipulations in place allow abortion if the pregnancy is a threat to the mother's life. To complicate matters, many states have also banned insurance companies from funding terminations, forcing women to pay thousands of dollars out of pocket. Some desperate women, like western outlaws, travel hundreds of miles and empty their bank accounts to put an end to the nightmare.

A year after Dawn's termination and 600 miles away in Indiana, another woman found her life suddenly tangled up in these state abortion laws and the fine print of insurance. A clerical mixup scheduled her anatomy scan at 24 weeks. Cynthia would have kept the late appointment if not for a nagging sister-in-law who was inpatient to know whether she would be welcoming a niece or nephew. The anatomy scan was moved to 22 weeks. When Cynthia finally went in for her appointment, the technicians thought they saw something off on the scans. After a Level II ultrasound and a fetal echocardiogram (a precision ultrasound for the heart) Cynthia's baby boy, William, was diagnosed with a fusion of the heart ventricles.

Cynthia was given a range of choices. There was a surgical option to prolong William's life but it was very expensive and definitely not guaranteed. Most children who undergo the surgery have high risks of developmental delays and educational delays, as well as physical complications that sometimes leave them worse off than before. There was also the option to carry to term, deliver William, bring him home, and then wait for him to die. Or Cynthia could have an abortion. It was then that Cynthia and her husband realized they'd have to go out of state if they wanted to legally terminate.

The next week or so was a logistical nightmare. Indiana has a strict 20-week policy: no ifs, ands, or buts. Ohio ceased to be an option the very next day. That left Illinois and Missouri, both of which have bans at 24 weeks. At 22 ½ weeks along, Cynthia had about week from her initial diagnosis to get any second opinions, research the heart disorder, screen a variety of abortion clinics, arrange for time away from her job, and get someone to watch her two-year-old daughter while she and her husband were gone. "It's amazing what you do when it's...what you have to do," Cynthia says in an interview about six months after her termination.

Cynthia called dozens of clinics around Chicago and St. Louis to get a feel for their practice before booking an appointment. A lot of them were narrowly focused on the mother's privacy and seemed inept at dealing with terminating a wanted pregnancy. One wouldn't even let her husband come in with her. He had to drop her off at the door and then pick her up when it was all over. "I was *very* uncomfortable with that," she says. She found there were even abortion clinic reviews on Yelp. "The things you thought you'd never need to know," she says. They finally found a doctor who would perform the procedure, a two day D&E, at North Western Memorial.

Though the doctors were incredibly helpful, she says, medical billing couldn't tell her if her insurance would cover the $15,000 procedure until the day she came in. She made a backup appointment at a clinic in St. Louis even though it was three times as far. Cynthia and her husband had a plan to drive through the night from Chicago to St. Louis if the hospital at Northwestern wouldn't accept their insurance. She and her husband had already driven about a hundred miles from Indiana; what was three hundred more?

Insurance is a tricky beast when it comes to abortions. Ultimately, both Cynthia's and Dawn's abortions were covered. But Dawn was able to move forward with her termination only by sheer luck. Under the abortion provisions in the Affordable Care Act, abortion is not covered under federal insurance[xiv]. As an employee of the state, Dawn falls into this category. She had the procedure just a few months before her insurance issued the ban on coverage. In total she paid a little under $2,500 for the procedure and insurance covered the rest. If insurance hadn't chipped in, it would have been closer to $10,000-$15,000 out of pocket. Third term abortions can be as much as $30,000.

Lack of coverage is an enormous problem for many women facing a potential abortion. The Affordable Care Act maintains that private insurance cannot be compelled to cover abortions. Ten states currently prohibit all comprehensive plans from covering abortion and over a dozen more prohibit coverage in the health insurance market (plans purchased through the healthcare exchange). In those states women and their families have to pay totally out of pocket[xv]. The House voted for this limited abortion coverage back in 2011 and also January of this year.[xvi] "We got very lucky," Dawn says. "I remind myself that if we decide to have more children and we have to go through this again, that we would not be in the same position."

To people in states where legislators have passed restriction laws, or tried to, a 20-week ban might not seem alarming. It's exactly halfway through the pregnancy and well past the 'first trimester of doubt.' But many women, like Dawn and Cynthia, are naïve about the multitude of problems that appear only after the 20-week mark, exactly halfway through a normal 40 weel term.

"I thought a 20 week ban was really reasonable before this happened to us," Cynthia says. "The thing I think a lot of people don't realize about these timelines is that it just forces people to make a decision faster than they're comfortable with."

Most of the time, these restrictive laws are not written out of contempt for women. They are written by people who believe there should be legal, ethical boundaries when it comes to unborn babies. "In Georgia there is no enforceable limitation on abortion. That is, you can have an abortion the day before you can deliver a full term baby in this state," former Representative Doug McKillip says in a recent phone interview. He believes that aborting a baby only days before it's slated to be born is morally reprehensible. McKillip thought it was necessary to draw a line. So he wrote the Georgia bill restricting abortion at 20 weeks.

The 20-week mark was picked because of medical research papers indicating a fetus could feel pain at 20 weeks. There are just as many papers that counter the 20-week delineation, so the medical world isn't sure either way. That hasn't stopped pro-life supporters from latching onto this demarcation.

Dr. Pettker, the Yale Maternal Fetal Medicine specialist, commented on these state-wide restrictions. Although he is not in one of the 20-week restricted states, he is adamant about the recent influx of abortion restrictions. "You're leaving providers like me hanging who are diagnosing something and want to give people the tools to do something about it," he says. "But you *can't* do something about it! So it's frustrating," he says, his fists convulsing in the air as if he were shaking someone's lapels. "They'd love no termination of pregnancy if they had their way."

"A legitimate attempt by a state legislature to discover the boundaries of Roe v. Wade."

Dr. Pettker does not exaggerate. States are trying to limit abortion timelines as much as they can. In March of 2013, Governor Jack Dalrymple of North Dakota signed two bills that are the country's most extreme to date. One prohibited abortions after 6 weeks, the time when maternal care providers can hear a heartbeat. The other made termination illegal if the reason is genetic. Legislators originally wanted this bill to outlaw sex selection, but unwittingly managed to ban abortions for any known genetic abnormality.

Governor Dalrymple, at a press conference, called the bills "a legitimate attempt by a state legislature to discover the boundaries of Roe v. Wade."[xvii] David Hogue is a North Dakota district senator who supported the bills. "My personal belief is that life begins at conception," he says in a recent phone interview. He would like to have the limit even sooner, or eliminate abortion altogether. "But somebody proposed a bill that said it should be the heartbeat because many people associate a detectable heartbeat with life," he says.

This April, after North Dakota's only abortion clinic sued the state, the two North Dakota bills were permanently struck down as unconstitutional. North Dakota hasn't been dissuaded from trying to push a pro-life agenda. Exactly a year prior to the court ruling (and only a month after the original 6-week bill), legislators passed a 20-week ban that has yet to be overturned. There is also a resolution in the state's constitution slated for a public vote this November expressing North Dakota's disagreement with Roe v. Wade. It's more of a statement than an enforceable act; since it is subject to federal law, the resolution wouldn't actually do anything. "If you believe life begins at conception you're not going to sit by quietly while federal judges highjack the rights of the unborn," Senator Hogue from North Dakota says. "You're going to keep fighting."

During the interview, Hogue was asked whether he would support a woman if she came to him with a diagnosis of Tay-Sachs, one of the worst genetic diseases obstetricians test for.

In Tay-Sachs the baby's cells are unable to clear a protein that forms around nerve cells. This task is akin to sweeping away dust that gets piled in the corners of a room. When this dust piles up, it crushes and suffocates the nervous system. Beginning around their toddler years Tay-Sachs victims stop being able to swallow, and lose the ability to talk or to lift their head. Simple activities make them so exhausted they just lay there. Their muscles shut down, then their brains. They are hospitalized with respiratory infections, unable to cough up any phlegm. Many develop seizures as they slide backwards into death. It can take as many as five years of this slow regression before they die. There is no known treatment or cure, only hospice care to make them comfortable as their disease progresses. Many families learn they have the recessive gene only after they've watched their own child fade from their lives.

As to whether or not North Dakota would allow mothers to terminate a fetus diagnosed with Tay-Sachs, Hogue paused to consider. "That's a tough question," he says. He explains he understands the accuracy of doctors' tests but just doesn't trust their ability at prognosis. He told a story about a woman who was told her fetus would be born with Down's syndrome but the baby was only mildly cognitively delayed. "You know, physicians who presume to know what kind of life the fetus will have after birth are sometimes wrong. So again—on whose side do you err?"

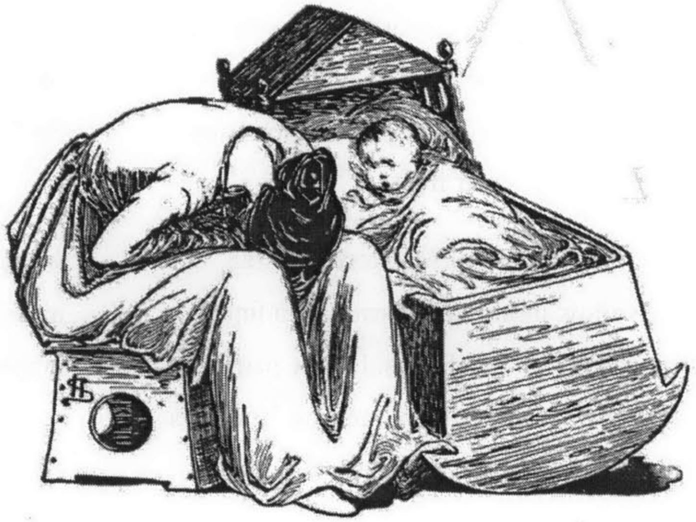
As a growing number of states try to annihilate Roe v. Wade, their legislators are often painted as zealots. But their arguments illuminate a pressing worry in our society. The laws, in part, are written to protect the lives of the disabled. That is not an undue cause. It is true that doctors cannot predict what degree of functioning a child will have. It is dangerous to terminate any impaired fetus without thoughtful consideration. On the other hand, legislators cannot lump all disabilities together. There is an immense difference between a child diagnosed with Down's syndrome and a child with Tay-Sachs.

After a severe prenatal diagnosis, women can be faced with diseases that have a vast spectrum of outcomes, like Down's syndrome or Cynthia's fetus's diagnosis of severe heart abnormalities. Other times, the diagnosis is clear-cut like Tay-Sachs or anencephaly. Though the timeline may shift, these diseases are always terminal.

Sarah, an accountant from California, watched her daughter Amelia die from Tay-Sachs six years ago. She was not tested for it during her pregnancy and thus had no choice but to accept her situation. Sarah spent three years nursing her increasingly deteriorating daughter around the clock before she died.lthough Sarah never tried to have more children, she has established relationships with other Tay-Sachs parents who have. She explains that people make a lot of different choices after they receive a Tay-Sachs diagnosis or experience first hand the death of a child from Tay-Sachs. She knows families that have blindly gone on to conceive and not do any prenatal testing. They have the child and roll the dice. She knows people who have chosen to adopt instead of ever getting pregnant again. She knows people who have gotten pregnant and then waited to do a CVS or an amniocentesis and then terminate if the child tests positive for Tay Sachs. She knows people who have done IVF and then had the embryos screened before implantation. And Sarah insists she understands each and every one of their choices.

"There isn't a good choice," Sarah says. She adds that there is no right or wrong decision. "There's no obvious choice. All of your choices suck. Any choice you make, it's not a great one; it's not what you want," she says. "What you want is to get pregnant and have a healthy child." Parents should be trusted to come to their own conclusions when it comes to a diseased or disabled child, she thinks. They know their family better than anyone else. The choice is hard enough. Why try to limit and oversimplify something so complicated?

Though Dawn, the mother who terminated after finding out her daughter had anencephaly, knows she made the right choice for her and her family, she still feels



the repercussions of the abortion. She had trouble with hugs and with people getting too close for months after the procedure. "Looking back on it now it's still, even talking about it, it still gives me the shakes," she says.

To women who have an abortion due to a severe abnormality, their child is very real and very wanted despite the decision to let them go. It's not uncommon that families want keepsakes of their terminated children after a diagnosis with a severe anomaly. Any evidence of their existence is precious. Since families who choose a D&E will never be able to hold their child, clinics often make footprints and handprints for the parents to take home. Dawn and Cynthia both have footprints of their children as well as their ashes. Small mementos of a life unlived; yet nevertheless loved.

There are many mothers who can't fathom killing the child they've been carrying for months; even if they know it will die shortly after their birth. But unlike Dawn or Cynthia they are the minority. Many find themselves clobbered with skeptical comments from coworkers, friends, even their doctors. They are told they're crazy or stupid. But these women don't budge, as some mothers feel they must, for those a few fleeting moments to meet the child they've been carrying inside of them for months. A child that might not even be born alive.

Birth plans are one of the most significant things mothers have to do when they're expecting a terminal delivery. Dr. Zink, the Maternal Fetal Medicine specialist in Texas, and Dr. Pettker, at Yale, both emphasize how much time they spend with their patients when it comes to the birth plans.

"We really try to set everybody's expectations before the event actually happens," Dr. Pettker says, explaining the process from a doctor's point of view. "We go through a long conversation of what are your expectations on what's going to be done in labor and after labor." During this conversation, a woman's primary doctor will bring in everyone ranging from high risk Maternal Fetal Medicine specialists, to nurses, to pediatricians or neonatologists to discuss options and likely scenarios.

For example, a common question is whether or not the mother would like to delivery via C-section or vaginally. It may seem simple, but consider the intricacies: What if she wanted to have more kids? If she chose a cesarean then all her following pregnancies would have to be delivered via C-section. But what if she really wanted to see her baby alive if even for a few moments? Then cesarean delivery would give her child the greatest likelihood of a live birth. In one woman's case, her birth plan was one of the few things that kept her focused. Problem after problem arose during her pregnancy, making for in intricate birth plan with an unclear outcome.

After suffering a miscarriage a few months before, Kelsey and her husband Stevie, a young couple from Arizona, were just praying for a heartbeat. They dreamed of having a big family, five or six kids, and were eager to start. At her 12-week appointment, on the threshold of her second trimester, Kelsey held her breath as the ultrasound technician tried to locate the heartbeat. When it finally fluttered across the screen, Kelsey breathed a sigh of relief, never expecting the "but." The ultrasound technician told them the baby had an omphalocoele (pronounced "im-falo-seal") and explained that the baby's organs were growing in a thin sac outside of its body. Kelsey burst into tears but was reassured that many infants with this growth abnormality went on to have surgery after they were born and did just fine. She was referred to a specialist for further testing.

After a second ultrasound with another technician, the couple waited an hour to see the Maternal Fetal Medicine specialist. Stevie paced back and forth in the claustrophobic, antiseptic smelling room. But Kelsey was calm. She was convinced everything was going to be okay.

When the doctor finally walked into the room, her eyes on Kelsey's chart, Kelsey immediately asked about how the doctors were going to fix the omphalocoele. "The omphalocoele?" their doctor said, "Oh that's the least of your worries."

In addition to a delicate sac of organs growing outside her body, their baby girl had the most severe form of anencephaly. She had no cerebral cortex all. She would be blind and deaf, have no awareness of the world around her, and exhibit only involuntary reflexes like twitching and sucking her lips. Kelsey, who as a Catholic believes all lives are sacred, wanted to carry her anyway.

Kelsey found that when she told coworkers about her choice to deliver the baby, and whatever that entailed, she would get responses like, *Why would you do that to* *yourself?* or, *How could you do that to your baby?* Over 90% of women who receive a diagnosis of anencephaly decide to terminate.[xviii]

Despite harsh reaction from those around her, Kelsey forged ahead. She took refuge in online communities and started a blog. Suddenly she could talk to other women in her situation. It helped to have perspective and advice from someone who had gone through it before. She bought tiny clothes, picked out a name and tried to feel normal. To prepare for her birth, her doctors devised a lengthy, detailed birth plan.

She insisted on having the child vaginally, but in Kelsey's case she didn't even know if she *could* have a vaginal birth. Not only would the omphalocoele likely get stuck in the birth canal, she might not dilate enough to get the baby out. Usually, the pressure of an infant's skull is what forces the cervix to open. Since Kelsey's daughter didn't have a skull, it was very likely that that wouldn't happen. In addition to considering medical decisions, there were endless details to contemplate. A nurse suggested a sign be put on Kelsey's door saying that they had lost a baby. This would prevent staff from entering with automatic congratulatory remarks about the tiny bundle in the bassinette. Her doctors asked how many family members Kelsey wanted in the room and when. If the baby lived to be a few days old, did Kelsey want a feeding tube put in? If the heart rate started to fade after delivery, did Kelsey want lifesaving measures or did she want nature to take its course?

Kelsey's birth plan was three pages long, and was signed by both her and her husband Stevie. They revisited it during appointments and when she went into labor. In a time of such stress and confusion, a written document grounding everyone involved is key. Of course, it's really more of a guideline than a steadfast edict. "In this business it all diverts from the plan," Dr. Pettker says. It's not uncommon that something unexpected happens and the medical team must adapt the plan in some way. Not because anybody changed their mind but because the scenarios changed. "We try to build those contingencies in but sometimes it's hard to do that," Dr. Pettker says.

Kelsey's team managed to follow her birth plan without any hiccups; it just went much longer than expected. On Halloween of 2012, Kelsey went into labor, almost two months premature. As predicted, the anencephaly prevented her from fully dilating. It took her five days and countless doses of Cervadil, a cervical softener and birth inducer, before she was able to push. Kelsey had opted for "comfort care" over life saving measures. She and Stevie wanted nature to take its course and simply be present for the birth of their children. The tiny infant, whom Kelsey and Stevie had named Kassidy, weighed only 2 pounds 11 ounces and measured just over a foot. Kassidy had died sometime during labor.

Kelsey explains that doctors usually have fetal heart monitors hooked up during labor but Kelsey had eschewed the monitor in her plan. She didn't want to know the moment she died. In an interview about a year after Kassidy's birth, Kelsey's voice still chokes with tears. "I almost didn't want her to be born alive. Which sounds bizarre," she says. She had read stories online of anencephalic babies having seizures before they died. Kelsey says, "I just don't know if I could handle seeing that. Or seeing her suffer. Or watching her pass away."

They got to spend over 24 hours with Kassidy's tiny, lifeless body, cherishing the only moments they would ever have to hold their little girl. Kelsey took a nap cradling her infant, exhausted after five days of labor. They gave the baby a bath and dressed her in diminutive, doll-sized clothes. Kelsey had a photographer take pictures of Kassidy, carefully posed in a hat to cover her malformed skull. Family members got to see the child and a priest came to the hospital to bless the stillborn infant. Kelsey says she wouldn't trade those moments for the world. For the women who choose to carry terminal infants, holding their babies for the first and last time is essential for their grieving process—though it doesn't make goodbye any easier. Part of letting go is knowing what you have lost.

Kelsey explains that she wanted to take Kassidy straight to the funeral home when they left the hospital, but Arizona law forbade her to transport a dead body. A previous stint as an intern with the Phoenix police department made her brutally aware of what the hospital morgue looked like. "It was just like a file cabinet," she says. "In my heart I just hoped Kassidy wouldn't be in a room like that." During their tearful departure a nurse picked up Kassidy, promising to take care of her. Kelsey walked out of the delivery room and watched the nurse in a rocking chair, Kassidy nestled in her arms. "You can't prepare yourself to leave your baby at the hospital and walk out empty handed."

But what if Kassidy hadn't died? Every so often a child defies the odds and somehow lives. This is becoming more and more feasible with intensive medical care and advanced, life saving technologies. There have been two little girls in Brazil with anencephaly, Marcela and Vitoria, who survived over a year and a half. The widely publicized Baby K from Virginia lived until she was two. And a little boy in Colorado, Nikolas, lived until he was three years old. Those that are told their babies are terminal, whether it's from anencephaly, a trisomial disorder or some other severe abnormality might be in for a surprise. What happens when a severely disabled child with a terminal prognosis lives?

Karen never really wanted children. She and her husband were inseparable, a pair destined to cook dinner together, to watch TV, to go camping on the weekends in the warm Florida weather, just the two of them. After eighteen years without a day apart, it never occurred to Karen that the "us" she had grown so accustomed to might change. One night on her way home from picking up her husband at the bowling alley, she told him some surprising news. At 42 years old Karen, was going to be a mom. She didn't even know how to change a diaper. She never guessed she'd be doing it for the next twenty years.

Karen didn't know that anything was wrong until after Donnie was born. Although she was seven years older than the typical age at which almost all women have an amniocentesis, because she did not believe in abortion she declined her doctor's advice to have any significant prenatal testing. In the delivery room the doctors tickled the bottom of Donnie's feet and lifted his arms to measure his reflexes, muscle tone, used a stethoscope to listen to his breathing and heart rate—a standard set of tests called an APGAR score. When they realized the tiny infant was practically unresponsive, they immediately called in a geneticist for testing. Donnie was diagnosed with trisomy 18, sometimes called Edward's syndrome. Trisomy 18, like Down's syndrome, happens when a chromosome usually found in a pair makes an extra copy of itself. When the 18th chromosome makes three copies of itself, the effects are far more severe than Down's. The extra copy causes the child to have severe mental retardation, malformed organs, especially the kidneys, heart abnormalities, feeding difficulties, breathing difficulties, physical problems like clenched, overlapping fingers, clubfeet and cleft palates. If a child survives being carried to term (though statistically unlikely), doctors estimate that half of children with trisomy 18 will die within a week[xix]. But Donnie celebrated his twenty-first birthday this past September.

Karen says, "They told us to pretty much plan his funeral and that he would not"—she pauses to take a heavy breath—"he will not go home. And they gave us hospice." It took a year of doctors' visits and bedside prayers before Karen believed that Donnie might not die after all. She has spent the past two decades trying to create an environment to stimulate a child physicians referred to as a vegetable. "He is not a vegetable," Karen repeats often and with devout conviction. She believes he recognizes familiar people since he lights up with a smile whenever a nurse or a family friend comes by to visit. He smiles and giggles during Karen's favorite show *The Price is Right*, which she insists is his favorite program too. Donnie will coo and smile during church music on Sundays. "I don't consider Donnie a challenge; I just consider him," she says. "He's one of us."

But Karen's life is much more than watching TV and singing with her little boy. During the few hours Donnie is at a school for those with special needs, where he has music, art and physical therapy, she cleans the house. She sets up giant body pillows in her living room, the floor covered by an enormous exercise mat. She cleans Donnie's two sets of feeding tubes and sterilizes the syringes. She organizes the overflowing medicine cabinet and bags up the dirty diapers (Donnie needs changing over ten times a day). She snaps clean pads on the changing table and smooths the sheets over the king-sized bed she shares with her little boy. She sits for hours filling out Medicaid paperwork, calling representatives to go over the financial details of Donnie's care. The house is usually quiet; it's just Karen. Her husband died ten years ago, leaving her widowed. Her whole life is Donnie.

When Karen talks her mind wanders, she loses track of what she was talking about and often asks for questions to be repeated. She is perpetually exhausted. When Donnie's bus pulls up after school she carries his frail, 55-pound body out of his wheelchair, into her living room and onto the floor. He will hold a ball or a soft, crinkly fabric book, toys you can find in the infant aisle. She never leaves him for more than a few seconds, terrified he'll choke on his own saliva. It is as if she is perpetually caring for a six-month-old baby. He has had five major surgeries and countless hospitalizations to treat pneumonia, the antibiotic-resistant infection called C. diff, intestinal blockages and urinary tract infections. Karen calls Donnie her perfect boy.

Many would have scaled down such intense treatment years ago, or at least sought out a way to ease the burden of 24-hour care. Karen doesn't consider Donnie a burden, but the strain of constant care has significantly marked her entire existence.

Karen didn't know Donnie had trisomy 18 before he was born. But those that do find out beforehand often face discrimination and judgment from vastly different sides. On the one hand, they can be questioned as to why they would bring a severely sick child into the world knowing how many medical resources will have to be employed just to keep the child alive. On the other hand, some people might question a mother's moral judgment if she chose to abort a child—even one diagnosed with a chromosomal anomaly as severe as Donnie's. How could someone possibly predict that child's way of life? What if the baby is more cognizant than the doctors predict?

There has been debate following recent studies that suggest trisomy 18 and similar abnormalities aren't as lethal as once thought. In a 2012 study from the journal *Pediatrics*, a team analyzed all trisomy 18 and trisomy 13 hospitalizations from the US Kid's Inpatient Database. They found that many children suffering from these "lethal" disorders were living past their first birthdays thanks to radical medical interventions such as creating a functioning esophagus and open-heart surgery[xx]. A lot of families hold out hope that their child might be the one that lives a meaningful life. But the fact is the majority of trisomy 18 pregnancies die before birth. There is no way of determining whose children survive, however impaired their lives. It is an opaque, uncertain future. The only thing doctors can say for sure is that if these children do survive, their lives will be supported entirely by medical intervention.

As technology progresses so does the meaning of futility.

Donnie, though he reacts to his surroundings, can't physically turn himself over. The stays at the hospital are long, the nights of vigilant prayer even longer. At home, Donnie consistently rips out his g-tube, spilling the thick, milky nutritional blend keeping him alive all over himself. Karen, awaiting her 66th birthday, worries she will throw out her back when she lifts Donnie. The future is hazier than ever.

The most certain thing about life is its uncertainty. But prenatal testing allows women an opportunity to plan ahead, even if the answers are not 100% clear. If the only thing a mother knows is that her child has an abnormality and that that abnormality is going to make life very hard for either the child or the entire family, why shouldn't she stop the problem before it starts? If doctors say the pregnancy is futile and the terminal child will likely perish within moments of its birth, why shouldn't she spare herself the agony of watching her baby die?

The words "terminal" and "futile" are shifting—diseases that were once death sentences can now be managed with medications, surgical interventions, and life-sustaining medical equipment. It is these in-between disorders that leave ethicists shaking their heads and talking in circles. We can see from the progression of the most common fetal abnormality, Down's syndrome, that as technology progresses so does the meaning of "futility." More and more disorders will fall into this category, like Donnie's trisomy 18. Perhaps even anencephaly. But what kind of life do those children live, suspended by medical intervention? Are they happy? Are they in pain? Are they even aware of their existence? Nobody really knows. Doctors are asked to make predictions about what kind of life a disabled child will have, and they can only answer with less and less certainty. There is no crystal ball.

Dr. Pettker is often asked what he would do when he's giving expectant mothers complex prenatal diagnoses. His patients ask *Doctor what would you do in this case?*

"And they don't know my religion, they don't know if I believe in abortion, they don't know if I have a brother with Down's syndrome, they don't know anything about me," he says emphatically, pulling back his fingers listing the variables. "But they still want to know what I would do in that situation. And I'm always surprised by that."

It's an understandable thing to want advice from your doctor, he says. But the truth is he can't answer the question. He tells them the things that would matter to him in his decision: whether or not he believes in abortion; his religion; whether or not a family member has something like this; whether or not there are other people in his family that might be affected. If the parents' chances of getting whatever they were dreaming for might be taken away or limited. If their dreams might be *expanded* by this. He cannot make the choice for them.

Getting the news that your unborn baby is critical ill, severely deformed, or even on the verge of dying sparks a complicated multitude of complicated questions. As Sarah (the mother who watched her daughter die of Tay Sachs) says, all of your choices suck. Not all parents have answers. But mothers have to guess the best that they can with the information doctors have available.

And yet our country treats prenatal testing like an unequivocal certainty. Either you know by 20 weeks whether you wish to terminate or you don't. Legislators are trying to control decisions and timelines they don't fully understand. In doing so, they unwittingly give overwhelmed, grieving mothers additional hurdles to reckon with. Cynthia, backed into a corner in her home state, drove hundreds of miles to do what she knew was right, despite the legal roadblocks.

The amount of care and medical intervention that a woman can handle is a completely individual choice and varies greatly from person to person. Dr. Ashley Zink, the obstetric specialist from Texas, remarks on how vastly different her patients have been over the years. "Anytime you get news that your baby is not going to be perfect, that's very difficult. But it's surprising the different ways that people deal," she says. "It's so individual."

Dawn and Kelsey both received a diagnosis of anencephaly. One chose to terminate while the other chose to carry to term. Both had their difficulties, both mourned the loss of their child, but each woman decided what was best for her and her family. It is shameful that governments are patronizing women and trying to demarcate lines in the murkiest, greyest area parents will ever know. We, as a society, must trust that women are not making these choices lightly. To simplify situations like these into pro-choice and pro-life debates strips them of their intricate, heart wrenching complexities. No one knows what they will choose until they are in that position.

"If you're totally pro-life you already know how to answer all of these questions," Latham, the bio-ethicist from Yale, says. "And if you're totally in favor of parents having the complete ability to decide the fates of their children then you know how to answer them the other way. But I think most people are kind of in-between and I think that makes it very, very hard."

These decisions are honest choices that happen every day. And yet women hide in the shadows, apprehensive to talk about their experience and be criticized by others. The women who shared their stories for this piece were coaxed out, afraid of their identities being exposed. Afraid of being judged. But history has shown mothers have always wanted what's best for their families and their children, whether that means medical intervention or letting go. These are not new decisions; our technology has simply accelerated the timeline.

Each choice is presented as one side against another; two totally dissimilar conclusions. Abortion or live birth. Black or white. But the choice to terminate and the choice to deliver futile pregnancies are not disparate. They are two sides of the same coin—they both stem from a mother's love.

here is the deepest secret nobody knows
(here is the root of the root and the bud of the bud
and the sky of the sky of a tree called life;which grows
higher than soul can hope or mind can hide)
and this is the wonder that's keeping the stars apart

i carry your heart(i carry it in my heart)

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Images:

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Interviews:

All interviews conducted in person or over the phone between January 19, 2014 and February 8, 2014. Last names have been withheld to protect the identities of the women. Those that are starred have stories & quotes included in the piece. Others served to highlight various opinions and situations surrounding futile prenatal diagnosis or children born with life-threatening disabilities during my research.

Anca, New York, February 8, 2014

Amy, Missouri, January 23, 2014

*Ashley Zink, M.D., Texas (UT Southwestern Medical Center), January 17, 2014

Courtney, Oregon, January 22, 2014

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*Christian Pettker, M.D., Connecticut (Yale New-Haven Hospital), January 15, 2014

*Cynthia, Indiana, February 6, 2014

*David Hogue, North Dakota (District Senator), February 7, 2014

*Dawn, Georgia, January 24, 2014

*Doug McKillip, Georgia (former House Representative), February 4, 2014

*Janet, California, January 22, 2014

*Karen, Florida, January 25, 2014

*Kelsey, Arizona, January 19, 2014

Lorena, California, January 27, 2014

*Sarah, California, January 25, 2014

Shawna, Oregon, January 22, 2014

*Stephen Latham, Ph. D., Connecticut (*Director, Yale Interdisciplinary Center for Bioethics)*, January 31, 2014

Tara, New Jersey, January 24, 2014