

Poor Prenatal Diagnosis

A Father's Journey

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Abstract. Through personal testimony, the author details the experience of fathering a baby with a poor prenatal diagnosis. The author invites the reader to follow his journey, from learning his wife is pregnant, through their experiences as a family with their unborn daughter's poor prenatal diagnosis, welcoming their baby girl at her birth, and ultimately finding peace in her early passing. Perinatal peer support is discussed and encouraged, drawing attention to the needs and concerns of the babies, women, and families who may not know to seek help in a similar situation. Great honor is given to the beauty and sanctity of life from the perspective of a father with a sick unborn child. *National Catholic Bioethics Quarterly* 14.1 (Spring 2014): 31–37.

“Every human person—no matter how vulnerable or helpless, no matter how young or old, no matter how healthy, handicapped or sick, no matter how useful or productive for society—is a being of inestimable worth created in the image and likeness of God. This is the dignity of America, the reason she exists, the condition for her survival—yes, the ultimate test of her greatness: to respect every human person, especially the weakest and most defenseless ones, those as yet unborn.”

—Pope St. John Paul II

There are moments in our lives that, because of their profound impact, help define the rest of our existence. My daughter Corrine Catherine's birthday (December 17, 2011) is one of those moments. My hope and intent in what follows is that I may help

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you understand more fully the beauty and sanctity of life from the perspective of a dad with a sick child in her mother's womb and that my witness will help you better understand and address the needs and concerns of the babies, women, and families who may or may not reach out for help during a very difficult time.

Corrine spent ninety grace-filled minutes with my wife, me, and our three teenage children before she joined her heavenly Father. Over the last two years, I have often been asked to share some thoughts, ideas, and—dare I say—wisdom regarding my journey from a dad's perspective; so much of the emphasis is typically placed on the mom and the sick baby (I believe rightfully so). As a general rule of thumb, whenever possible I like to keep things simple, and I think that especially applies to being a dad of a sick baby in the womb.

Keeping It Simple

You can't get much simpler than the character of Forrest Gump played by actor Tom Hanks. During one exchange with his girlfriend, Jenny, Forrest is asked,

“Do you ever dream, Forrest, about who you're gonna be?”

“Who I'm gonna be?”

“Yeah.”

“Aren't—aren't I going to be me?”

My simple advice to dads is to just be you. Be the father you envisioned you would be before you found out your baby was sick. Be yourself and be open to and accept God's invitation.

As men, we are often portrayed in the light of our Neanderthal ancestors as “hunters and gatherers.” Some think that when men are faced with difficult circumstances, a primordial instinct kicks in to hunt more deer and gather more nuts and berries! I was born and raised in the city of Philadelphia, where the only thing I was taught to hunt were sales and bargains at the grocery and department stores.

Don't worry about gathering enough nuts because you will come across many of them in your journey. Your baskets will overflow!

Many perceive one of our central roles to be a protector of the family. That doesn't change whether your child is born or still in the womb. You can still parent and protect your baby by being his or her most steadfast advocate. You can stand up for their rights when others may want to treat your child as a disease and not as a precious baby. Instead of crawling into an emotional cocoon (which is tempting at times), you can prepare for the best-case scenario, the worst-case scenario, and everywhere in between. I urge you, however, not to let yourself be slow-walked through the door where only the worst-case scenarios are discussed. I'm not trying to promote the idea of false hope. You must not forget that with God all things are possible (not guaranteed as we want or perceive the outcome to be). However, there is a tendency in our academic and scientific arenas to forget this and to think that we have achieved some sort of superior intelligence, on a par with or greater than that of the Almighty.

Be there for your wife. Turn off the television, get off the computer, go to *all* of the doctor appointments, and just listen to her and comfort her whenever needed. You don't have to come up with magic words. You don't have to look for your Superman cape. More often than not, just being there is the best medicine.

God gives everyone many opportunities throughout the day to get closer to him. Many of these opportunities are never realized or suppressed; there are thousands of reasons why we don't act on God's invitations. The invitation to be a father to a sick child is hard to ignore.

God does not give you a sick baby to "punish" you in any way, shape, or form. That's important to understand. He simply asks you to be the best dad you can be to one of his children who just happens to be sick in human form. The baby's soul is perfect and will be reunited with God when his or her mission on earth is complete. You need to be an advocate for your sick baby and allow that mission to unfold. As a dad you should know that your willingness to accept God's plan and be a positive witness to it will propagate waves of positive energy and love throughout the world. I say that from first-hand experience.

This energy is not confined by the laws of physics. The spiritual energy you create by loving your sick baby, and therefore witnessing God's love, will increase in magnitude and have more impact as time marches on. The law of conservation of energy does not apply here. Spiritual energy is created when our souls respond to an opportunity presented by God to be a beacon of his love. These tiny and frail babies can be a more positive influence to those whose lives they touch than many of us who will live to be old enough to collect Social Security and beyond.

An Expert Witness

I used the word "witness." That's a big part of what I do for a living. I examine evidence, write forensic reports of my findings, and provide expert witness testimony in court regarding the construction and functionality of improvised explosive devices (IEDs), sometimes referred to as homemade bombs. I have served as a United States Navy Explosive Ordnance Disposal (EOD) Officer and have worked for the Federal Bureau of Investigation as a special agent for the past sixteen years, the last ten of which have been at the FBI Laboratory in Quantico, Virginia.

It took over two years to become qualified as an expert in hazardous devices after an intensive training program. I've often entered the witness stand during some high-profile cases, after being told by the lead prosecutor, "You are our star witness" or "You are the clean-up hitter." (No pressure there!)

I have had no such formal training to prepare me to take on one of the most important witness assignments of my life. I was not given two years to get qualified. The amazing thing is that you don't need specialized training to be a witness for God. As St. Francis of Assisi said, "Preach the Gospel at all times, and when necessary, use words." I hope that you will be able to see and understand that I speak from my heart, which has been tempered by the redemptive power of suffering. What I have to say is no less true than things that can withstand the scrutiny of a stiff cross-examination in a court of law. I hope to be a star witness for God. I am still on that witness stand and will not step down until God calls me home.

In March 2011, as I was sitting at my kitchen table in the morning reading the newspaper, my wife Paula came downstairs and looked very nervous and a bit shaky. She held out the pregnancy test, and as I stared at the prominent plus sign, she said, "I'm pregnant!" We have always been open to life and to having more children, but

it had been eleven years since our youngest was born, and with my wife in her forties, we thought our chances were about as good as hitting the Mega Millions lottery (which I occasionally still play by the way!). Well, we did win the lottery, so to speak: God decided to give us the blessing of another child when the odds were against us. My children were ecstatic, as were my wife and I. My youngest was especially excited and was really looking forward to being a big sister.

At the twenty-week ultrasound, all of the children came with us to the appointment. We were going to make it a special day. We were going to go shopping afterward, maybe pick out some baby items and necessities, and go out to dinner. We were leaning heavily toward finding out the sex of the baby, but I did not make the final decision until the ultrasound technician asked us. We knew that if the baby was a boy, we'd name him Colin, and if it was a girl, we'd name her Corrine. The technician did her job very well. She was professional and very pleasant and talkative. We could not sense that our baby was sick. She told us early on that the baby was a girl. The kids were very happy, although at the time Paula and I sensed a slight bit of disappointment from my son Sean, who was hoping for that elusive brother!

When the technician finished taking all of the required measurements and pictures, she said that she was going to get the radiologist to come and discuss the results with us. We still we did not sense that anything was "wrong." We sent the kids out into the waiting room. When the radiologist came in, he did not waste any time before telling us that our baby was very sick. He said that based on the formation of her brain, she had holoprosencephaly (alobar), a hypoplastic left heart, and a facial deformity. Actually, I am only now able to state what the radiologist said, after I have had considerable time to process it. On that day, it sounded like he said, "Your daughter has supercalifragilisticexpialidocious." He continued to say that these conditions were all indicative of trisomy 13, which is lethal. Not knowing our position on the sanctity of life, he started to go down the road of intimating that the best position to take with such a diagnosis would be termination, that we would not be wrong, and that it would be okay.

We did not let him get out of first gear before we made him realize that was not an option for us. My wife and I were in an interior waiting room. Our heads were spinning, we were crying, we were worried about our baby. She's going to die? She's not going to make it? How can this be? We felt numb. I'm trained to disarm or render-safe bombs and forensically examine the aftermath of an explosion. I just felt like I was in the middle of an explosion with debris still raining down around me.

The Baby and the Bathwater

Here we are, at that critical moment when a mom receives a devastating diagnosis for her child. A mother who wants a baby, who is excited about the arrival of the baby, but who has just received news that her baby is very sick, news that her baby may not make it to term and, if she does, may be stillborn or only live moments beyond birth. I have no ill feelings toward the radiologist, who probably only knew of, was trained in, or believed in one option as being the best for all of his patients in

these circumstances. I believe that he was advising what he believed was the “best,” but his best had severe limitations, which he was either unaware of or simply chose to ignore or dismiss.

My purpose is not to engage in a debate between pro-choice and pro-life. We chose life. I do however want to talk about choice in another sense. Consider this: if one believes in choice, even if one is passionate about the legal right of a woman to choose the fate of her baby in her womb, then you *must* concern yourself with helping that woman and her family with making the *best* decision. It does not take a scholarly physician or proverbial rocket scientist to realize that the best position to be in when making any kind of decision, particularly a critical one, is to have all pertinent information available.

If you only present one “option” to the mother, is there really a choice? If you use euphemisms to avoid an expression that may offend or suggest something unpleasant, are you really communicating the truth? The gravity of these questions becomes even greater when that single “option” is presented by a doctor, a nurse, a healer, an authority figure, or a friend—someone who, after all, is supposed to regard your health and well-being as their prime directive.

There is another choice that I present to you as one who has “gone down this road,” a choice that gives the family the ability to experience hope, patience, humility, generosity, compassion, and the greatest virtue of all, love. Only when these virtues become redefined or misunderstood does a well-intentioned but misguided healer or helper or friend think that the only or the best “choice” for a worried and emotional mom is to prematurely end the life of her sick baby in the womb. Misplaced compassion is the greatest enemy of these precious but frail babies. This misplaced compassion is rooted in fear of suffering and a lack of understanding about the positive nature of parenting a sick baby in the womb and beyond.

I’m sure you’ve heard the catchphrase “Don’t throw out the baby with the bath water.” This idiomatic expression is used to suggest an avoidable error in which something good is eliminated when one is trying to get rid of something bad or, in other words, rejecting the essential along with the inessential. The phrase originated in the early 1500s. Thomas Murner was a German Franciscan priest who spent much of his time learning and teaching the humanities as a doctor of theology. He used the phrase in one of his greatest satirical literary works, *The Great Fool*, in which he warned other theologians of the period of the dangers posed by the Reformation.

How interesting and appropriate that the word baby is used in that expression! Doesn’t it seem intuitive that you don’t heal a patient by killing him or her? Of course, if the disease is now defined as the baby itself, if these are synonymous, if instead of two patients (mom and baby) there’s now only one, the only one visible to the naked eye, then it becomes easy to convince a woman to rid herself of something harmful. This veneer covers the truth, but it is infinitely thin. In the eyes of some well-intentioned but misguided healers and counselors, it only needs to last long enough for the second patient (the baby) to become the victim of an idiomatic tragedy.

If I challenged you to find a woman or a family who would get up in front of an audience and profess that prematurely ending the life of a sick child was the *best*

decision they ever made, and not simply a “hard or difficult decision at the time,” I’m sure you’d find some if you looked long and hard enough. But I would wager that if you accepted the challenge, you would also find thousands of women and families who regret their decisions, felt pressured, and thought that they did not have any other choice. Ultimately, most would choose not to discuss the matter in an effort to suppress their feelings of grief, sorrow, and guilt. It’s simply too painful, so please just make it go away. Stop the pain! Does that sound like the best option or choice for a woman?

Even if you think, “Well, it’s the only logical choice because I know of nothing better,” this should compel you to search for other options. For those looking for options and answers, technology has made that search an easier one. Through the hard work and dedication of some amazing professionals, perinatal hospice programs exist throughout the country. These programs, affiliated with hospitals and health care practices, combined with peer ministry organizations, are the answer. They provide a positive alternative for the distraught woman or family.

Health care providers, counselors, and clergy need to know more about perinatal hospice and peer-support options to get the word out to help those in these difficult situations. My wife and I are products of perinatal peer support from many different ministries and from several different states. We’ve been especially grateful for the support of the Office for Persons with Disabilities of the Diocese of Richmond, Virginia. Working closely with them, my wife and I have established the Embracing Grace Ministry in the diocese. Embracing Grace is a perinatal peer ministry. Our mission is to serve parents and their families who receive a poor prenatal diagnosis, by journeying alongside them and offering resources and support encouraging the option to carry their child to term.

Graces from Corrine

I know personally that Corrine was responsible for bringing many people closer to God, not the least of whom was my father. Although raised Catholic, he had fallen away from the Church not long after marrying my mother and had dug his heels in extremely deep with issues and excuses that hardened his heart toward God and the Church. My mother is a wonderful faith-filled woman who “worked on” him for fifty years to no avail. I also tried my best to break the ice that encrusted his heart and that prevented the love, peace, and joy of the Holy Trinity from entering.

Not long after witnessing the birth and death of his granddaughter Corrine, he made a good confession, embraced his Catholic faith, and is now a second-degree Knight of Columbus. If that is not a miracle, then I hope to learn what one is. There have been other instances of people (priests, nurses, doctors, students, and strangers) telling us directly about how they have come to know and love God more deeply through experiencing Corrine’s gift. My other children know firsthand what unconditional love means. They loved and continue to love their sister Corrine, not on the basis of what she looked like, what she wore, or what earthly things she achieved. They love her simply because she is their sister who, like all human beings, is created in the likeness and image of God.

The following, written by one of my daughters, expresses the influence of Corrine on our family:

On December 17, 2011, Corrine was brought into the world, letting out a powerful cry as she was welcomed into the embrace of her mother and father. My dad brought her across the hall to meet her siblings, grandparents, and uncle. We each got a chance to hold and greet her as she made cooing sounds to each of us. After my mom was out of the operating room, Corrine was reunited with her, where she peacefully fell to sleep joining her Eternal Father in heaven. She received the sacraments of Baptism and Confirmation, took her first bath, and was clothed in a baptismal gown made by her grandmom. During the two hours Corrine was with us, she received the same amount of love as one receives in a lifetime.

Corrine has taught me that God has a plan for everyone, even the small, weak, and defenseless. Corrine did not speak one word, yet she has impacted so many lives. Although she was the most frail and weak person one could imagine, she has caused faith to blossom in people where there once was none, opened the eyes of doctors and nurses to the sanctity of life, and demonstrated a small portion of her “inestimable worth” through the humility of one who was deemed incompatible with life. How ironic it is that she was able to epitomize life despite societal and medical labels to the contrary.

Through this experience, I have become closer to my family and appreciate my siblings more in everything they do for me and accomplish in life. I am more aware of the sacredness of life, how fragile it is, and how quickly it can be taken away. I have more respect for life and believe that no life should be cut short due to a disability, even in the womb. Parenting starts in the womb. Cutting Corrine's life short would have caused my family and me more pain. By letting Corrine live the full life God had planned for her, I was able to meet my sister and now find peace in knowing she is in a better place looking over me.

The loss of my sister has inspired me to become a nurse so I can become a caretaker of those who are weak and defenseless. I would like to specifically focus on becoming a neonatal nurse so I can join in the rejoicing of life but also help counsel those who are mourning the loss of life. Having gone through the experience of mourning the loss of a baby sister, I can relate to families whose baby has received a poor prenatal diagnosis. I will be able to share with them how to fully prepare and celebrate the life of their child. Being a nurse would give me the skills to make a positive impact on the mind, body, and soul of countless people. Corrine has changed my life and has inspired me to change the lives of others through compassion and healing.

I am sure there are many more instances of Christ working through Corrine that I, her father, will never hear about. I don't need to know what they are, as long as God hears them.

