

Life expectancy: On not praying for a miracle

by [Dayna Olson-Getty](#) in the [September 22, 2009](#) issue

At my 20-week ultrasound appointment, my husband and I learned that the baby that we are expecting has a fatal birth defect. Sometime very early in his development something went drastically wrong. His skull never formed—the whole top and back part of it simply did not exist. We will probably never find a medical answer to why he developed this way. Babies with acrania have a fairly good chance at living to full term and even some chance of being born alive, but they usually don't live more than a few days after birth. We can expect that if he makes it through birth, our little one will live for just a few minutes or hours.

As Eric and I shared our news about our son's short life expectancy with friends and acquaintances, several people responded by saying that they will be praying for a miracle. We are not particular about who prays for us or how they pray. We are grateful to be upheld in prayer, and we have sensed that we are receiving strength we didn't think we'd have because of these prayers. (Eric commented that he has friends of all three Abrahamic faiths—Christians, Muslims and Jews—praying for our son.) But the choice of some of our friends to pray for a miracle has made me think hard about what I pray for and how I pray.

When I found out I was pregnant, we were, like most new parents, overjoyed. Once we made it past week 12, when the most serious danger of miscarriage was over, I breathed a huge sigh of relief and settled in to the reality that we were going to have a baby. At his eight-week ultrasound he looked so much like a little sea creature that we started calling him "Flippery." At every checkup, his heartbeat was strong. At 18 weeks, right on schedule, I felt him move. We started collecting donations of baby gear from friends, and I made lists of all the things we still needed to buy. I planned my maternity leave, and we started thinking about how to turn our guest room into a baby room. We signed up for BabyCenter e-mail newsletters, tried out various name possibilities, and even began to think about where our child might go to elementary school. Each week Eric posted updates on Facebook about which

fruit or vegetable our little one was currently closest to in size. Eric's mom reported that a flurry of knitting and crocheting was under way in Vermont in preparation for the first grandchild. I compared pregnancy symptoms with my friends who are moms, read pregnancy books, signed us up for birthing classes and started collecting maternity clothes. In every part of our life, we began making room to welcome this little life.

Then came his diagnosis. The very afternoon that we learned of it, we named our son Ethan James. We named him because just an hour before, we had to decide whether we would end his life early or I would continue to carry him until he dies. Eric and I have both spent years as theology students and could easily write papers (and probably a book) about the Christian ethics of this decision, but in the moment there was no need for complex moral reasoning. Only one thing mattered: We love this child. We love him with a love that is far fiercer and stronger than we imagined it could be. All this making room in our lives and getting ready for his arrival had, without our realizing it, made us into parents. We have no power to change anything about his development or diagnosis or the length of his life, but we choose to love him with our whole hearts and to provide for him for as long as God gives him life. We choose to parent him to the best of our ability, even if the time we have with him is achingly short.

But I am not praying for a miracle. At first, I wondered if this was because I lack faith. It is true that I have a hard time having confidence that God will supernaturally heal those I love when they are deathly ill. Maybe this is because I lived through my mother's excruciating death from cancer, despite many prayers for her healing. Probably it is also because I am culturally a rational Westerner, more likely to put my confidence in the technology of medicine than in the healing power of God.

But the truth is, I saw Ethan's ultrasound photos. I saw with my own eyes that this little boy doesn't have a cranium—the whole top and back of his head are simply missing. On the cross-section scan of his abdomen, I saw the little white oval that is a kidney and the gray empty space on the other side where his second kidney should be, but isn't. We are long past the stage of pregnancy when these structures are supposed to form, and there is no hope that they will spontaneously and naturally form now. I know that it *would* take a miracle—the ex nihilo, flesh-and-bone-creating kind of miracle—for Ethan to be made whole.

I desperately want Ethan to be born whole. I would give up one of my own arms or legs if it meant that Ethan's skull could close over and his brain form normally. There is nothing I want more in life than to raise this little boy and to have him outlive me. I want to hold his newborn children in my arms when I am old and know that they will live on long after I am gone. But I am not praying for a miracle. I am not capable of praying for healing while simultaneously preparing for Ethan's death. I have to choose one or the other—the two possibilities are simply too much for me to hold together. Eric and I only have this one opportunity, now, in these days of waiting, to parent Ethan well. We don't want to waste this precious opportunity by denying the reality that his life will be very short or by failing to acknowledge that what he needs most from us is our preparation to care for him in his dying.

Over the past few weeks, Eric and I have begun these strange and unexpected tasks of parenting. With our hospice team, we've started working on a written plan for Ethan's medical care so that he will be protected from pain and surrounded with love as much as possible during the few moments of his life. I have been searching for the right scripture texts and liturgy for his funeral service.

A few nights ago, between work and grocery shopping, we stopped by a baby cemetery. As we walked among the tiny grave plots with their decorations of sippy cups, baby rattles, pinwheels and Matchbox cars, we tried to imagine what it would feel like to bury Ethan there. We have offered his car seat and stroller to friends who are newly expecting and have been shopping instead for a wooden infant casket. Although I haven't found the strength yet to buy anything, I've begun to think about the kind of clothes Ethan will need for his birth and burial. All the while, he kicks away inside of my womb, letting us know that he is still full of life and energy. These are not the tasks I expected to carry out during pregnancy—and they certainly are not on the monthly to-do lists in my pregnancy books—but they are what Ethan needs from us now.

I have not been praying for the miracle of his healing, but I have been taking great comfort in the miracle that is already assured—the miracle that Ethan's life will not end with his death, but will be joined to the eternal life of the God who made him and gave him to us. Sometimes this promise is offered to people who are grieving as if it is somehow supposed to take away the pain of burying a loved one—and as far as I can tell, it doesn't. My body is still going to ache for him when we come home from the hospital without him. Years from now I will still feel the pain of his absence and wonder about the person he would have grown up to be.

But there is something about his life—the life that God put in him—that is not ephemeral and fragile like his body. In this way, Ethan is no different from any of us. Our bodies are frail and fallible too, and they will all die sooner or later, but we have the promise of resurrection into a life that is not constrained by our frailty and that comes from the One who breathed life into all creation.