Katherine and Nate, parents of Joey and younger son Benjamin (3).

Joey was diagnosed in-utero with severe holoprosencephaly (brain malformation) and died 2 weeks after birth.

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| 1 | Title: *A diagnosis in-utero of holoprosencephaly.*  <https://youtu.be/aYKT9Db1HRM>  First-time parents Nate and Katherine describe learning at the 20-week ultrasound that their baby had holoprosencephaly - his brain was not fully formed - and being referred to perinatal palliative care.  TC: 5:50  **Katherine:** My name is Katherine Anderson. This is my husband Nate. We live in Chicago. And we have a son who's three years old, almost four, whose name is Benjamin. And we also have the son who would be six, whose name is Joey.  we both got married a little older in life, and we waited about a year to start trying to have kids after we had a nice honeymoon, and super excited to start our family. And we got pregnant actually fairly quickly after trying and everything was going great, we went in for a 20 week ultrasound which was like a higher level ultrasound, I think a level two at that point, right, which is more in depth. And I had brought to the hospital, I had brought one bag of goodies for a boy and one bag of goodies for a girl, and so I was going to pull out whichever one [00:09:00:07] we're going to find out the gender that day. We did find out the gender and found out that Joey was a boy, and after the ultrasound tech said I'm going to leave the room, I'm going to go bring in the doctor and Katherine kind of looked at me, I didn't know what that meant was our first time, and the kind of one of the head doctors came in and started to just have a look on her face that was gloom, downcast and very, you know.  **Interviewee:**  Somber.  **Interviewer:**  Yeah, somber and Katherine knew right away, I didn't -- her instincts kicked in, I didn't really know what it meant. But I will never forget the look on the doctor's face, mixed with what then came out of her mouth, which I don't remember everything that came out, because I remember looking at her face more so than the words, but ultimately that your child, your baby boy has a condition called Holoprosencephaly, and what [00:10:00:06] the imaging is showing is that it's alobar, which means it's the worst kind of Holoprosencephaly. And what that means is basically his brain did not form appropriately in utero. And he maybe had 10% or 20% of brain matter, the rest of his brain was just fluid and hollow. So that was a shock. She knew more than I did, I didn't really understand what still what it really meant, I wanted to go to, you know, start researching. But it was a very, yeah, it was a brutal diagnosis, and we knew it was not good at the moment, but we didn't know what all translated to. I'll let you -- I'll pause and let you kick in from there.  **Interviewee:**  Well, I don't know that I knew more until we did start researching. But I heard fatal, fatal diagnosis and terminal diagnosis and knew that we may never meet him. [00:11:00:01]. But we were able to, we were able to meet him. So that catapulted us into a lot of appointments, being moved from a midwife to the high risk specialists, and meeting with a palliative care team that would take care of Joey potentially after he was born the neonatal palliative care team. |
| 2 | Title: *Considering the option of terminating the pregnancy: “We felt we wanted to let this little life be whatever God wanted it to be.”*  <https://youtu.be/Lg0Lwt5fyrQ>  First time parents Nate and Katherine describe their decision-making process in deciding to continue the pregnancy following a devastating diagnosis in utero. The doctors looked to them to decide what to do between the ultrasound, birth, post-birth. "It was weighty." They received advice from an adult palliative doctor and heard about older children with it who helped them the types of complications and issues their son was likely to have. "We decided not to terminate his life and also not to prolong it." They describe how the doctors seemed confused by this decision, even as they were very respectful. The pregnancy was a time of great uncertainty and anxiety.  TC: 12:50  that day they brought us to meet with -- we met with the high risk doctor, and we met with the a geneticist or a genetic counselor, who tried to explain to us, you know.  **Interviewee 2:**  What it was.  **Interviewee:**  The genetic counseling would be a good idea for us moving forward because it could be caused by a genetic disorder. We did eventually find out that it was not caused by a genetic disorder. Probably that week, if not that day, we’re given the option to terminate the pregnancy. And we both just felt like we wanted to [00:13:00:05] let this little life be whatever God wanted it to be. And we continue to get advice from some physicians at our church, there's a wonderful doctor who worked at Northwestern who was in geriatric palliative care, and he gave us some advice about how to proceed and since we didn't want to terminate the pregnancy, what then we could -- how to treat Joey after he was born. And we also through a friend met with a -- I'm trying to remember his title. He was he was a neighbor of --  **Interviewee 2:**  My coworker.  **Interviewee:**  Yeah, neighbor of a friend of ours. And he was a I think, a pediatric neurosurgeon.  **Interviewee 2:**  [00:14:00:08] He’s worked on this condition, on these babies and done surgeries.  **Interviewee:**  Yeah, pediatric neurosurgeon. And he just really did explain to us about the quality of life that children have with alobar holoprosencephaly. He explained to us that especially the alobar type wouldn't really never walk or talk. And there are some parents who go through a lot of surgeries with their children. We found out that a lot of the children will always need a feeding tube, a breathing tube, and have hundreds of seizures a day. So a lot of those things played into our decision making about just allowing God to do whatever he wanted through Joey's life. We decided not to terminate, but not to prolong his life at all.  I remember walking into a room of 10 doctors all with their white jackets on, and some of the best minds in the room, kind of --  **Interviewee:**  In the world.  **Interviewee 2:**  But letting -- they were all looking to us to help decide the birth plan, and the palliative care post birth, it was actually fairly daunting experience, yet at the same time, what it taught me was, we have some of the best minds in the room that really did [00:16:00:06] have good answers of what to do. I mean, at some point, everyone threw up their hands and go, we don't know what causes this, we don't know how to really fix it. And we're looking to you to make decisions on what to do between now and birth and then post birth. And so it was daunting, and that it was very weighty on us, mixed with, we get some voices of, you know, reason and counsel from that team. But at the end of the day, it was kind of in our hands of what to do. And Katherine and I, I would say, part of the thing was, we start looking to -- I went home and Googled right away, start Googling everything, you know, which is good and bad of course, it's pretty bad at the end of the day, but we want to understand the condition. And as Katherine said, we decided we weren't going to -- we weren't going to take control of whatever God was doing in this. [00:17:00:03] We weren't going to take his life and we weren't going to prolong it. And we were very affirmed in that decision. They were shocked, I mean, I think the look on their faces was disbelief, because I think they could, you know, from a birthing place, a place that does puns of birth a day, the doctors couldn't quite get their head around, like, why would you carry this to term? Why would you carry this baby through and actually birth it when you know it's a death sentence. So every meeting was that much more weighty and difficult, and it was filled with tears and anxiety and questions and prayer and counsel, but at the end of the day, Katherine and I both felt it took time to get here, but we eventually got on the same page about hey, we're not going to do many interventions, most families [00:18:00:09] that would carry a baby with holoprosencephaly to birth, I researched that the oldest baby with holoprosencephaly made it to 14 years old, alobar, ultimately they’re vegetables, they live, you know, on a machine and wheelchairs and don't speak or barely move. So yeah, we literally kind of went like this, and just kind of surrendered to whatever God was going to do with our little baby Joey. And it was it for a guy who likes black and white and doesn't love a lot of gray, it was a lot of uncertainty for many, many months.  **Interviewee:**  I don't like uncertainty either.  **Interviewee 2:**  Well, that was probably the most challenging period.  **Interviewee:**  It was. And it felt like -- well, I realized once he was -- I felt like we were grieving, we were grieving what Joey's life would have been. But [00:19:00:07] then we were able to actually meet him. So yeah, it was interesting, I realize like the pregnancy was a lot more of an anxious time, still a sad time but very anxious because we didn't know what would happen. And then after he was born, and passed away two weeks later then it feel like we were actually able to start grieving. |
| 3 | Title: *Decision-making about quality of life, with no judgement*: *“The medical field has advancements that our ethics haven’t quite caught up with.”*  <https://youtu.be/Vky9jVM1MZs>  Parents Nate and Katherine describe how they gathered information from others to inform their decisions after birth. The feeding tube was a hard decision. They talked with other parents, and a palliative care doctor from their church, and read from Facebook groups. Stories of others helped them see what his quality of life was likely to be. Kate talks about her fear of regret.  TC: 22:30  **Interviewee:**  So we went through a lot of research gathering to find out how we wanted to make decisions about Joey's life. We found a Facebook group as well, that did give us a lot of information from wonderful families that are caring for babies and children with holoprosencephaly.  **Interviewee 2:**  And some had care, you know, they still had babies with holoprosencephaly, they're still managing, and done more interventions.  **Interviewee:**  And even were able to walk alongside some people that were delivering within the same month as me with holoprosencephaly. And we [00:23:00:04] did also talk with some doctor friends about -- I would say that the one of the biggest decisions was about a feeding tube, because it was a little easier to decide that if he stopped breathing on his own, that we would not intervene with that, the feeding tube was a harder decision. And I was really blessed by a woman from an organization called Isaiahs Promise. They sent outfits for Joey, they sent gifts for him, and even on his first birthday sent a gift.  **Interviewee 2:**  Your sister connected.  **Interviewee:**  Yeah, my sister connected us with that organization and I had a number of conversations over the phone with a mom that had a baby with a terminal diagnosis as well. And so she and I talked a lot through the feeding tube, because different faiths [00:24:00:06] believe that that actually is a good thing to do and is necessary and should -- you should prolong life with a feeding tube. But the physician from our church who was a palliative care geriatric doctor, actually told us that if a person is not able to eat, that it's actually not painful for them to not eat. And he talked to us about how to keep his lips wet, if that was the case, and how to just make sure that his mouth felt moist because that's where they could have some discomfort. So we once we made -- yeah, we made that decision. I would also say that back to the Facebook group, in order to answer your question about what quality of life overall where we, you know, [00:25:00:08] would we want for our child. We did learn that children with holoprosencephaly really never walked or talked. And if they were -- if the child was able to breathe and breathe on their own, I think that we would have, and, you know, sometimes eat on their own, I think that we would have continued their life. I have many friends with children with Down syndrome, they're just beautiful and bring a lot to this world. But so, we read specifically about one little boy who was, I don't know, six, between six and eight. And the family was really frustrated because they had to sedate him in order to feed him, because he had so many -- like these babies have hundreds of seizures a day, [00:26:00:04] so they kept his body sedated, like asleep 22 hours a day in order to nourish him, because if he was awake, he would cease. And that to me did not sound like life, or a quality of life that I would want my child, because in addition to that, the child had already had dozens of surgeries, shunts in the brain. So I just thought if we really have to keep the child asleep, to keep it growing, to keep it alive that seems like medical intervention, and the medical field has advancements that our ethics haven't quite caught up with.  **Interviewee:**  I have a lot of compassion for parents that are making these decisions. Just, you know, I think it's important to think, will I be okay with this decision in six years? Will I miss having held my child, if you decide to terminate, or, you know, even will I want to think I had done everything that I could have, [00:59:00:03] I know that we made the right decision for ourselves, but I have compassion on people on all ends of the spectrum. And you really just have to know that you're okay with your decision.  I think the advice is the other piece we learned through it was, you know, no judgment, right, I mean, some people may have [01:01:00:04] aborted their child at the 20 week, some may not, some would have prolonged life, as I got to even literally talk to families from the Facebook group that I met on the phone or over text or email, everyone kind of has a different disposition. And we respect their decision. If they ask for advice or counsel, great, but I learned there's so much more gray in this world, and we believe God allows people to live in the gray even though a lot of people would say they're such black and white, I would quickly push back and say, actually, there's more gray than we think or no and less black and white. And we have to be comfortable with that, with living in the gray and the uncertainty and surrendering to what's happening. But yeah, affirming people's decisions in that. |
| 4 | Title: *Perinatal palliative care “got to know us and really heard our hearts. They counseled us through the birth practices.”*  <https://youtu.be/SMbQRTA7g24>  Parents Nate and Katherine talk about the ways in which they perinatal palliative care team counseled them and cared for them all the way through the birth practice. "We felt we were driving the decision-making and they were there to counsel, advise, provide direction." The medical team respected their decisions to carry the baby to term and helped them plan a safe delivery for the baby and the mother.  TC: 29:10  we felt like we had really bright, intelligent and compassionate minds of our doctor team. Dr. Henner jumps out at us, and we had Dr. Peacemen who end up delivering him was very like helpful in the process [00:30:00:01], and several other team members that we didn't see as many as much as Dr. Henner. But very cared for, we felt very well listened to. We felt like we were driving the decision making and they were there to help counsel and ask questions and help direct --  **Interviewee:**  Our options.  **Interviewee 2:**  Yeah, we felt -- there was a piece of hey, why would you carry this baby to term, there was a little somewhat overt and somewhat subvert tones of that. Looking back on that, I do understand why that advice came about, but they respected our decision immensely when we said we're going to carry Joey to term, and just surrender to this. So it was very -- again, those weren't arrived quickly, those were not easy decisions, a lot of tears and research and counsel, you know, but yeah, we leaned on people that we knew that we trusted, [00:31:00:06] strong ethical doctors that we were able to meet with and -- go at it, I think you're going to dive in, say something.  **Interviewee:**  I was just going to say that there was a decision making along the way to about how to also kind of protect our fertility, and there was a big decision, because his head was filling with fluid, he wasn't able to regulate the spinal fluid coming out of his spine and filling his head. So his head was abnormally large. And it was worrisome that I could potentially need a vertical C section. And that that could cause problems in future pregnancies. So there was a lot of decision about, there really wasn't do we let her go into labor, it was like, [00:32:00:09] we decided to deliver it 37 weeks, there was an option about draining the fluid in his brain, but the doctors together were able to kind of say to us, that's something that probably puts Joey's life at more risk than you would want. And Dr. Henner, was able to kind of say, I think that that's something that might be more on the termination side than you would want as a family after she had gotten to know us and really heard our hearts. So even in that, you know, we were like, what is this option? Oh, it could help with a vaginal delivery that would be safer, or a regular C section that would be safer. So they really like counseled us through even the birth practices that could be helpful in our family in the future, building our family in the future. [00:33:00:09] |
| 5 | Title: “We didn’t think we would leave the hospital.”  <https://youtu.be/nS8A_ai1a9Y>  Parents Nate and Kate describe: the extraordinary care they received in the hospital following their son's birth, including a dedication ceremony in the hospital. They discuss the challenging feeding issue; no car seat, no nursery at home. Their friends rallied. "We winged it for two sweet weeks. .. There have been some redemptive moments in this. ... We had over 80 people meet him."  TC: 34:50  we really didn't think we'd leave the hospital. We were in the hospital for four days, I think for four days, four nights. Ultimately, they treated us like royalty and they gave us, [00:35:00:04] this is a pediatrics hospital downtown Chicago on the like the 50th floor. And they put us in a corner room with windows on like a private floor, we had corner windows that were like floor to ceiling almost not quite but close. And it was the air and water show in Chicago that weekend, so we had jets flying by. And we could see the Lake Michigan, we felt like, I mean, in some ways they truly did -- I mean, well, they treated us really well at the hospital, and we had the best care, some of those, you know, I respect nurses to a whole new level, how well they cared for us and were so thoughtful with letters and notes and, you know, up all night with us and checked in with us after and we've had a good relationship whereas like, on Joey's first and second birthday, we ordered them cakes, we brought some gifts to them. And so there's been some really neat redemptive moments in this. But back to my story, we didn't think we'd leave the hospital, and [00:36:00:02] we didn't buy a lot of stuff for baby to come home for Joseph to come home.  **Interviewee:**  I didn't have a shower.  **Interviewee 2:**  Well, back to some of the other comments we were making was about basically feeding. So these babies with holoprosencephaly either can't learn -- they don't learn to swallow well, and so feeding them is which then results in a feeding tube. And we decided a feeding tube is prolonging life, meaning an intervention that we don't really want to do for his entire life. So we had to feed him with a syringe, we tried to get him to breastfeed, it worked for a little bit and then kind of didn't work. But so we had to like almost put droplets into his mouth and he would swallow them. But at the end of the day, Dr. Henner, our palliative care doctor was, you know, they're very concerned about the feeding issue, that's the biggest issue with these, and with some of these babies, and so we're feeding him and all sudden, like, well, he looks to be okay, you guys can go home. And I was like, [00:37:00:06] what do we do now? And so we didn't even have a car seat to bring him home, and that's illegal by the way. Hospitals don't let you do that. Well, we did bring them home, I think Katherine held them in the lap, and we drove carefully. And all of our friends who had just had babies started like sending us stuff. So we got like, you know, a little baby bed for him and like blankets, but we didn't have really anything for him. So it was really sweet to come home and we had to buy a rocking chair, we didn't have anything which was --  **Interviewee:**  We realized we didn't have any arm rests, like because our couch just like it was like --  **Interviewee 2:**  It was a very bachelor couch that I had brought into the marriage, but, you know, I guess shame on us for not having little more stuff, but I guess we really didn't think we'd come home.  **Interviewee:**  We didn't want to have things that would be a reminder for a long time.  **Interviewee 2:**  That's right. That was hard to buy and then keep in the [00:38:00:07] house right.  **Interviewee:**  And I should say, my friends had a prayer shower for me, but there were no gifts, but they had a prayer shower.  **Interviewee 2:**  Yeah, they gave us like a tree to plant on his behalf it was really sweet. It's really sweet. So, you know, there were some interesting moments. I laugh because literally we came home I think we did a makeshift little like cradle bed for him with --  **Interviewee:**  It's like a Moses basket.  **Interviewee 2:**  A basket that we had, and we put it on top of like a wine rack or something. And yeah, we were just winging it, we just winged it for two weeks. And we had a -- I will say the next two weeks of his life were very sweet, very difficult, because, you know, of course you're up all night with a baby and trying to figure out how to feed him and hospice would come and friends were coming every couple hours, so it was -- I don't -- it was a blur and we didn't sleep much at all, but it was also some very sweet [00:39:00:05] two weeks we had with him in our arms.  **Interviewee:**  Most people wait a little longer to have their baby meet people. And we had over 80 of our friends and family meet him in those two weeks, it was really special plus all the doctors and nurses. I will also say, one of the things that was really special at the hospital that the palliative care perinatal team did for us was, we were able to have a like a dedication ceremony in the hospital. And so a few hours after he was born, our pastor came and our siblings were there, our parents, and some dear friends were able to --  **Interviewee 2:**  25 people came. We’re not supposed to have that many people in like a delivery [00:40:00:02] room. And they made an exception for us, but I don't think they knew how many people and I think we like, we paraded in like 30 bodies into like this room. And everyone's like, all the docs like what is going on here and it was really sweet. We sang some songs, we prayed kind of dedicated him to God, and it was a really special, sweet moment.  **Interviewer:**  That happened how long after he was born, after his delivery?  **Interviewee:**  The dedication ceremony at the hospital was about three hours after he was born, maybe five hours after he was born, I was a little out of it. |
|  | Perinatal palliative care: "The hospital helped us have a dedication ceremony in our delivery room"  Parents Kate and Nate describe how the hospital allowed their friends and family to come into the delivery room following the birth of their son, to celebrate his life, in anticipation of his death  <https://youtu.be/DOnq-ogpkLY> |
| 6 | Title: *“It was very weird to have a newborn with a DNR paper on our fridge. . . It was one of the most uncertain times we could ever be in as humans.”*  <https://youtu.be/_7adqimGWs0>  Parents of a newborn with a life-limiting condition share how strange it was to be caring for their newborn at home when they knew he was not going to survive because of severe brain malformation. They describe his two weeks of life at home. Nate names the anxiety he felt at living in such uncertainty.  TC: 42:50  In bringing Joey home -- in bringing Joey home, we were surprised at it. They sent us home with a do not resuscitate paper to put on our fridge, and that was so weird, that was very weird to have a newborn who if anything happened, this legal document says [00:43:00:05] don’t save my baby. So that was strange. And we were able to go through almost two full weeks without many issues. He was still eating from a syringe a couple times would suck on a bottle. Had wet diapers was waking up every three hours kind of to eat. And there was even some talk about, oh, do we bring him in for a checkup? Do we bring him in for his normal, you know, most babies go back after a week or two for a checkup. And then we started to notice some hard breathing kind of right, right as we were thinking what are next steps, you know, like towards a normal life. And the doctors have explained [00:44:00:03] to us that he was able to make it that long because his brainstem was completely intact. So while there was not other brain matter cortex, his brainstem was intact, which does the work of regulating organs and things. But 12 days after he was born, he started struggling to breathe, which began the worst day of our lives. He had a very strong heart, everything else of his body worked. So he would stop breathing for even three to four minutes sometimes, but then would take a deep breath and start breathing again until it was Thursday, August 31st that he passed away [00:45:00:03] in the morning. So during that time, we were giving him morphine so that he wouldn't be in pain.  **Interviewee 2:**  Use little bits of it. Yeah.  **Interviewee:**  I think, I mean, everyone holds new babies all the time, but it was very, very rarely the Joey was put down, was like, he was always in someone's arms.  **Interviewee 2:**  He was.  **Interviewee:**  And my mom and my sister stayed with us during that time in our small apartment, and my sister actually had an eight month old as well, so we were all together. And in some ways, that's, you know, probably what would have happened if you bring home a new baby, families around to help take care of them, but it was very special that that they were able to be there [00:46:00:04] to help us and to also then grieve with us and say goodbye to him.  **Interviewee 2:**  Yeah, I think the emotions for me, I would saying anxiety, uncertainty, yet trying to be in the moment. But I mean there were times where I'm like, you know, we could -- he may live two, three years, four years, we didn't know. I mean, it was one of the most uncertain surrendering times that probably one can really be in. Because like you stated, you know, coming home, knowing our baby was going to probably die, but uncertain when and yet he's in our care now. We had hospice coming, but they come for a little bit and there wasn't a ton they would do, they just kind of like check in how are you doing? What can I provide for you? They were great. But it still was in our care. And [00:47:00:08] yeah, it was a -- man, it was a blur, you know, a lot of little sleep, but I do have good sweet memories of those two weeks, I do have sweet memories that were -- it just kind of like we were in it, you know, we just went through it day by day, hour by hour with a lot of uncertainty, you know, people -- we had meal plans where people gave us meals every night. That was awesome. Because, you know, we didn’t have to cook and that was sweet, and we could just care -- be with each other. And yeah, we took nice long walks with him and had family that supported, but it was when I think about life in general is probably one of the most uncertain times we could ever be in as humans. |
| 7 | Title: *Our newborn’s end of life: “his life was short, beautiful, what it was meant to be.”*  https://youtu.be/GbcfQvsL0So  Parents Nate and Katherine describe their two-week old son Joey's end of life at home and how it felt for them. Hospice had prepared them. The breathing at the end was especially difficult. Nate: "It wasn't really real for me until the hearse picked him up and drove him away. Then I fell down and wept. I think I was in automatic mode until then." Katherine: "It was really really weird to be 35 years old and in charge of my baby's funeral. It was really really hard." We made "the right choices for Joey."  TC: 49:10  he did pass away at like two, three am in our arms, in our bed. We were sleeping with him. He had been having trouble breathing for about 48 hours, 24-48 hours, so we weren't -- we were preparing ourselves for -- he just was gasping for air. And we knew even hospice said, prepared us, so we had about 48 hours of that, that was brutal, that was probably the worst time, and then we kept him in our bed that night, didn't really sleep, it's kind of like rubbed his back and [00:50:00:07] sang to him. And then he officially did pass away in our bed at like three or four am one night on the 31st. And then that was tough. I mean, there was some sweet memories we had there. We had a lot of people come to our home, we prayed, and we singed kind of songs with him. Yeah, it wasn't really real for me. And this is me, I'm not going to speak for Katherine until the hearse picked him up and drove him away. And then I literally I walked away from everyone that was there, there's like four people there. And I walked to the back of our yard and crumble, like my knees crumble underneath me and just kind of fell down and wept, started weeping. And that was real. I don't know why that moment was so real. I think I was in like automatic mode up until then, trying to just like, be a dad and care and try to navigate things. [00:51:00:00] So I'll pause there and let you share.  **Interviewee:**  I would just say, as you see I cry all the time. So I didn't quite have as cathartic of a moment as he did. But it was really weird to be, I think I was 35 years old, and, you know, in charge of a funeral, and in charge of, you know, calling the hearse to come to our house.  **Interviewee 2:**  For our child.  **Interviewee:**  Just really hard.  **Interviewee 2:**  Not a grandparent.  **Interviewee:**  Really hard. I don't think that's what God intends for life.  **Interviewer:**  But that's what you needed to do as Joey's [00:52:00:03] parents, and you did it, you did it.  **Interviewee:**  Yeah, it was the right choice for Joey, he got to have the life that he was meant to have.  **Interviewer:**  And he touched --  **Interviewee:**  His life was short, his life was beautiful, and it was -- it was what it was meant to be. |
| 8 | Title: *“I would be lying if I said it didn’t rattle our faith in God . . . I think it’s OK to have Why questions and not have perfect clarity.”*  <https://youtu.be/XZbHuUfpYJU>  Parents Nate and Katherine share that as people of deep faith in God they still had big Why questions. "We didn't believe God intended this to happen."  TC: 53:10  I would be lying if I didn't say it didn't rattle like our faith, like our faith in God, meaning a lot of why questions. Both of us would be lying if we said, oh, we're great, and, you know, God intended this, no, like, no, we didn't believe that, that that's what God wanted. So we did have a lot -- we had a lot of why questions throughout those months and even a couple of years and still do, you know, and I think that's okay. I think that's okay to be in some of those why questions and not have perfect clarity [00:54:00:04]. We still believe that God allowed this to happen. And we didn't love the outcome, but there's some redemptive moments that we've had, and we don't regret decisions we made, we feel very comfortable and I think we could say that right, I think we feel very comfortable and confident with the decisions we made, and how it all kind of played out, but it was brutal, and, you know, I'm like we've been through this everything else pales in comparison. |
| 9 | Title: *Finding support: “Our faith community really held us up.”*  <https://youtu.be/cO30GiDkvkk>  Parents Nate and Katherine describe how their faith community supported them and helped them get through their son Joey's short life and death. Nate encourages parents to "lean into community. Have real friends who give good counsel. Don't just trust your Googling ability. Lean into your faith."  TC: 55:55  our community really held us up, really, like held us up. And [00:56:00:03] when it was even hard to pray, they were praying for us more. And I had a friend that would send me a worship song every day, every day for, yeah, even for about three months afterwards, she still sent me a worship song every day. That was really sweet. Yeah, so it was the people around us that helped us both at the hospital and friends and family.  **Interviewee 2:**  I would piggyback that a little bit and say community, so lean into fret -- be in community even before you get pregnant, don't mean you have friends that are genuine, real transparent friends, not Facebook friends, but real people that, and you couldn't be from Facebook, but it's evolved into a real relationship. And so don't dismiss the need for community that are sound people, good minded ethical people that will speak into you and give good advice. We would hope they have some form of, you know, a lens with a framework for God and their faith. But at the same time, lean in to seek good counsel from people and don't just trust your Googling [01:00:00:00] instincts or Googling ability. And then lean into your faith, you know, the mix of emotions are going to, you know, people will say, oh, you're mad at God. Yeah. Real and that's a real emotion, that's okay. I mean, when we read through scripture, you know, Job was mad, it was cried out, I mean, a lot of David cried out in the Psalms to God, and it's okay to cry out and be angry and be upset, and that's an okay emotion to have. And I had to work through that and to learn about that myself. |
| 10 | Title: *Grief: “Have grace with your spouse.”*  <https://youtu.be/NHi8MMyV8lM>  Parents Nate and Katherine talk so tenderly about coming to understand how they differ in their grief response and supported each other. "We were trying to be gracious with each other and let the other grieve the way they needed to. That's tricky." They worked with a grief counselor in the prenatal period and continued after. Nate describes how complex it was and how he lacked the skills. "It was a tricky time." TC: 1:02:05  One other thing would be just to have grace with your spouse, and how they are going through the process and grieving and, you know, coming to understand it. Yeah, Nate was really sweet to me, because that's what he said, like, I was crying every day, and he would just hold my hand or run by back, and I was also pregnant during all of that.  **Interviewee 2:**  That C section was just the recovery.  **Interviewee:**  Yeah, it was hard on my body. But I also remember, I would take my tears and put him on his cheek because he hardly cried. So we were just trying to be gracious with each other, and let the other person grieve with the way that they needed to.  **Interviewee 2:**  [01:03:00:08] That's tricky. That's not easy. Because everyone grieves differently, but why aren't you grieving like I'm grieving.  **Interviewee:**  I have to be okay that he wasn't crying, and I knew he was still feeling it, you know, but not the same way.  **Interviewer:**  Did you have the grief counselor before Joey's death did you start working with a grief counselor before he died?  **Interviewee:**  Yeah, we started working with the grief counselor, probably when I was about six months pregnant. So we had two and a half months before Joey died. I would sometimes go by myself too and we would -- it was kind of an every other week thing.  **Interviewer:**  And you found that helpful.  **Interviewee:**  Yeah, it was very helpful to be seeing her during that time.  **Interviewee 2:**  It's hard to show understand to your spouse when you're trying to just understand your own feelings number one, the complexity of our own, what's actually happening in the side, and then to try to enter into what she's going through and then for her to do that to me. Well, that's a complexity that I didn't have the skill set, I really couldn't and it was tension for us, you know, [01:05:00:02], yeah, it was a tricky time.  **Interviewee:**  You were really sweet to me though. Thank you.  **Interviewee 2:**  Not all the time. Not all the time Katherine, but thanks for sharing that. |
| 11 | Title: *Pregnancy after child loss: The anxiety about having more children. “The way I have coped is just to assume the worst.”*  <https://youtu.be/NuwL4BRSIKI>  Mother Katherine describes how difficult and sad it was trying to have another baby. "I will never have an ultrasound again and expect good things. I cope by assuming the worst." They have had a healthy son, Benjamin. “It was redemptive.”  TC: 1:06:50  we decided that we definitely wanted to continue having children, and we actually struggled having Benjamin, I had two miscarriages after Joey, and then it took us another kind of eight months before I got pregnant with Benjamin. And that was a really sad [01:07:00:09] time that was really sad time of trying to have another baby, and wondering if you ever would. It was really hard to be around pregnant women during that time. And when we did get pregnant, I was definitely still worried then also about miscarriages. But when we made it past that stage, about what would happen at the 20 week ultrasound and yeah, I would say I have anxiety in regular life anyway, and then throw these concerns into the mix. I mean, I don't think I will ever have an ultrasound, like ever have an ultrasound again that's enjoyable [01:08:00:02] or that I walk into expecting good things, or Nate wants to expect good things, wants to kind of say this is different, this is going to be fine. I feel like a way that I've coped is just to assume the worst, I'm not sure that that's a great thing that my therapist would say that's a great thing. But it's a way of managing expectations. So it was amazing when we found out that Benjamin was a boy, for his pregnancy, decided not to do genetic testing, because we similarly decided that we wouldn't terminate him if there were any issues. So we found out at 20 weeks that he was healthy and everything looked normal. [01:09:00:07] And I was even able to have a VBAC after Joey's C section. So that was yeah, it was a wonderful day when he was born, a wonderful day.  **Interviewee 2:**  It was awesome.  **Interviewee:**  And I think my anxiety definitely lessened after the 20 week ultrasound, then I felt a lot more at ease, knowing that he was developing the healthfully, and yeah, he was born at 39 and a half weeks and was a healthy baby.  **Interviewee 2:**  Yeah, it was redemptive, it was sweet and he is joyful, he is a joy. |
| 12 | Title: *Ritual in bereavement: “Because Joey lived for two weeks, we spend those two weeks (with his little brother) celebrating his life.”*  <https://youtu.be/_tjEHITcA5E>  Katherine and Nate share and show how they honor Joey always and especially in the two weeks between his birthday and his death day. "Benjamin (younger brother) calls it a celebration. We need candles."  TC: 1:11:50  **Interviewee:**  So because Joey lives for two weeks.  **Interviewee 2:**  I'm going to get --  **Interviewee:**  We spend those two weeks kind of celebrating his life, so this was his Moses basket that he slept in, and it's filled with some memorabilia.  **Interviewee 2:**  Little Joey and the kangaroo, this has his heartbeat in it when he was still in utero, and then we got a lot of, you know, blankets from our friends.  **Interviewee:**  [01:12:00:04] Programs from the funeral.  **Interviewee 2:**  Here are his ashes.  **Interviewee:**  I was going to say we actually keep his ashes in there, and I just --  **Interviewee 2:**  And this is his funeral. So yeah, this is our little memory that we bring it out every birthday and we do a birthday dinner we sing happy birthday to him, we make a cake and Benjamin now he knows he has a little brother in heaven, and he still talks about his brother, a big brother in heaven I should say.  **Interviewee:**  I do have to explain that to his teachers, because he says he has a baby brother Joey. So I put that out, that stays in our room usually, but the two weeks that he was alive from August 17th to August 31st we bring that downstairs and it's right in our living area. And we do I think we have like a photo in every room of the house of him.  **Interviewee 2:**  This is just our photo book of him.  **Interviewee:**  This was a photo book.  **Interviewee 2:**  Got memories from all the people that -- all the people that came in, [01:13:00:03] we won't go through too much here. But it's fun for us to actually relive these because we don't look at this every day either.  **Interviewee:**  We usually look at it during the two weeks of his life, and Benjamin calls it a celebration now, Benjamin calls Joey's birthday a celebration, he goes we have to celebrate, we need candles to celebrate. |