

The Impact of Undetermined ~ A Parent's Perspective

by Magali Leialoha, Mother of Kai Ea Leialoha

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I need to open by saying that it is with some trepidation that I come before you today.

Although my husband, Mark, and I want nothing more than to help others survive the horrible experience of losing their baby, I have suffered an almost paralyzing fear in anticipation of addressing you....the anxiety comes from the fact that I know, inevitably, a discussion about the "undetermined" cause of death will be accompanied by a cascade of unanswered questions, and among those questions has to be....were they somehow unintentionally responsible for their baby's death? As a result, in agreeing to address you, I have also consented to the idea of completely exposing myself, and in so doing, I will be giving each of you....people who don't know us, our character, or how much we loved our son....the opportunity to judge us.

Of course, it is because of this fear, because of the inherent sense of guilt which endures even two plus years after having been notified Kai's death certificate would have "undetermined" typed on its face, that I realize I have an obligation to address you and to share our story because ultimately you share the same objective as we do....we all want to lessen the unbearable amount of suffering parents experience when they lose their babies to an undetermined cause....and the apprehension, the guilt, the fear of being judged which almost prevented me from being here, is all part of that experience....we hope, therefore, that in sharing our story with you, in exposing ourselves to you, we will be providing you with a new sensitivity and the perspective you will need to better serve your clients.

So, with that, let me share the story of our beautiful son so I can provide you with the context for how we came to find ourselves in this no-man's land of "undetermined".

Kai was born 10 days early, at 6:32am on Tuesday, May 3, 2005 in a hospital about a mile from here – in spite of his early delivery date, he was the picture of health, weighing 8 pounds, 9 ounces, stretching 21 ¼" long, and scoring a 9:9 on his appgars.

We spent a wonderful two days together in the hospital...then on day two we were visited by the lactation specialist who explained on that night we were to experience "cluster feeding" and that I would need to be up to feed Kai every time he cried. In anticipation of this, the evening of his second day with us I asked my nurse if she would teach me how to breast feed in bed. Mark and I went to sleep at 12am. Then at 12:40am, Kai started crying. I know because I looked at the clock to see how much time he had allowed us to sleep before wanting to feed. Let the fun begin, I thought! I started to put my bed in an upright position, but then remembered that the nurse had taught me how to breast feed lying down, so I put my bed back down and took Kai into bed with me. I then very carefully assumed the position my nurse had taught me....I lay on my left side with my left arm above my head, head resting on my arm and then put Kai tummy to tummy with me. I had freed him from his swaddle so he wouldn't overheat, put a pillow behind his back, latched him onto my left breast and then put my right hand on my breast. By the time we were all situated, it was probably 12:44am. Kai was feeding just fine and then I dozed off. I woke up about 5 to 10 minutes later when I realized Kai wasn't nursing anymore. That had happened over the past two days, so I knew I just needed to stroke his hair to get him going again. I did that, but there was no response. I then decided to try tickling his feet....mind you, we were in the dark....when I tickled his feet and there was still no response, I began to get nervous, but very practically told myself I was being a hyper-sensitive first time mother. So I picked him up to wake him up and reassure myself that all was well.

Instead, his head dropped. I screamed for Mark who was sleeping in the room with me. He turned on the light....we saw Kai's color was off....a yellow/blue color....he wasn't breathing, so Mark started administering CPR and I pushed the help button, screaming "I killed my baby, I killed my baby!" I was the one holding him....what other explanation could there be?? Within seconds a bunch of people were in our room and rushed off to try to save Kai. They took him away a few minutes before 1am.

Eventually a doctor came in and told us that although they had managed to resuscitate Kai, he was brain dead because in the process of their trying to save his life, he had suffered a number of seizures. I was also assured that it was nothing I had done, that this was simply "bad luck". I believe it was explained to us that Kai would never recover and that we needed to consider taking him off the respirator. At that point, hoping to realize some good out of this nightmare, we asked if we could donate Kai's organs to other children. From there Kai was transported to CPMC's NICU unit where he was examined by multiple doctors to determine if he was a suitable organ donor, as well as to try and figure out what had caused him to stop breathing.

By Friday, we had learned that Kai could not donate his organs because he didn't meet the weight requirement to be a donor. At 6:00pm that day, then, 83 ½ hours after he was born, we turned off Kai's respirator. He died in our arms about 40 minutes later. At about 9pm the Assistant Coroner came to visit us in the hospital to interview us and to take Kai's body away to conduct an autopsy. He told us he presumed this was a case of SIDS, but also said that because Kai had been on a respirator for over a day, if he had suffocated all evidence would have been erased, so there would be no way for the coroner to "prove" I had been responsible for killing our son.

The Monday following Kai's death I received a phone call from Lorraine Lee, our public health nurse. She was the first to explain what SIDS was and how, although I was nursing Kai, I could not have known that he stopped breathing. That SIDS babies exhale and then simply don't inhale again....there is no struggling, no pain or panic...no hint that something is wrong (like a light turning off). That it was not unusual for a baby to die in the arms of a caregiver. That we were not alone.

Over the next few weeks, we got connected to First Candle, we received a copy of the *SIDS Survival Guide* which we poured through, we were connected with other SIDS parents...we explained to our friends and family that Kai had died of SIDS. We embraced this community. We began the process of healing.

Then, about 6 weeks after Kai's death, I called the pathologist to find out the status of Kai's autopsy report. It is at that point that my world began to crumble. He explained that he planned to label Kai's death "undetermined" rather than "SIDS." I didn't understand...I recited for him the Centers for Disease Control's Definition of SIDS...

"the sudden death of an infant less than one year of age that cannot be explained after a thorough investigation is conducted, including a complete autopsy, examination of the death scene, and review of the clinical history."

The San Mateo County Health Department's Definition of SIDS is:

"the death of a baby who is younger than 1 year old without a known cause." It goes on to say that... "a baby's death is not considered a case of SIDS when a specific cause is discovered, such as carbon monoxide poisoning. By definition, SIDS is considered the cause of a baby's death only when the death remains unexplained, even after a thorough investigation."

I went on to say that a diagnosis of SIDS is essentially an exclusionary diagnosis, one that is made by ruling out all other possible causes. How then could Kai's death be labeled "undetermined"?? Didn't "undetermined" by definition mean SIDS?? The pathologist explained there were three reasons he chose "undetermined" rather than "SIDS":

First, he said he understood I had a precipitous labor...this was untrue...although I was fully dilated when we arrived at the hospital, and Kai was born just 32 minutes after we arrived, I had opted to labor at home rather than in the hospital (I gather this is rather unusual for a first time mother)...indeed, I had gone into labor at 1pm the previous afternoon.

Second, he noted that Kai's umbilical cord had been wrapped around his neck as he was being delivered. I responded that while this was true, no one seemed alarmed, on the contrary, I was simply told to stop pushing and the midwife unwrapped the cord. I also said I thought this was rather common in delivery.

Third, he said that because Kai had been nursing when he died, the pathologist could not rule out oronasal obstruction as a cause of death. Although he went on to say that between us he didn't think that was what had happened.

Those last words I didn't hear...I had been condemned...it is a devastating thing to learn you might have contributed to your baby's death. The autopsy report was coming and the "undetermined" cause of death on the death certificate may as well have said "mother". I am not exaggerating when I tell you that it is only because of a wonderful husband who never doubted me and an amazing support network made up of family, Lorraine, First Candle, and Dr. Krous of Children's Hospital San Diego (to whom we had been introduced by First Candle as a result of the finding in the autopsy report), that I survived the feelings of guilt that ensued.

Perhaps the best way for me to demonstrate this is by sharing with you a letter I wrote to Dr. Krous about a year after Kai's death, after he graciously agreed to provide us with a second opinion autopsy report, because it will give you a clear sense for the impact the "undetermined" finding had on me even a year after Kai's death.

Dear Dr. Krous,

Mark and I want to thank you for having taken the time to review our son, Kai's, autopsy report. As traumatic and painful as the experience of losing Kai has been, we have been blessed to have met some truly exceptional people along our journey. Indeed, yours was the voice that calmed me on one of the most horrific days of my life...the day we received Kai's autopsy report...the day his cause of death was labeled "undetermined"...the day I felt somehow implicated in having contributed to our baby's death. I often wonder if coroners and pathologists appreciate the power they wield -- the fact that the words they choose in declaring a cause of death or the circumstances surrounding that death can so impact a person's life -- condemn her to a life of despair, regret, guilt, or set her free to begin healing. How many parents desperately seek absolution in these words?

I cannot possibly express the depth of gratitude I feel for the fact that in your assessment of Kai's case you noted that although oronasal obstruction as a result of his sleep position was possible (as was stated in the original autopsy report), there was nothing in the records that would substantiate this possible cause of death. With these few added words you set me free.

The burden of guilt one feels as a parent whose child has been hurt is a heavy one -- imagine, then, the weight one feels when one's child dies, especially in one's own arms. It is guilt so great as to be life-threatening. What an awesome responsibility you and your colleagues bear, then, when investigating the death of one's precious little baby.

I thank you for respecting the power of your position and for demonstrating such remarkable sensitivity and consideration in describing your findings -- you have helped me find the courage to try to become a mommy again.

Magali

[By the way, Dr. Krous found Kai's death to be "Unclassified Sudden Infant Death".]

I want to be clear that we are NOT debating the "undetermined", the "unclassified", or "unexplained" classification. After months of reflection, I understand why Kai's death was labeled undetermined. I understand there are times when there are too many questions for a coroner to feel comfortable classifying the cause of death as SIDS,...but I think it is essential for you to understand that the word "undetermined" is not just a word, for those of us where the "undetermined" classification is accompanied by the suggestion of responsibility, it is a sentence.

Some parents with the undetermined classification may be lucky in that their coroner will show the sensitivity Dr. Krous did with us; however, in other cases the coroner may place families at risk with the insinuation of guilt. Those are the families who need extra help from you. And I believe there will be more and more of these families as the overlap between SIDS and undetermined becomes greater. Indeed, one has to wonder, following the Journal of the American Academy of Pediatrics' finding that bed-sharing

may be a “risk factor” for SIDS, how many coroners are now going to label a baby’s death undetermined simply because he/she was in bed with the parents (even though SIDS is still the underlying cause of death).

So, in anticipation of your dealing with more parents like us, I’d like to share with you a few things you should know when working with this population:

First, they may have a mindset of guilt...

- As I mentioned in my note to Dr. Krous, the guilt can be so great as to be life threatening.
- I don’t pretend to speak for all families who have received the undetermined classification, but I don’t believe I’m alone in this...you may truly find parents who are on the precipice.
- For me, the role of being a mother which I had so looked forward to and prepared for, became the sword that caused me pain.
- You need to follow up with the undetermined families immediately after the coroner’s finding is announced and reinforce your support.
- Approach them understanding they may be feeling guilty and try to put them at ease.
- Ensure them you are not there to judge them, but to help them.
- That no matter how the coroner classifies their baby’s death, it does not negate the fact they lost their child suddenly and that they need support.

Second, they may have a sense of confusion...

- If the official definition of SIDS is “the sudden death of an infant less than one year of age that cannot be explained after a thorough investigation is conducted, including a complete autopsy, examination of the death scene, and review of the clinical history”, then why doesn’t our situation apply?
- Our experience seems to fit SIDS, not only in terms of the formal definition, but in terms of our overall experience; yet we’re being told we somehow fit outside this world.
- Does that mean, because we’re no longer officially a SIDS family, we no longer have access to support?
- Again, make sure your families know you are there to support them regardless of cause of death and that they should still feel justified in utilizing the exact same resources set up for SIDS parents.

Third, they may feel the sense of having lost a community...

- The SIDS diagnosis gives the parents something to hang their experience on.
- It offers an explanation that family, friends, colleagues, strangers can understand.
- Without that label they can become lost, feel alone, untouchable.
- Again, make sure you communicate that your involvement in their life is about sudden infant death, not SIDS per se.

Fourth, they may experience a sense of vulnerability,

- This isn’t helped by the fact that details in the autopsy report are a matter of public record for anyone who might be curious to see them.

- The “undetermined” classification and many of the details related to how the coroner arrived at his/her finding will live on beyond us...there in black and white, which just furthers the feeling of vulnerability and is very hard to move past.
- Bring your own personal experience into your interactions with these parents – remind them that coroners and pathologists are just people and they come to work with their own set of biases.
- For example, if you know the pathologist in your county has a tendency not to label infant deaths “SIDS” except when a baby dies between the 2nd and 4th month of life or between the 3rd and 6th month of life, or to never label the cause of death “SIDS” when someone is in the room with the baby at the time of death, or never to label the cause of death “SIDS” when there is bed sharing,...let the parents know. What I've learned is that at this point there is no fool proof diagnosis of SIDS; this is not an exact science.

Fifth, they may experience the sense of losing the opportunity to bring some good to the situation

- This, I'm certain, will not be applicable to everyone.
- But, as I mentioned, it was very important to Mark and me for some good to come from this situation...first we hoped to help other families by donating Kai's organs and soft tissue, but when we learned both were impossible, we were told that we could find comfort in the fact that Kai's statistics would further SIDS research. When we learned his death would be labeled undetermined, we saw our last bit of hope dashed.
- If you have parents who express this same distress, let them know that the statistics related to the death of infants with an undetermined classification are indeed included in the SIDS research...mainly because, as I understand it, researchers themselves understand there is inconsistency in the classifications of these infant deaths.

In closing, let me say that we/I have managed to survive the guilt and, as you can see from my big tummy, we are now moving forward in life, with hope (our baby is due December 17th). That said, the guilt will never be completely erased from my mind; however, I learned along our journey that only I can exonerate myself. Only I can find it within me to embrace life again. This is a message that I'm afraid you may not be able to deliver to your clients yourselves unless you've gone through this situation personally, so I would suggest that you identify someone among your past clients who may have had an experience with the undetermined classification and may be willing to speak with your new clients who are faced with the same challenge, as I think that could prove very helpful to them.

And finally, you can tell your clients there is at least one couple out there you know whose baby actually died of undetermined causes who has made the decision that, when asked, they will explain to people their baby died of SIDS, as it makes life much, much less complicated...what your clients should take away from that, is that they should feel comfortable doing whatever feels right to them...whatever will make life in the wake of this tragedy survivable.

Footnote: On December 14, 2007 Mark and Magali Leialoha welcomed their second son, Ea Kunane, into their lives. In the Hawaiian language, Ea means life and Kunane means little brother.



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