

Breaking The News: Suggestions For Telling Parents That Their Baby Has Died, From A Bereaved Mother's Perspective

Nancy Maruyama, RN, BSN

Our first child and only son, Brendan, was born on a sunny June morning in 1985. Born full term, he weighed 8lbs 9oz with Apgar's of 9 & 10. He was the first grandchild on both sides. Our lives were perfect.

A mere 140 days later, on a rainy October morning, we experienced the worst day of our lives. I dropped Brendan off at the sitter's home at 7am. At 10am, I received a call that is every parent's worst nightmare. Our son was unresponsive. The sitter and I both called 911, and the paramedics arrived quickly to transport him to the nearest hospital ED.

I was working as an RN at a hospital in Chicago. As I yelled to a co-worker to call my husband, I took off running to the parking structure. It was pouring rain as I drove like a maniac on the expressway to get to the hospital as fast as I could. I prayed. Praying that he was not dead, and praying to have the police stop me because I knew I should not have been behind the wheel.

In 1985, most nurses wore white uniforms, white hose, and clinic shoes. I had my name tag on that clearly identified me as a nurse. I ran to reception and when I asked for my son, I saw the color drain out of the ward clerk's face. I knew that it was not going to be good news, and her face confirmed my worst fears. I remember feeling faint and short of breath as I fell to my knees. I walked, with some assistance to "the room." You know the room. A room out of earshot of others waiting in the ED. A room that is painted a drab, pale green, that has no windows – only couches and a phone, where I waited for my husband and the doctor. Prior to my husband's arrival, the ED physician came and spoke briefly to me. He told me that they were working hard on our son and doing everything they could to resuscitate him. From seemingly out of nowhere, a chaplain appeared next to me. The doctor exited the room, as I waited for my husband and all of our family members. The chaplain did not speak, but sat next to me and held my hand until my husband arrived.

Once my husband arrived, the doctor came back in to talk with us. It was now past 1pm. Three hours had passed since Brendan arrived at the ED unresponsive. The doctor had a very kind face. He sat across from the two of us, placed his hands – one on my knee and the other on my husband's knee – looked us in the eye to tell us that they were doing all they could, however, Brendan arrived in asystole. I knew what that word meant, but at that moment, I could not comprehend what he was saying. I remember crying to him that he needed to save our baby regardless of how compromised he would

be. He left the room only to come back to us a short time later to notify us that our son, Brendan, had died.

The events that followed really helped to set the way we would cope with our acute grief. A nurse brought us to Brendan. The room was cleared of all machines and resuscitation equipment. All of the tubes that had been placed in his body were removed. Brendan was wrapped in a warm blanket (a nurse had thoughtfully used a blanket from the warmer), and in a bassinet. Someone brought in a rocking chair to sit in while rocking Brendan. They dimmed the lights and closed the door for privacy. When I needed to take a moment, I passed by the nurses station. I cannot tell you their names, but I clearly remember the color of their hair. For a long time, I thought they had their heads down because they could not bear to look at me. I felt that I was a terrible mom. I was a nurse and I should have known that something was wrong. I thought if I had been home with him, instead of being back at work, I might have saved him. This is what I thought and felt every time I passed the nurses station. I realized later, that, because I was a nurse, they understood that they were not immune to loss, pain, or grief. They kept their heads down and hid behind their hair because there were tears in their eyes. By that time, our families had arrived and all had the opportunity to hold Brendan and say goodbye. I was not able to hold him; it was his body, but my son was gone. I have made my peace with that choice.

“ The staff allowed us to stay with Brendan as long as we wished; there was no sense of urgency for us to leave. We received all of his belongings when we left, and we were so grateful for that gesture. ”

The staff allowed us to stay with Brendan as long as we wished; there was no sense of urgency for us to leave. We received all of his belongings when we left, and we were so grateful for that gesture. They were soiled with breast milk from the moment of death, but if you try to take it from me, there would be a fist-fight. Because we were young parents, we did not own a camera or a video camera. His belongings were really the only memento we have from that day.

Going home without him was unbearable. Later, I met a woman who, like us, had, experienced the death of her infant daughter years before. She was one of many people who held my hand and helped me to cope with Brendan's death.

Over the past 34 years since Brendan died, I have learned many things from newly bereaved parents that I want to share:

- Please use our child's name. He/she is not an it. To us, he/she is a thou.
- We know you are uncomfortable being with us; there is no way for us to make you more comfortable because we are in a nightmare. We are actually hoping for you to show us the way.
- Do not Hit and Run with the bad news. Please stay and allow

New subscribers are always welcome!

NEONATOLOGY TODAY

**To sign up for free monthly subscription,
just click on this box to go directly to our
subscription page**

the parents to ask questions. Let them know what will happen next. Be prepared to repeat explanations several times. The parents will be in a fog. It is difficult to comprehend and absorb this tragic event.

- Use the dead words. Avoid passive words like lost, expired, or passed. As hard as it is for you to say dead and as hard as it is for us parents to hear it, it is crucial for us to be able to grasp what your meaning is.
 - When we hear that you lost our baby, we immediately think that you put our baby on a gurney and have forgotten where you left him/her. We are trying to comprehend what it is you are saying. Also, please put up the side rails if the deceased baby is unattended on the gurney. This is important to the parents. We know that our baby won't roll off of the gurney, but it just feels wrong to us.
 - Using the term expired sounds more like a library card and not a baby that has died.
- Please make eye contact (unless it is culturally inappropriate). Not making eye contact can be perceived that we are such horrid parents that you cannot stand to look at us. Please sit if we are sitting; hovering over us makes a terrible situation even more uncomfortable.
- Provide a private area or room where the family has access to a telephone while they are waiting. A staff member needs to check on family often while they are there.
- Give family permission to talk and express feelings. You are in a position of authority, and the parents will look to you for guidance.
- Speaking to all family members or friends that are present will help to avoid miscommunication during this time of stress.
- Allow the family as much time as needed to hold, rock, and say goodbye to their child. A quiet room, free of resuscitation equipment, with a rocking chair and dimmed lighting is appropriate at this time.

- Explain what will happen next. Where will the baby's body be taken? When will they be able to see their child again? What about an autopsy? If the mother is breastfeeding at the time of the child's death, she will need information about how to handle this. Ask Social Services for resources that you can give the family regarding grief and bereavement support.
- Return all belongings to the family, even if they are soiled or cut. It is the parent's decision on whether or not to dispose of these items.
- Be prepared to answer...“Was my baby/child in pain?” “Did they suffer?” “Were they afraid?”
- Please do not try to find something positive in our loss. Avoid platitudes, religious dogma, or advice. Even if you are a bereaved parent, one can never truly know another's grief.
- It is ok to tell us that you are sorry for our loss. We know our baby's death is NOT YOUR FAULT. Your emotional side may feel a sense of responsibility because our baby could not be saved. Please be brave with us.
- Tears are also OK. There is truly nothing sadder than telling parents that their baby has died.
- Mementos are very important. A photograph, a hand or footprint, or a lock of hair will have tremendous meaning for the bereaved families. I have talked to many parents that wish they had a memento of their beloved baby, myself included.
- Families judge staff by their level of compassion as well as their medical skills. Make sure to care for yourself during stressful events. It is difficult to be present for anyone else if you do not refill your cup. Vicarious trauma is cumulative. Please remember: Physician Heal Thyself.

“ It has been 34 years since our son was alive for 140 days. I believe he lived his whole life in 140 days: full tummy, love, kisses, dry diaper, hugs, and love, love, love. He has taught us many things about ourselves. He taught us not to take things for granted. He taught us that you never know what happens next. He taught us unconditional love. ”

It has been 34 years since our son was alive for 140 days. I believe he lived his whole life in 140 days: full tummy, love, kisses, dry diaper,

Readers can also follow

NEONATOLOGY TODAY

via our Twitter Feed

@NEOTODAY



hugs, and love, love, love. He has taught us many things about ourselves. He taught us not to take things for granted. He taught us that you never know what happens next. He taught us unconditional love.

His life and death brought me to my role in the universe. In time, we had two "rainbow" babies who are the lights of our lives. Sadly, they grieve for the brother they never knew. Brendan will always be our firstborn even though we hold him in our hearts and not in our hands. We often take family photos where one of us is holding his picture.

Please refer bereaved families to local support organizations. In Illinois, you can refer all infant deaths, birth to age one year, to Sudden Infant Death Services of Illinois, Inc. regardless of cause or manner of death. 1-800-432-7437 (SIDS) and www.sidsillinois.org. While we cannot take away their pain and suffering, we can walk alongside them and companion them through their intense grief.

Disclosure: The author has no disclosures.

NT

Corresponding Author



*Nancy Maruyama, RN, BSN
Mother of Brendan 6/1/85 – 10/18/85 SIDS
Executive Director
Sudden Infant Death Services of Illinois, Inc.
6010 State Route 53, Suite A
Lisle, IL 60532
630-541-3901 office
630-541-8246 fax
www.sidsillinois.org
nancy@sidsillinois.org*