

Forever Angels



Hello Everyone,

It is very difficult to find the strength to "do battle" when one is grieving, but perhaps for some, having a focus or goal such as advocating for the right to be recognized as a living entity when loss occurs before 20 weeks, can facilitate grieving. What I am talking about are the birth statistical practices of some US States and all Canadian Provinces and Territories in which hospitals do not accurately records births if a baby is lost in utero before 20 weeks gestation. This practice makes it emotionally difficult for parents whom have lost a co-multiple in utero by 20 weeks. The loss of a child, even well before 20 weeks, causes worry about the impact on the remaining child(ren) and the remainder of the pregnancy is very stressful as a result. Some families need a death plan in place prior to delivery as well as a birth plan.

The heart breaking part is that at delivery, only the live ones are officially counted. Depending upon when the survivor(s) is delivered, there may be opportunities for holding, photographing and taking hand and foot prints of the deceased baby as well as the survivor, but nevertheless, the deceased baby's delivery is not recorded before 20 weeks gestation. It feels as if the system is broke.

I'm left with a few questions:

- what's so special about choosing 20 weeks? Who decided on 20 weeks and why? (not a bereaved multiple birth parent, I am sure);*
- whom is it going to hurt to acknowledge on paper a deceased fetus/baby before 20 weeks other than the parents, and no doubt his surviving co-multiple(s)?;*
- how do officials think the survivor(s) is going to feel being declared a "singleton birth" - or "twins" in the case of a triplet pregnancy?;*
- doesn't it show compassion to acknowledge that a woman has carried a baby and felt it move for all those weeks?;*
- what psychological damage is done to the parents (and co-sibling[s]) when the other baby is not acknowledged?;*
- wonder if this lack of acknowledgment adds any extra pressure to the spousal relationship?;*
- wonder if this lack of acknowledgment affects/delays bonding with the other baby(ies)?;*
- if I was pregnant with a single baby and lost it at 19-1/2 weeks (or 12 weeks, or 15 weeks), does that mean I was never pregnant? It would be argued that I had had a miscarriage and that would be correct. But wait! - that's an acknowledgment of my single pregnancy. If I was carrying two, or three, and lost one before 20 weeks, this would, by statistical procedure in some States and Canada, be labelled a single birth, or in the latter case, a twin birth. And that's not statistically correct.*

I would put forth that when losses in a multiple birth pregnancy are not recorded before 20 weeks, multiple birth statistics are not accurately gathered and no doubt there are

many more of at least "singleton" twins out and about, than was previously thought. Further, unrecorded losses before 20 weeks makes it very difficult to accurately record occurrences such as Vanishing Twin, Multifetal Pregnancy Reduction, maybe Twin-to-Twin Transfusion Syndrome or loss for other reasons (e.g. growth discordancy, severe anomalies).

In order to ensure that each family receives the compassion, support and resources they need, why does it truly matter when a fetus or baby was lost within the multiple birth? Surely if each can be seen on an ultrasound and a heartbeat recorded, that is a life that needs to be acknowledged. If you doubt me, just ask the parents.

As per usual, feel free to write to us about anything at all. We love to hear from you about what is important to you.

*Thinking of you,
Lynda*

Loss of One Twin in Utero: Keeping Walker and Losing Willis

My husband Michael and I found out we were having twins on October 20, 2006 which also just so happened to be the day we were married. I was attending school in Tuscaloosa, Alabama at the University of Alabama and I started to feel so sick I could barely eat. I knew right then that I was pregnant, I just knew.

Michael and I were both excited and we went to the courthouse and got married as soon as we left the doctor's office that day. We were just glowing and telling everyone at the courthouse that we were expecting twins. Nothing could bring us down. We spent the next few months guessing what sex they would be. On December 4 we found out they were both boys. We named them Walker and Willis after each of our grandpas. I loved both of those babies with all my heart.

I continued to be sick even in my fifth month and had trouble keeping food down, but I told God all the time I would suffer through whatever, if only He would keep my babies safe. I really believed that He would. I never expected the news we got on January 3 when I went back in for a routine ultrasound. Twin A no longer had a heart beat and from that moment I just went into complete shock. I started crying right there on the ultrasound table and I just couldn't believe it. The doctor came in and told me he was sorry, he said we now had to focus on getting Walker here safely. He sent me to a specialist who said that Walker looked very healthy and that Walker might even go full term. I was so thankful to still have Walker fighting as he did, but of course I always thought of Willis and wondered what happened to him. I even wondered if it was my fault. I wondered why God would not want me to have both of my babies. My mother in law told people that I needed to stop talking about Willis and focus on Walker. That really hurt, how dare her! Willis was just as much my baby as Walker, and he was Walker's brother. I will never stop talking about him.

At home, I began to have anxiety attacks. I would wake up at night and just panic because I would not feel Walker move. Most of the time I would just shake because I was so nervous and scared for Walker. After several late night visits to the hospital and an ultrasound that showed Walker was not doing very good, they sent me to Huntsville where I was to remain in the hospital and be monitored until Walker was born. The nurses were so wonderful to me in the hospital. They comforted me and tried to reassure me that Walker looked wonderful on the heart monitor. And at night when they would hear me crying, they came in to hand me tissues and get me whatever I needed. I don't know what I would have done without my nurses. Dr. B., the specialist, was heaven sent. I don't know if Walker would be here if it was not for him. He took such good care of us and he is the one who made the decision to put me in the hospital.

On March 6, 2007, at 11:22 p.m., Walker Joseph was born and Willis' little body was delivered too by C section. Walker was beautiful and was sent immediately to the neonatal, he was only three pounds. It sounds weird but I really thought more of Willis those first couple of days, because I knew that now I had to start saying my goodbyes to him. After all those months, he had been with me, even in death he remained in me. Now I had to give him up. I held him close, and talked to him. I wondered 'why' so many times, but that question will not be answered here on this earth. I know there was a reason.

I remember the hospital staff who handled the birth certificates came and had me review Walker's birth certificate. I noticed it said he was a single birth and I started to cry. I asked her why it didn't say twin. She said he was not considered a twin anymore but she would ask for me. In the end, they would not change it. It hurt but I tried to understand where they were coming from.

Walker is doing well, he is four months now and twelve pounds. He is a blessing, but of course I will always wish Willis was here with us. But Walker fought so hard even when his brother was gone. I often wonder what he thought when Willis was no longer beside him kicking and was no longer moving. I thank God everyday for Walker and thank my nurses and my doctor that I now have a precious baby. I often think about how I used to pray that God would take care of both of my babies and I now see that he has. Walker is here with us and Willis is in heaven where no pain will even touch him. That is what comforts me the most. Thankyou so much for this opportunity to share about my babies.

Sincerely,
Brooke, Florence, AL

You cannot do a kindness too soon, because you never know how soon it will be too late.
Proverb

Down the Road.....

How are things for you and your family? Most of the time great, 2-1/2 years helps with the pain.

How long is it since your loss? 2-1/2 years

*We lost, e.g. one of twins, two triplets, both twins....*One of our twins, our son Charlie

What helped or supported you the most at the time of your loss? Having Thomas

What helped you the least? The people who couldn't understand that we knew both babies so well by 38 weeks of pregnancy, and didn't get the pain of the shock of the stillbirth.

Do you celebrate any anniversaries? Every birthday belongs to both boys.

If so, how/what do you celebrate (e.g. Birth Day, Death Day, other)? I take a vacation day from work so I can have the space to be happy and sad together with Thomas. We wake up extra early to bask in the happy memory of the morning of my planned section, when we thought everything was perfect, as it had been for the previous 38 weeks. I make 2 cakes. We write birthday messages on foil balloons for both boys, and Thomas signs his brother's balloon too. We let Charlie's balloon go free at the end of the day, just before sunset.

Is there something that you would have appreciated, perhaps annually, on your anniversary of loss by your family or friends that would have helped, even a little bit? For their first birthday, my friends bought Charlie a hurricane lamp with a candle in it. It was great to have someone acknowledge that it was the first birthday for 2 little boys, not just one. Each year their birthday is the anniversary of the happiest and saddest day of my life.

How is Mom at this point in time? Still crying, but only when I give myself permission.

How is Dad at this point in time? Also still crying about half the time we talk about Charlie.

If you have a survivor(s), how have you chosen to let them know about their co-sibling(s)? We have several pictures of Thomas and Charlie the day they were born around the house. In Thomas' room,

certificates from the house of parliament welcoming each of them hang over the change table. We talk about "your brother" to Thomas.

What would you offer by way of support to another family who recently lost one, more or all of their children? A message of hope. The pain rips you apart, and your world ends. But you keep breathing, and living, and the pain does become manageable, and there is still a world out there.

Anything else you might like to add. My thanks for you having this newsletter

Letter to the Editor, re July issue #07-07 of Forever Angels

Hello Lynda,

Having been in both "shoes" (the parent of a twin who died, and the health care professional looking after women who have suffered a loss) I have ZERO tolerance for "the office is too busy" to return calls. "Focusing on the living" is no excuse, that mom is still living and in desperate need of attention. When a mom has a still birth or death in my practice, they actually get more postnatal visits [from me], not less. I also make these home visits, as the last thing I expect a greiving mother to do is attend my office, which is decorated with photos of happy families and smiling babies, not to mention the other moms and babies in the waiting room.

After the traditional 6 weeks of care, I also make sure I make a point of flagging the anniversary of the loss in our office scheduling program. I want to remember to make that call and check in with the family (but acknowledge my own limitation with remembering things a year ahead). Before computerized appointment scheduling it was an old fashioned notation on the last page of my calendar. Whatever works, the family deserves to know they are remembered.

The slowness of autopsy and lab results is a source of frustration to parents and health care providers alike. I wish I could make them move faster. But since I can't, a quick call to the family to say I've looked in the computer again, and the results still aren't in, at least acknowledges that you too value the information, and the parents' need to have it. Even if the answer is we don't know.

Elizabeth

NOW ON LINE.....

Back issues of *Forever Angels*. We are working on going even further back but if you would like to read some back issues of *Forever Angels*, please check them out at the Loss Support Network section of MBC's WS at www.multiplebirthscanada.org.