

Forever Angels



Hello Everyone,

I hope this finds all well with you. Well, the Opinion Piece in Issue #07-07 really brought in thoughts from some of our readers. With it polished up a little and edited to fit the criteria, I also sent it to our local paper and one national Canadian paper. With encouragement from the MBC Board of Directors, it was felt that bringing such a topic to the attention of healthcare professionals and other parents, could be a valuable step towards change. While our local paper confirmed receipt, unfortunately they chose not to print it. I heard nothing from the national newspaper. I certainly wish we could interest the general public in understanding what the loss of a child(ren) means for a family and to share some of the ramifications, many of which are exacerbated by untimely (if any) test results from some doctors' offices. It's always good to speak up and let them know what you need but even so, a topic may not always get the attention it rightly deserves.

I have included some of the feedback from our members. I understand I am speaking to the converted and those who walk that particular journey. Nothing will change for grieving families without the attention of the physicians and their staff as to the negative effect these long, drawn out vigils waiting for information can take on families struggling to come to terms with the loss of their child(ren). I am not about to give up in this regard and I hope you won't either. Keep pressing for answers you need!

Don't forget to let me know if you change your e-mail address and do write in about anything at all. Together we can do so much more from providing a shoulder, maybe some important advice or just an outstretched hand when the road is particularly bumpy.

*Thinking of you,
Lynda*

No pessimist ever discovered the secret of the stars, sailed to an uncharted land, or opened a new doorway for the human spirit. Helen Keller

Feedback from Forever Angels, Issue #07-07.....

Lynda:

My sympathies to the parents who are having such difficulties getting the facts! There may be a few reasons why these obstacles arise.

1. Most of the information from autopsy, pathology report or record review is best discussed in person at a doctor's visit. Doctors may not want to just release it to parents in the mail without a visit to discuss the

medical findings and address whatever concerns the parents may have about future pregnancies or whether the problem could have been prevented.

2. Doctors grieve, too...they may feel very awkward at confronting the parents and revisiting the loss. True, they should be professional & compassionate, but skills vary quite a bit on this point, and their human awkwardness may sometimes override their willingness to be confronted by angry, hurt, devastated parents.

3. Also, from the doctor's viewpoint, there may be concerns about information in autopsy or pathology reports that could implicate them in the baby's death. I recently learned of a \$22 million U.S. judgment for wrongful birth in a doctor who didn't offer to test for a genetic problem in a couple's second pregnancy (their first child was affected by a hereditary condition and the second had it, too, both children are living in this instance, but it's an example of the medicolegal climate in our country). It's a sad reality, but it is the environment in which at least U.S. doctors practice.

Even with these considerations, parents still need & deserve information. It's probably too much to expect doctors to appoint a staff person to call parents every 2 weeks to tell them "we haven't heard anything." It would be best for parents to schedule a consultation with the doctor about 2 months after the loss. Usually that should be more than enough time for all reports to come in and for the doc to have had a chance to discuss results with parents. An appointment on the schedule means that the doc and staff know they need to have all data together by that date to review with the parents.

In some cases, especially when there is suspicion of possible error in management that may have led to the loss, parents may need to bring in an attorney to sue to get a copy of records, or could set up a consultation with a different OB or maternal fetal medicine doctor to review their records.

Hospitals sometimes need to put together a meeting between everyone involved in a case to meet with parents/patients. They are usually pretty aggressive about getting all the clinical people together ahead of time to review the case so they can discuss in detail with the parents what happened. Approaching the hospital, rather than the OB or head of NICU, may make more sense in complicated situations.

I hope these thoughts help, but I agree with you that parents should get prompt, honest information and shouldn't have to fight for it, so they can work through their grief and make appropriate plans for the future if they should choose to try for another pregnancy.

Beth Pector, M.D.
Family Physician, Illinois, U.S.A.

Editor's Note: These grieving families are more than willing to go into their doctor's office to discuss any findings. In truth, there aren't any results to share, for one family even after one year.

Hi Lynda

As both a family physician and someone who has lost a baby I felt I ought to reply. Generally speaking, I don't like receiving direct outside phone calls when I'm in my office, but if I receive messages passed on by my reception staff from anyone about anything, I always action them in some way, whether it's by inviting the person to come in to the office to see me, or returning the call, filling in the form, or whatever it happens to be. There's no excuse for just

ignoring messages and requests for information. But I know a lot of doctors do this, and I can only think it's because they are disorganized, lazy, inconsiderate or a bit of all three (I don't accept "too busy" as an excuse). There is a doctor shortage across most of Canada and unfortunately this doesn't help, because maybe some doctors feel they are such a precious resource that they don't have to be particularly efficient or considerate - they will still have lots of patients because people don't have much choice. Unfortunately I don't have any easy answers about what to do about this problem.

Name withheld

Lynda, You are so right. We have had that exact situation with the death of our 29-day old [twin] granddaughter. Our son gave permission for the autopsy almost 4 months ago. For a while he called the doctor to get the results always getting "They're not in yet." When I ask him, he just doesn't want to talk about it anymore. He is trying to move forward and focus on the surviving twin. This lack of knowledge and consideration on the doctor's part is most disheartening. It seems to me that the doctor has not fulfilled his obligation to the parents.

Rise, Grandmother

Success is the maximum utilization of the ability that you have. Zig Zigler

There are no short cuts to any place worth going. Beverly Sills

QUESTIONS.....

Ques: [My twin grandchildren will be 4 on 7th Sept, 07. One tragically died in a car crash 10th July, 07. How do we celebrate the surviving twin's birthday?](#)

Ans: [I am so sorry to hear about the loss of your grandchild and under such a circumstance. I can understand your conflict. As this is the first birthday they will celebrate, and your surviving twin grandchild is old enough to understand that his co-multiple will not be there, how about asking him what he would like to do? It could be a real gift to all of you to let him guide you through this first time around. If he doesn't have any ideas on how to handle it, ask if he would like two cakes each with a name, or one cake with two names and "Happy Birthday" sung twice. There is no right or wrong way to celebrate this birthday and nothing about it is going to be easy. Expecting some tears, is a given. If, in spite of everyone's sadness, you can find a place to celebrate your living grandchild, that would be good and certainly encourage your surviving grandchild to still view their birthday as a special occasion. You may wish to limit attendance at this first birthday alone to the family or it may be a helpful diversion to invite one or two young friends/cousins/neighbours, whichever works. Your grandchild may guide you by stating his wishes, it could be that he may even speak for/about his deceased co-twin. Go with his flow](#)

where prudent. [You don't mention if your grandchildren are boys, girls or one of each, so I hope I am not offending by referring to "him."]

For the adults, you may wish to spend a little time together perhaps with tears and hugs, perhaps with letting a biodegradable balloon go into the sky, or a homing pigeon. Your surviving twin grandchild may or may not wish to be a part of that process.

I hope this gives you a place to begin. If you would like to talk to another grandparent about how they handle their anniversaries, just let me know and I can arrange it.

May you find peace and comfort in your memories.

Lynda