From Bliss, To Barely Breathing: Finding The Light Again After Infant Loss

By Ginger Nichols, Certified Genetic Counselor at MotherToBaby Connecticut

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Twelve years ago I was still blissfully 24 weeks pregnant, unaware that in a couple days I would be admitted to the hospital for two hellishly long weeks of bed rest listening to the constant beeps of the fetal heart rate monitor; feeling alone and terrified for the health of my unborn baby. My son, Lincoln, was delivered at 26 weeks, weighing only one pound. He was in the NICU in preemie diapers that were too big for him, and I was by his side for one week listening to the constant beeps, whirs, and alarms of his monitors. Sounds that will haunt me to the end of time. Lincoln died in my arms a week after he was born, and while I wasn't exactly aware of it at the time, thus began my post-traumatic stress disorder (PTSD). After grieving, my husband and I agreed to try again. We experienced several miscarriages, which were also heart breaking in similar and yet different ways from the death of Lincoln. Then, I finally had my miracle baby and gave birth to a healthy daughter. The day I brought her home from the hospital I realized

My daughter, a.k.a "Miracle Baby"

just how high my anxiety was. I wondered how I could manage without the help of the nurses. And I was terrified that she would stop breathing. 10 years later, she is still breathing fine. (I might even admit to the fact that I may still check on her once in a while in the middle of the night. And maybe, just maybe, I am considering the reality that I will still want to check to see if she is breathing even when she is off to college).

October is Pregnancy and Infant Loss Awareness Month.

I know through my work as a prenatal genetic counselor and experiences of friends and family that, unfortunately, I am not alone in facing pregnancy and infant loss. For those of you who have ever experienced a pregnancy loss or the death of a newborn, we are gut wrenchingly sorry.

We know, and research has confirmed, that women who have experienced a pregnancy or infant loss will experience many of the same grief stages that anyone does after the death of a family member. There may be some who don't understand how a miscarriage can be so upsetting, but, for those of us who have had one, we know that the moment we saw that positive pregnancy test we were already planning maternity leaves, nursery décor, baby's hair color, and colleges s/he would attend someday.

We can feel numb after a loss, but we can also feel many things, one after the other. Several strong emotions can be felt at once, such as shock and denial, sadness, grief, anger, or helplessness. However, for pregnancy loss there may

be other feelings, such as feeling betrayed by our bodies ***(Why couldn't I carry a term pregnancy?)***, to guilt over the possibility that we did something wrong ***(Was it the toothpaste I used?)***. And let's not even talk about how many happy pregnant women you suddenly see ***everywhere*** and how the number of diaper and baby commercials seems to have ***tripled*** after you've lost a baby or newborn!

Women with previous losses are a vulnerable population in their subsequent pregnancies.

There is no real "normal" in grief, and we all respond to stressors in unique ways. Our pregnancy stories vary and we will experience loss and grief in individual ways; however, there are some common themes. Research has shown that women who have had any type of pregnancy loss are at risk for depression, anxiety, excessive worry, stress, sadness, and / or lack of enjoyment in future pregnancies. We may also feel guilty about the times that we do feel happy. We worry about experiencing another loss, and wonder how we would ever survive that emotional pain again.

Depression or Post-traumatic Stress Disorder during pregnancy.

Research shows that women who have experienced pregnancy or perinatal loss can be 4 times more likely to develop symptoms of depression and 7 times more likely to suffer from PTSD than women who have never experienced a pregnancy or perinatal loss. This same research showed that most women with depression or PTSD don't receive any type of treatment. Depression during pregnancy has been associated with an increased chance for miscarriage, preterm labor, preterm delivery, low birth weight, diabetes, high blood pressure, preeclampsia (dangerously high blood pressure), cesarean section, and post-partum depression/mood disorders. Similarly, some studies looking at pregnancies in women with PTSD have suggested that there might be an increased chance for ectopic pregnancy (egg implanting in fallopian tube rather than uterus), miscarriage, hyperemesis (extreme morning sickness), high blood pressure, preterm contractions, preterm deliveries, or low birth weight.

For more information, you may also want to read the MotherToBaby fact sheet on depression in pregnancy found athttps://mothertobaby.org/files/Depression.pdf or stress in pregnancy at: https://mothertobaby.org/files/Stress.pdf .

Finding healthy ways to help you feel better is important. Your health care team may be able to refer you to a local therapist who specializes in working with women who have had pregnancy losses. The earlier you seek help, the better you may do. You don't have to go through this alone. Sometimes medications can be discussed, but often therapists can help teach you coping techniques with breathing exercises, meditation, or baby safe yoga. Each person's treatment plan should be personally designed after discussion with their health care provider.

Signs and symptoms of depression.

Remember, there is no "one size fits all". Meaning signs and symptoms of depression can be different among people, and they might change over time. Most people will not have all the symptoms at once. Having a "bad" day or two now and again is normal and is not true depression or anxiety. Women with depression and or anxiety have symptoms that are present most of the time, last for at least 2 weeks or longer and make day to day life hard to enjoy.
1- Feeling **overwhelmed.**
2- Feeling **guilty** about not being able to juggle all that life is throwing at you. You feel like someone else could do better than you are doing so far.
3- Feeling lost or not able to understand what is happening or why or how to change it. Scared to talk about it or reach out for help out of **fear of judgement** or worse.
4- Feeling **angry** and short tempered or **easily irritated**. You have **less patience** than ever before and can't seem to get into check. You may resent all those around you including your spouse. Rage is a good description of your emotions on a regular basis.
5- Feeling **numb** or empty.
6- Feeling a level of **sadness** you have never felt before.
7- Feeling **hopeless, helpless,** and **weak.**
8- Changes in **sleep** (too much or too little).
9- Changes in **eating** habits (too much or too little).
10- Lack of **concentration** and focus.
11- Feeling like you are **disconnected** from everyone and everything.
12- Feeling like you should be feeling better – except **you still aren't feeling right**.
13- Feeling like **you want to escape** and run away from your life.
14- Feeling **suicidal** or wanting to harm yourself.

Finding brightness in a dark situation and moving toward the light.

I think one important step in recovery is to find a health care provider that you trust for your next pregnancy. My OB team would let me just sit in their office and cry, and never once did they look at their watches and make me feel like I was taking up too much of their time. I also remember that instance when I voiced my concern about being a "Nervous Nellie" since I worried about every little thing. My doctor held my hand and said, "Not so, research has shown us how mothers with pregnancy and newborn losses can develop PTSD, and we understand." For these compassionate moments, I am thankful. In my line of work, I have found that many OB teams do understand. Some OB groups are likely to allow quick ultrasound peaks for Moms to see the baby's heartbeat, which might ease some of the anxiety in future pregnancies. MotherToBaby can also help ease stress when it comes to questions about medications, diseases and other exposures during pregnancy.

I hope reading this blog doesn't trigger heightened anxiety, but, instead, motivates you to build an important mental health support system around

you. Be gentle with yourself, and maybe eat some chocolate. Because when life throws you a curve ball full of grief, a good support system with great listening ears and shoulders to cry on can be a comfort. Life will never be the same, but remember you are not alone and there is hope.

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MotherToBaby is a service of the international Organization of Teratology Information Specialists (OTIS), a suggested resource by many agencies including the Centers for Disease Control and Prevention (CDC). If you have questions about alcohol, medications, vaccines, diseases, or other exposures, call MotherToBaby toll-FREE at 866-626-6847 or try out MotherToBaby's new text counseling service by texting questions to (855) 999-3525. You can also visit MotherToBaby.org to browse a library of fact sheets.

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