



Don't Be Late For Your Life

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Joscelyn's Mommy

Our departure from Florida Hospital for Children is imminent! After 22 emotion-filled days and 23 mostly sleepless and lonely nights later, we are going home! As happy as this prospect makes me, I'll confess that I also feel a bit of hesitation and anxiety.

My daughter is coming home after having had two radical brain surgeries and a shunt placement procedure. For weeks, she's had a staff of highly trained professionals tending to her needs round the clock and monitoring her closely for any signs of post-surgical complications. Once we take our still very fragile baby girl home, will we be able to recognize all of the danger signs of possible infection, shunt malfunction or other concern?

We will also have to be very vigilant to look for any sign of seizure activity. Dr. B says he holds his breath for the first six months after hemispherectomy, waiting to see whether or not the seizures return. Joss will stay on her anti-seizure medication for the next six months as a precaution while her brain heals. If she remains seizure-free for that period, the surgery is considered to have been successful and we can wean her from the medication. And what happens if she does have another seizure? The cycle begins again: Seizure monitoring to identify the seizure focus likely followed by more surgery, then more waiting and collective breath-holding.

I sometimes catch myself wanting to "fast-forward" through the next few weeks and months, even years sometimes, to skip ahead to the part in my life story when we're finally "settled," Joss is doing well and everything is more or less going according to (my) plan. I can finally relax and be happy then, right?

I think it must be human nature to delay or postpone our happiness like that. When we're kids, we say, "I'll be happy when I'm a teenager;" then, "I'll be happy when I'm in college," then, "When I'm established in my career, or married, or pregnant, or retired." We always think we're going to be happier at some point in the future. The fact is, if we (I) don't appreciate happiness right *NOW*, right in the midst of the chaos, messiness and unanswered questions of life, then the anxiety, depression and discontent that we (I) seem to be always struggling against will just continue to crowd it out.

As singer Mary Chapin Carpenter says:

"A change of scene would sure be great / The thought is nice to
contemplate / But the question begs, why would you wait / and be
late for your life?"

I don't want to be late for my life. I don't want to look back one day and realize that I missed the best parts of *my* journey because I was too focused on the future to feel myself living in the present.

Yes, I have plenty of reasons to feel stressed and anxious—but for how long should I put off allowing myself to be happy? Until Joscelyn is past the six-month mark? There go the holidays this year! Until I stop missing Nick so much? There goes the rest of my life! No, it's obvious that instead of waiting until conditions are perfect, my only real chance at happiness lies in celebrating the moments of beauty, humor and frivolity that still regularly occur on a daily basis, even in the midst of my grief and anxiety and in the face of an uncertain future. [Nick was their teenager who died in a terrible accident just a few months before they were told Joscelyn would have to have half of her brain removed.]

Joscelyn (like all children) inherently seems to know how to live for the joy of the moment. She undergoes radical brain surgery, comes out of sedation and does this: Smiles!

One week later, a second surgery. Yep. Still smiling! A week and a half later, another surgery to install a shunt to divert the excess cerebrospinal fluid from her skull to her belly cavity. She looks and feels pretty beat up but still, somehow, finds a reason to smile.

Babies don't fake smiles like grown-ups do. Joss is actually happy here! Despite having been removed from the safety and security of her home, despite having been poked, prodded and sutured, despite the fear she feels whenever someone in scrubs or a white coat enters her room, our little girl always finds her smile again. Our brave little warrior princess is teaching us to find our smile again, too.

We may be heading home, but our battle isn't over by a long shot. We still have to get our little girl walking and talking and comfortable using her right arm, leg and hand. It could take years. The battle will be long and at times, we may feel discouraged but like our brave little warrior princess, we will make the most of every opportunity to smile.

Because life, my life and yours, is happening *now*. I don't want to be late for it.