

DADDY

Bent-
Legs



TOO !!

Even More Musings from a Disabled Dad ...

Written by

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DADDY BENT-LEGS, *TOO !!*

Even More Musings
from a Disabled Dad ...

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~
For Mommy
~

HAPPY 5th WEDDING ANNIVERSARY

July 12, 2008

Dearest Elana:

Wow, five years ... what a milestone! :) And what an amazing, blessed five years it has been too. I am so glad that we have had these first five years where it was just us, where we had ample time to learn about each other. Each year that passes, I discover new bits & pieces of you: your goofiness, your intellect, your persistence, your emotionality. Our next five together will be very different, of course. But I'm excited to see how our genetic code will mix together to form the child God has given to us. It'll be very challenging, very fun - and again, something new.

I remember the first week of marriage to you - walking around on the cruise ship like I was on a cloud. Looking at my wedding ring and thinking: "Wow, I'm actually married. How cool is that!"

Cooler still, those feelings of great elation have never left me. If anything, my feelings are much stronger, run deeper now. Looking back, I really appreciate how far we have come.

Love always,
Husb-N



Our little family: Elana, Jake & me

FIRST MOTHER'S DAY: May 10, 2009

Now that Jake is living a life outside of your tummy
Welcome to your first official Mother's Day
As an honest-to-goodness Mommy!

Though it may seem at times
That you represent little more right now
Than milk from a breast
Remember that Jake is still a baby
Still growing
Not yet knowing
That he will soon love you best.

You are a mother, his mother
No one other.

You are his mother mild
The one whose voice he will most depend
To calm, to soothe, to sing
The only one to bring
A true sense of safety, assurance and love
To our small, helpless child.

You are his mother strong
To mentor, mold, model, and shape him
To discipline and to teach
Good from bad
Right from wrong.

Our son was a gift from God
And for many years to come
You will be a mother to Jake.

A blessing bestowed upon you,
On us,
With an all-knowing Wisdom that only one
Will ever be qualified enough to be a mother for Jake.

Only you, his mother.

Forward

*"The LORD gave and the LORD has taken away; may the name of the LORD be praised."
(Job 1:21, NIV)*

So this is the sequel, a part two.

My first book was published back in October 2009, about a month after Jake's 1st birthday. Anyone wanting to pick up a copy can still find it on Amazon.com, [here](#).

Close to five years have passed since that first book, the original **Daddy Bent-Legs**. A lot has changed since then. My wife Elana passed away on August 17th, 2013 about three weeks shy of Jake's 5th birthday.

Elana was first diagnosed with an auto-immune disorder right around the time of Jake's 1st birthday. Initially, it was diagnosed as Sjogren's Syndrome. Then another doctor thought it was Lymphedema. For the next four years Elana had to take daily doses of Prednisone, a powerful steroid - all the while not 100% sure of what she was battling. It wasn't until she got really sick - at the beginning of July 2013 - that Elana was finally given a correct diagnosis of Lupus. By then, it was already too late. Her liver & kidneys had been aggressively attacked by the Lupus and were shutting down. In the end, doctors did everything they could to save her but it wasn't quite enough.

Those last four years were hard on my wife, I know. She already had Arthrogryposis to deal with - a disability far greater than my own cerebral palsy. Confined to a motorized wheelchair for pretty much her whole life, Elana's body was severely limited. Her new auto-immune troubles and steroid pills just piled on top of all that. It really wreaked havoc on her physically: she had even less joint flexibility, increased soreness, rashes, bloating, weight-gain. And yet Elana simply carried on as Mommy (full speed ahead), rarely complaining about anything. Nothing would hold her back. Nothing could stop her. Nothing except a sudden and brutal flare-up of Lupus in the final six weeks of her life.

This book has been assembled in memory of Elana, a wife & mommy gone too soon. I've compiled the very best of my blog posts from www.daddybentlegs.com - including, as well, a small collection of Elana's own writings, personal emails and poetry. The first **Daddy Bent-Legs** ended with an acknowledgement and celebration of Jake's first year of life. This sequel picks up with my son at 2 1/2 years old and carries on until Elana's death, Jake's 5th birthday and another 8 or 9 months beyond. The book's end pages commemorate Mother's Day 2014, the first Mother's Day without Mommy.

Elana & I had an amazing life together, as a disabled married couple and as disabled parents. I always hoped we would eventually write a book together too. It would have been nice if Elana & I had a bunch more time to cobble something a bit weightier, more substantial.

It definitely could've been truly great. Alas, this is all I got. For now, this will have to do.



Me, Jake & Mommy circa Jake's 1st birthday



Jake & Mommy. Here Jake is 2 1/2 years old. Thirty-two months, actually :)

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Since I'm dedicating this book in remembrance of Elana, it's only fitting that my wife - Jake's mommy - gets to speak first. The first couple years of Jake's life, I really struggled as a parent sometimes. I was frequently tired, run-down and not sure where I best fit in amongst Elana's new Mommy routine.

I was sleep-deprived, yes. Sometimes just plain lazy. Other times, I lacked confidence. Elana was never afraid to confront me and set me straight. This is the letter she wrote me, encouraging me to do better. This is Elana, in her own words...

Don't hold back

July 18, 2010.

My dearest Neil,

When I first fell in love with you, it was because you were fun to be with, you made me feel special and I couldn't wait to spend every minute with you. Those things are still true today. Sharing my life with you for the past 7 years has been amazing...and having Jake has been the icing on the cake.

When I was pregnant you were so excited! You bought outfits and toys, chose a name, felt the baby kick, took care of me when I was sick, worried about me when I was bleeding and helped me keep my faith when we thought we had lost our little "spidey."

When I was in the hospital you stayed with me day and night, you watched over me and Jake, you sat by me while I nursed him, and you participated as much as possible with bathing and changing diapers. You were a very proud and involved daddy, as well as a very loving and supportive husband.

When we came home, things slowly started to change. You left the basic duties of caring for Jake to me...his baths, diaper changing, feeding, even entertaining him. Sure you were there to help when I asked you, but initiating and offering to do these things, with excitement and genuine interest would have meant the world to me. Of course you can't do these things by yourself, but neither can I. I do them by being present during these tasks. That is how I can best be his mom. So when he thinks back he will know and remember that I was there. Just think about the ways I would want you to be involved if you were an able-bodied man...you can still be involved by making your presence known. That is all Jake or I could ever want from you, your time and attention.

The care aides are here to "aid" us, not replace us. We are the parents and we need to take care of Jake together...nothing is sexier to me than when I see you being involved with him, whether it be taking off his shoes or reading him a book, I love it! I wanted to have your child and raise him with you...it hurts and frustrates me when I have to do this with an aide rather than my husband, the love of my life.

I've thought long and hard about why this happened, why you changed, why you are less involved than you could and should be...I think it all comes down to fear. You are afraid of failing, of being less than the perfect dad, of not being able to do anything for him until he is 3 years old (your favourite mantra),

so you withdraw to things that are safe, like the tv and the computer, and leave the majority of the baby-raising to me and the aide.

Let me end by saying that I know things have changed recently...you are trying much harder and I appreciate that. What I wish is that you wouldn't have to "try" to do this or that, but that you would just "want" to. I pray that you will examine this fear, find its source, stare it in the face and fight it. Share with me why you are struggling so that I can understand rather than blame. Together we can do this. I love you.

*He's holding back, he's hiding
But what, I can't decide
Why won't he be the king I know he is
The king I see inside?*

Taken from "Can You Feel the Love Tonight" – **The Lion King**

*The following is a blog post that Elana wrote, almost two full months before *my* blog site even launched.*

He'll get there

March 26, 2011

My two-and-a-half-year-old son was busy scanning the room for his next activity. He quickly looked around and settled on the toothbrush in my hand.

"You want to brush your teeth?", I asked him.

"Yeah."

This is his latest word for positive responses...it has recently replaced "okay."

"Go ask Tita to give you your toothbrush." Pitter, patter and he was off to her room.

"ake up Tita, 'ake up!"

"Please Tita can I have my toothbrush?" I asked on his behalf.

Soon after he came over to me and we brushed our teeth together. It was then that it hit me. A moment of clarity in my tenuous parenting journey. Prior to this I had never forced him to brush his teeth, I just did it in front of him every day and would occasionally ask him if he wanted to do it too. It had been over 6 months since he had last said yes, and even then it was more chewing on the toothbrush rather than any actual teeth-cleaning. Tonight, though, he was brushing up and down and all around, really getting those teeth clean. So what was my great revelation? That just like his previous developments, sitting, crawling, walking, talking, he came into tooth brushing on his own accord, in his own time. All I did was model the action and provide the opportunity. Could it be that for future progress it might be this easy?

Model and opportunity. Model and opportunity. I can almost taste the relief. Trust the process. He will find his way when left to discover it. Clarity of speech, politeness, sharing, empathy, reading, writing, arithmetic...you name it. He'll get there.

Now, if only I can hold on to this moment...

My first official blog post for www.daddybentlegs.com ...

Thirty-two months

May 18, 2011

My son Jake is 32 months old.

Before becoming a father, I never understood why parents still bothered with the "he's / she's so-many-months" thing once their child got past 18 months. I mean, why not just round down or up to the nearest half-year, right...? My son Jake is 2 1/2 years old - I could just say that.

Yah, I could. But I get it now. I get it why parents stubbornly stick with measuring their child's current life span in months. It's because each month is so important, so different than the one that came before ... or the month to come. Jake is growing up fast. He's learning new stuff every month, every week, every day.

I remember when Jake first learned to walk at around 15 months. At fifteen months, Jake was walking perfectly. Far better than me on crutches with my bent legs. And certainly better than his Mommy in a wheelchair with legs that don't work at all.

It was a strange thing to see our son exceed the physical capabilities of Mommy & Daddy combined at a mere 15 months of age!

A few months after that, Jake learned to jump. My legs can't jump - they don't have the power and muscle coordination to do that. To jump, the best I can do is push up on my crutches and get a little hop or vault that way. Even so, I remember there was a brief period of about two weeks when my little hops were actually better than Jake's first attempts.

For two whole weeks, I was a mentor - a "Hop Master" even, wow!

Imagine that. I held the record for two whole weeks. 😊

Parents as opportunity-makers, Part 1

May 20, 2011

Like me, my wife was born with her physical disability. Elana's disability is far more limiting than mine, though. For most of her life, Elana has been stuck in a motorized wheelchair with a disability called [Arthrogryposis](#). For whatever reason, there wasn't enough amniotic fluid in her mother's womb - and, as a result, Elana was born with bones and cartilage that never properly developed. Elana's legs and arms are stiff; her joints almost completely fused.

Her whole life, Elana has had to depend on the hands of others - the hands of her care-aids, hired help 24/7. My wife cannot get out of bed by herself, cannot go to the bathroom by herself, and cannot have a shower or get dressed by herself. Despite my disability (Cerebral Palsy), I can do all of those things fairly easily. By myself.

So yah, my wife has more than her fair share of physical limitations. And certainly, that sucks. But really, honestly, I am more often amazed (every day) by all of the things Elana **can** do. The fact is, whatever Elana can do, she does - nothing much can stop her.

Looking at both of our physical limitations, I'm sure there are a few folks out there weighing the practicalities of two disabled people entering into marriage together. For those people, our decision to have a baby - to have our son, Jake - must seem like pure insanity.

But we did it, and I'm glad. Best decision ever - on both counts. I never really knew if I'd make a good husband or father - and truly, I still have my doubts, sometimes. But with Elana, I was confident. I knew 100% that she would be a good wife and excellent mother, I just did.

Elana was born to be a mom. Right from Day 1, Elana has strived to be the best Mommy possible. Like everything else, Elana has to rely on her care-aids (and other hands) to help care for our son, Jake - but again, everything she can do as a Mommy, she does it.

Elana is fond of saying that we, as Jake's parents, are opportunity-makers. Jake doesn't care that his Mommy and Daddy are disabled - he just needs us to be his parents, to be present, to be involved in everything. Even with all of the extra helping hands, it's amazing to me how readily Jake seeks Elana or me out first. Elana can't pick up Jake with her hands, for instance ... but from a very early age, our son learned how to hop up on the foot-rests of Elana's wheelchair and then crawl up onto his Mommy's lap for comfort.

I can't pick up Jake easily, either. I need to be sitting on a chair or the sofa first. My disabled body, at my age, has difficulty going down on & getting up off the floor! But it's an easy adjustment, for both me and Jake. And if he needs my help with his coat or shoes, Jake knows to come and sit with me on the sofa, rather than go to the floor. Jake is a typical boy, and he is learning to appreciate a bit of rough-housing

with his Daddy now. But again, not on the floor. We go to the bedroom and wrestle each other on top of a cushy king-size mattress.

In everything, Jake just wants to learn, experience and play. I take him to the park and we kick a soccer ball around together (...I use a crutch, not my legs). Or Mommy takes Jake to the playground, and even though she can't climb up on the equipment with him, Jake is happy just to have us there and to have his Mommy & Daddy be his opportunity-makers.



Parents as opportunity-makers, Part 2

May 20, 2011

Yesterday, we took Jake to Crescent Beach - our first trip to a beach this summer. Elana loves going to the beach. When the sun is out and the weather is warm, Elana wants to be outside and near the water.

Crescent Beach is nice. It's not a far drive from where we live, and it's much quieter than the more trendy and populated beach at nearby White Rock. Plus, the parking is free and easier to find as well.

Most beaches around Vancouver (on Canada's westcoast) are at least somewhat accessible to people with disabilities. Crescent Beach, for example, has a nice paved walkway bordered with a ribbon of grass down the entire stretch of beach - so Elana & her wheelchair can move around easily ... as long as she sticks to the paved path. The beach itself, though - the actual sandy beach - is not accessible to a wheelchair at all.

When we got to the beach, Jake was quite happy to stay on the paved path with Mommy. However, the tide was quite far out and, for me, the huge expanse of sand littered with its small, shallow puddles of sea water was just too inviting to ignore.

Even for me on crutches, most of the local beaches around here aren't particularly easy to traverse. But I looked out at the smooth, flat sandbar stretching out over the horizon and I wanted to get out there. But to get out to all of that nice smooth sand, I needed to navigate through a series of obstacles first: the rocks, the uneven ground, the drift wood strewn about, and the masses of seaweed and moss.

It's been over a dozen years (at least) since my crutches and I last stood far out on a sandbar. But I'm a parent now. I knew Jake would enjoy himself out there - and I wanted to fulfill my role of Daddy, Opportunity-Maker.

And so I made my way out to the smooth, wet sand. Elana's care-aid carried Jake out to meet me. And just as I expected, Jake had fun hunting for shells and throwing fistfuls of gooey muck. Using a crutch for a pen, I etched Jake's name in the sand. It was a momentous occasion. I felt like an astronaut planting a flag on the surface of the moon. The care-aid snapped several dozen photos of me and Jake, together. It felt great to be out there.

But then I looked back at the shore - looked back at Elana, a tiny speck ... stuck on the paved path, stuck in her wheelchair. I felt sad for my wife. I knew that she must have been feeling sad too. But I know that Elana wants to be an opportunity-maker for Jake too, always. Even if it means that she has to sacrifice her own happiness at times.

And now, here we have our same trip to Crescent Beach, told from my wife's perspective. Once again, this is Elana, in her own words...

Bound

May 20, 2011

Today I feel very wheelchair-bound.

Sitting in this spot I can see countless rocks and people reclining on logs, all looking out to the sparkling water and smooth sand. In the distance I can see three little people exploring, their voices drifting back to me among the backdrop of the footsteps of passersby. Even though they are far away, I can distinguish some features of the tiniest body out there... his arms and legs and his orange shirt. He is throwing rocks into the water. He is with a man and woman who are taking pictures of him and pointing out things for him to see and do. The man is his daddy, bent-legged and on crutches but following him closely. The woman is crouching beside him, pointing to all the wonderful scenery. She is my care-aid. Where is his mommy? Wheelchair-bound. Watching with a smile and moist eyes as slowly they make their way towards me hand in hand. My heart swells. My baby is home.

Last year I thought it was hard when a different woman took him down to the water. He was crying...didn't like the coolness of the water against his legs. She thought it was good for him. I died a little. My sweet baby. I should be the one holding him there, deciding whether or not he was comfortable with this new experience. But he didn't need me. Her hands were steady, her feet brought him to the water's edge. Not mine.

Today was different.

"Mommy, come!"

He implored me to follow him but I could only explain why I couldn't. He looked at my wheels with a level of understanding. A few weeks ago it was at a playground. "Mommy, come!" He wanted me to climb up on the play structure with him. "Sorry babe, Mommy can't. My legs don't work." He cried and asked me a few more times until he gave up and ventured out on his own. A few days ago it was changing his diaper. "Mommy, come!" "You want me to change you?" I asked him. "Yeah, Mommy." He answered, expecting me to come closer and confused why I wasn't. "Mommy can't change you, Jake, my hands don't work." My throat swelled.

I thought it would be easier when he needed me. Asking for me, calling my name, checking to make sure I'm nearby. But it's not. I have to force him to connect and cooperate with someone other than his mommy, even when he's not ready to do so. But what choice do I have? I'm bound.

Tossing aside my disability

May 26, 2011

I've gone through a few pairs of crutches in my lifetime. They get beat-up, well-used. I am hard on them.

Growing up with a disability, my crutches have become many different things to me. Yes, my crutches help me to walk ... to stay balanced, that is their most obvious function for sure. But they have many other uses as well. When I was much younger, they were sometimes just play-things. I would often hand a crutch off to a friend and it would instantly transform into a machine gun, a sword, or a robotic arm. I personally liked challenging all of my able-bodied friends to jousting matches - I almost always won. It was one of the few opportunities I had where I was actually able to demonstrate a slight bit of physical superiority over them. And yes, it felt good.

My crutches are also all-purpose tools. I use them as ball-kickers. Or extra-long arm reachers. As handy built-in door stops. Or high-in-the-tree apple pickers. You get the idea. I see my them as an extension of my physical body. My crutches truly are a wonderful pair of extra appendages. But still, it's weird. For everything they have been to me over the years - and for all the times I have depended upon them greatly - I sometimes forget I even have them. There are actually many times during the day when I can toss my crutches aside, when I don't need to use them. Like walking around the house, for instance, I can move around by holding onto walls and furniture. And in those moments, on occasion, I can forget about my disability - forget about my crutches altogether. Honestly.

My pattern of forgetting started early, as a young boy. I remember all of the long trips we took as a family every summer to visit my grandma & grandpa - a six-hour drive from Vancouver to the Okanagan Valley (located in the interior of British Columbia). With our car packed full of luggage and me & my sister loaded along for the ride in the backseat, the first part of our trek usually lasted about 1 1/2 hours until we reached the small town known as Hope ... to stop for breakfast. My Dad would park at the same favorite diner, and we would all get out of the car, stretch our legs, and then head inside for some greasy scrambled eggs or pancakes.

That's how all of these trips usually unfolded at the start. One year, though, things went decidedly different: I remember. I couldn't wait to get out of the car and enjoy my plate of pancakes and syrup. And it was right then, with me getting out of the car for the first time since leaving Vancouver (a full 90 minutes behind us) that I suddenly remembered what I forgot.

I forgot to pack my crutches! They were stuck at home, tucked away in my bedroom closet.

Muttering a few quiet curses, Dad directed us all back inside the car to begin the 1 1/2 hour drive back home to retrieve my crutches. The pancakes would have to wait. I had forgotten my crutches several times before, of course. But getting all the way to the little town of Hope...? That was the worst - far and away, the worst.

Tossing aside my disability, an addendum

May 26, 2011

Of course, I wasn't the only one forgetting about my crutches. My parents and sister were often guilty of that too. And it's a big part of the reason why I had such a normal childhood.

All of my able-bodied friends, they'd forget as well. I remember that one summer when I was fourteen, for instance. My good friend, Sandy, invited me to stay at a cabin with him and his family for a week at Boundary Bay. The cabin was right on the beach, and every day, Sandy and his two brothers and sister and I would all walk far, far out onto the sandbar looking for crabs trapped in small pools of sea water. In the morning, the ocean's tides would retreat for miles, it seemed. We would always wander way, way out and wouldn't start heading back until we saw the tide begin to creep in again later in the day.

I liked hunting for the crabs. At first, I tried using the tips of my crutches (...like chopsticks) to catch them. I quickly realized that grabbing them with an actual pair of hands was far more efficient. And so I threw my crutches down in the usual not-so-careful manner ... then plopped myself down onto the sand, and started some bare-handed crab fetching.

I liked this new method of crab hunting much better. It was a lot of fun. So much so, that one day, I just left my crutches behind. Yes, I just left them - lying in the sand. It just seemed easier somehow. Though I don't really know why. Without crutches, I was a bit hobbled of course - but as long as someone gave me an arm to lean on, I managed to move along ok.

But anyway, yah, we apparently stayed out a little too long that day. The tide came back quicker than everyone expected, and when I went back to retrieve my crutches from the spot where I had left them, they were gone. Washed away by the tide.

The next morning, when the tide was out again, Sandy's entire family conducted an exhaustive search of the entire beach. My crutches were eventually found. Sandy spotted them - waterlogged and buried in sand, with a small horde of baby crabs crawling all over ...

I remember when I first told Sandy's mom that we had lost my crutches on the beach. I was having fun, I said, and we had all lost track of the time and tide. I had forgotten about my crutches, I said.

I remember how dumbfounded Sandy's mom was: *"You forgot about your crutches...? How could you forget your crutches?!?"*

Here is a post I wrote as a lead-up to Father's Day 2011.

A Daddy Baptism

June 4, 2011

This year will be my third Father's Day.

On my first Father's Day, Jake was nine months old. Though, of course, the first *unofficial* Father's Day is the day my son was born: September 10th, 2008. I remember seeing my son; holding Jake in my arms for the very first time. What an amazing moment that was. I was in awe - and in just a few short seconds, I felt like a totally different man. My brain experienced a massive chemical shift in a mere instant, and I was forever changed.

I was a father. Wow.

It was like I had died, the old me gone. My son was born, and I was born again as something better. A daddy baptism ... that's how it felt, really. Any guys out there who aren't daddies yet won't understand me. But as soon as you become a father, you get it.

Jake is my own flesh and blood, a genetic cocktail mixed by God. A gift. Babies are born into the world helpless, completely dependent on their parents for survival. It's a huge thing to be responsible for a tiny life. And yet it's not a burden - not at all. It's more like a hockey player being counted on to score that overtime goal in a Game 7 of the Stanley Cup Final. It's big and important for sure - but it's ultimately a responsibility you **want** ... it's the good kind of adrenaline and pressure.

Having said all that, though, I think most men still end up coming into parenthood at a distinct disadvantage when compared to women. It's a generalization, yes - but, on the whole - I think women are wired with the kind of innate paternal instincts that a lot of guys simply don't have at the start. My wife, for instance, first became excited at the prospect of having a baby almost a full two years before she was even pregnant! Whereas me, my excitement didn't ramp-up until the last two weeks of Elana's actual pregnancy.

Not only are women gifted with their superior maternal instincts ... but they also get a headstart with the whole parent-child bond thing. Carrying around a big tummy for nine months is part of it. So is the breastfeeding. The first year, I remember, all Jake did was sleep and eat ... and the bulk of both, he did while attached to / laying with Mommy.

Speaking for myself, I didn't exactly know where I fit at first. Some of that can be attributed to always having another pair of helping hands to work around. And by that I mean, figuring out how to best fit with Elana and all of her 24/7 care-aids. Of course I was already used to having care-aids around, yes. I have been married to Elana for eight years, so I should be used to all of that by now, right?

Adding a baby into the mix is a big change though. Once Jake arrived onto the scene, it was like a whole different dynamic for me. I had to get used to fitting in with Elana's new Mommy routine and, by extension, the new routines of her care-aids as well. I had to get more in tune with my own physical disability too: figure out how much I could take on and how hard I could push myself, before my body would push back.

Jake is going to be three years old in another three months. My son is growing up into an active, playful, and talkative little boy. No longer a baby, he is far easier for me to handle. I take him out for rides on my scooter, we go to the park to play soccer, and we play Xbox together. All really important father-son bonding stuff.

After almost three years as a father, I'm finally starting to really ... truly ... absolutely ... and beyond a shadow of doubt actually **feel** like one. I may have officially become a father on the day Jake was born but looking back it's obvious that, like my son, I've grown and learned a lot since then.

I'm not just a father, I'm a real Daddy now.



Next, my post for Father's Day 2011 - the actual day. 😊

Happy Daddy's Day

June 19, 2011

I woke up early this morning and found a Father's Day card resting on the keyboard of the computer out in the living room. A blue envelope with "*Super Daddy*" written on the front (...by my wife, of course). At thirty-three months, my son is still too young to scrawl that on his own. Nevertheless, it *is* true that Jake does indeed like to say the word "super" a lot these days - it's one of his favorite words that he combines with everything.

Anyway, I opened the big blue envelope to discover a big red Elmo on the front of a card with "*Happy Daddy's Day*" inscribed in bold letters on the inside. Elana told me it was a card that Jake picked out all by himself. He even managed to scribble a signature (or some semblance of one) on the bottom of the card, in pen.

The card also says,

To the best Daddy in the world...

I know for certain that Jake is far too young to have an accurate opinion about that. But still, I can't help but treasure the card for what it represents. My son is growing up. He can pick out a nice Father's Day card all on his own. He can scribble a signature. He is also very good at giving both his Mommy and me totally spontaneous hugs now, too.

And pretty soon (in the not-so-distant future), Jake **will** have an accurate opinion of me as a Daddy. Of course about all I can hope for is to maybe, occasionally, measure up to **SUPER** and **WORLD'S BEST** status. But really - no matter how old Jake gets - I just want my son to always know that I love him and that I will be there for him no matter what.

Hopefully, I'll stay worthy enough for all of those spontaneous hugs for many, many years to come.

In this post, I mention that my camera batteries had died and I wasn't able to snap any photo of me & Jake on the swing together. My batteries did indeed die, this was true. The photo I've included below is from a visit to a different park a few weeks later...

Picture this

July 11, 2011

It was another day at the beach for us yesterday. This time, we went to Kitsilano Beach (aka Kits) in downtown Vancouver.

Jake had so much fun at the playground that he didn't want to leave. The sun was gone and all was quite dark when we finally did leave. The playground equipment has an accessible wheelchair ramp so Elana was able to drive her wheelchair up onto the platform.

And me, I did a couple of things at the playground that I haven't done in over twenty-five years. I swung on a swing and I slid down a slide. If I wasn't a Daddy, I probably wouldn't have bothered with either. But Jake is almost 3 years old and he is still a little timid of swings for some reason.

So I got on the swing first. It was a big saucer-shaped swing, and when Jake saw me get up into it, he was immediately excited. First, he helped push me from behind - giggling the whole time. Then he climbed on with me.

Next was the slide. I was a little worried about it, honestly. My body is getting older and a little less flexible (over and above the lack of flexibility I already have due to my cerebral palsy).

But, in the end, I couldn't resist my son: *"Come, Daddy - come! Slide with me..."*

Unfortunately, the batteries of my camera died and we weren't able to take any photos of me on the swing or me on the slide. But Jake was still talking all about it afterwards, right up until his bedtime.



Another post from Elana, short but sweet.

Socks off

July 29, 2011

Well, I taught my son how to take off his own socks today and he did it, all by himself!

"Pull down by the heel," I explained.

"*Oh, heeeel...*," he said with awed understanding.

This may seem very ordinary to you, but to me it's amazing. Not just because he did it for the first time, but because I have never, ever been able to take off my own socks and yet, here I am, able to teach him how to do it. "Those Who Can, Do; Those Who Can't, Teach." I give that saying a whole new meaning!



*Elana's forth - and final - blog post. I know she *wanted* to write a lot more but she was always far too busy being a Mommy to keep it going. After this entry, all blog posts are solely from me.*

Raising a sensitive child: Why I parent a different way

August 14, 2011

"I should be able to just say 'No!' and not have it be such a big deal!" My husband exclaimed, a bit bewildered by our son's reaction.

Hmmm. He should, shouldn't he? Well, he definitely could. Millions of parents do.

"No, you can't have that!" they say as they steal away the coveted object.

The child cries, the parent ignores and after a few minutes all returns to normal. But what takes place during those few precious minutes? A very important lesson is learned about what to do with those very real and very big emotions. Bury them. Deny them. Get over it. Move on.



Truth: the accompanying photo shown below was snapped mere moments before the events retold here. I can see it in Jake's face, plain as day. I should have known.

Crying over spilled skim-milk frappe

August 17, 2011

Oh, to be inside the mind of a toddler.

Jake's current fascination is with water, and watching it spill on the floor. Any liquid will do though - the messier, the better.

Yesterday, Elana & I took Jake for a walk up to Starbucks. I hadn't had my Coconut Cream Frappuccino fix for a while so I was really looking forward to the indulgence.

Elana had her usual chocolate chip mocha frappe ... and I bought Jake a mango smoothie because he usually loves it. As soon as we all sat down with our drinks at a table outside, however, it became clear that Jake was into sipping from everybody else's straws and not his own. I don't mind sharing one or two sips - and I can even tolerate the mangled straw afterward, resulting from my son's unrefined "chew-suck" eat / drink etiquette.

But yesterday, I barely got to drink my coconut frappe - Jake hogged it. Honestly, I wasn't really caring too much right then because Jake was in such a good mood. Actually, he mostly is an amazingly well-mannered, well-behaved child - but yesterday, he was particularly bubbly, sing-songy and comedic. Both Elana and I even commented how delightful our son was and how lucky and blessed we were.

If only that proud-parent moment could have lasted a little bit longer. In the very next moment, Jake suddenly decided it might be fun to throw my vente coconut frappe to the ground, spilling it all. It is moments like this that I wish my reaction times could be quicker and it really sucks to be disabled.



Where did September go?

October 12, 2011

Here it is, the middle of October already. Jake's third birthday (complete with a Spider-man cake) has come and gone, and the leaves on the trees are in full Fall attire. Bright reds and yellows are everywhere, a chaos of color, and everything feels like it is in a state of flux.

Just like the seasons, things in life change. Sometimes predictably, and sometimes not. A few weeks back, Elana found out that her dad has lung cancer. A couple of months before, Dad had a bad cough. He has had bad coughs before, but this one was worse. This one scared him. It was enough to make Dad finally quit smoking after a lifetime of cigarettes. Of course Elana is proud of her Dad for quitting Cold Turkey like that (we both are), it's just too bad that he didn't quit maybe a couple of years sooner.

The very same day Elana found out about her dad's cancer, one of Elana's care-aids suffered a miscarriage as well. A very bad, sad day most definitely. And yet, at the same time, a harsh reminder of just how precious life is.

Life is a blessing. In amongst the chaos, we can sometimes lose sight of all the beautiful colors.

And November marches on ...

November 18, 2011

Elana's dad starts chemotherapy in a couple of weeks. The earlier radiation treatments helped to shrink the tumor. Now the plan is to kill the cancer cells altogether. A man of strong Christian faith, Dad is staying positive - and with God's help, I know he can beat this.

Cancer treatment is a slow process though. It's a long road ahead, a real test of patience.

Winter is officially here. We got our first snowfall yesterday. I like snow. It's a reminder that Christmas is just around the corner. I like Christmas too!

The photo below is from Christmas morning (2011). Jake loved the hockey table! On a sad note though, Christmas 2011 would be the last for Elana's Dad. He passed away a few months later on May 26, 2012.

Merry Christmas

December 24, 2011

I got Jake's Stiga hockey table all assembled and hidden away until tomorrow - I can't wait for him to see it! That has to be one of the best things about being a parent: getting to experience the joy of childhood all over again.



The (Disabled) Parent Experience

February 26, 2012

Becoming a parent is like getting on a roller-coaster. It's a fun and exhilarating ride, sure. But parenting is also a series of ups & downs and unexpected twists. The rise and falls are a daily occurrence ... sometimes in rapid succession, one after another.

My son Jake has a lot of energy. Stereotypically speaking, toddler boys are more rambunctious compared to girls. And not only that. Apparently, boys born to less physically-active parents can often be all the more energetic. Elana read that somewhere recently. In any event, this certainly seems true in our case. Jake has a boundless reserve; a battery that just goes and goes and goes. Some days, it can be a real challenge to tire Jake out - but it's very important that we do, or else his energy can morph into aggression and bad behavior.

Jake is three and a half years old, and already he is becoming quite an athlete. My son, a mini sports jock. All by pure fluke, of course. Yes, Jake has definitely overcompensated for his less active, physically disabled parents. At three and a half, he is becoming more aware of our physical limitations, too. And that sucks for Elana and me, let me tell you. So much of parenting a toddler is about being able to act quickly. If you intercept fast, you can avoid escalations like toys being thrown across the room and other such displays of raw, honest emotion.

Man, I wish that I were faster sometimes! Certain parenting strategies are so basic and simple ... and yet, for disabled parents, not easy to do. Occasionally, it can feel like Jake is getting the better of me and that I'm not in full control of a situation simply because of my slow disabled body. I know that Elana really struggles with that too. And while it's true that we can (and do) call on Elana's care-aids for help, having to instruct someone else to intervene quickly takes time and is still a fair bit slower than if I just had my own able-body. The fact is, in his best "I'm-still-a-toddler" episodes, Jake can go from happy to sad (or mad) in a mere instant and being slow and disabled is a real disadvantage.

All those times of feeling slow, powerless, inadequate, and feeling like a bad parent ... those are the DOWN roller-coaster moments. The descent feels like an eternity. In reality, it's not though. And in the end, it's all of the good up moments of parenthood that redeem everything else. On the whole, Jake is a wonderful child: inquisitive, funny, sensitive, helpful, and highly snug-gable.

So that's the ride - being able to survive the ups & downs and, at the same time, being able to see parenthood for what it really is: a once-in-a-lifetime, thrilling experience.

Vindication

April 10, 2012

My last blog post focused on how frustrations with my disability can lead to frustrations with Jake. March was a difficult month for both me & Elana in that regard, for whatever reason.

This month is different. Jake seems more relaxed and happy overall and it has made parenting challenges a lot easier. Elana and I have gone through short stretches where nothing we're doing as parents seems right, and then a good day, week or month comes along and I feel vindicated.

There are many different ways to parent, and differing opinions on what approach is best. From the start, Elana & I have tried to follow the strategies of [Attachment Parenting](#). With an AP philosophy, the emphasis is on gentle discipline and maintaining a positive relationship / bond with your child. Doing things the AP way removes the need to depend on rewards and punishment. Following the AP method is very difficult at times, and it requires a lot of extra patience and dedication. And yes, there are times when I'm tired that I simply don't have patience ... and I yell and get mad at Jake. I remember how critical I used to be of other parents not being able to "control" their children. But the fact is, misbehaviour and the occasional toddler tantrum is going to happen every once in a while. I get it now, that parenting is really hard and, as parents, we can never truly control our child. Jake is his own person, with his own will and wants.

With AP done right, there is no punishment or time-outs. Instead, we use "time-in" and give Jake the chance to cool down and get a handle on his emotions. In the end, it's just a more respectful, gentle and supportive way to parent - and it works. Jake cleans up his messes, does little chores, and gives spontaneous hugs by his own free will - and it feels great to see that. So obviously, we must be doing something right.

The slow creep of frustration is held in check for now

In memory of Dr. Ken Tittle

April 22, 2012

Dying is a fact of life, there's no escaping it. As Christians, we know that we're all going to end up in heaven sooner or later, it's just a question of timing. Still, death is cruel and unfair the way it sneaks up unsuspecting and takes special people away from us.

Dr. Ken Tittle was a very unique Christian. He loved words. He was a great speaker, an even better writer, and he was able to think and speak in ways most people cannot. He was a true philosopher; a one-of-a-kind man of God. While many Christians often like to put God in a box, Dr. Ken saw God as the epitome of "out-of-the-box" thinking. For me (and countless others), Dr. Ken will undoubtedly be remembered for his penchant towards deep thoughts, intimate discussions, and beyond-the-curve logic.

Dr. Ken's most important life's work was, and is, **Mariposa** - a ministry he started over 30 years ago, so that people with disabilities had a group (...and later, an online / email-based forum) to talk freely & openly about disability in the hope that we may come to know and better value ourselves as individuals and Christians. I first met Dr. Ken back in the Summer of 2002. At that time, I had only known Elana for about six months and was myself still very much a Christian "newbie". Even so, Elana somehow convinced me to go away with her to San Diego, for a week-long Christian retreat / church camp. Elana first met Dr. Ken there the year before, and his whole **Mariposa Ministry** had such a profound impact on her that she wanted me to experience it for myself.

All I can say is, wow. What a wonderful introduction to Christianity that was! So raw, so honest, so liberal. So very different than what I had expected. Dr. Ken immediately impressed me as someone *real* - a real Christian with flaws (and not afraid to talk about them). He was a great man, plain and simple. Dr. Ken was a techie like me and, like me, also loved photography. I had a tremendous amount of respect for him almost straight away and he became an influential steward on my path to knowing Jesus.

It's unfortunate but a lot of able-bodied Christians today still have a hard time wrapping their heads around **DISABILITY** and what it means to the church, as a whole. To the narrow-minded Christian, a disability is strictly a physical ailment ... something requiring prayer for *physical* healing only. Speaking from personal experience, I've had several people come up to me (...even complete strangers) praying for an instant, miraculous healing of my Cerebral Palsy and bent legs. And every time, when the miracle healing doesn't happen, all of these wonderful prayerful able-bodied people suddenly don't know what to do with themselves.

They might think: "*Well, my prayer for physical healing didn't work, so what should I do now ...? How can I reconcile / make sense of this?*"

For a lot of these people, it's black-and-white: there is only complete success or complete failure and nothing in between.

But the reality is, God delves into many different shades of grey all the time. For me, God is big. Big enough to be far beyond complete understanding and comprehension by any of us in our earthly realm. Is God capable of spontaneous full-body healing? Yes, He most definitely is. Am I shocked or disappointed when God doesn't answer all of those prayers for complete healing of my physical disability? No, I am not.

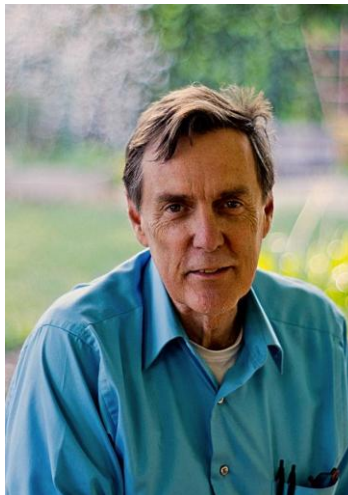
My disability is an important part of who I am, and of what I have become. This is my journey. This is the life God chose for me and it's up to me to make the best of it. More than any other able-bodied person I have known, Dr. Ken truly understood what it meant to be disabled ... he really got it. I remember when I emailed him an early draft of my book, **DADDY BENT-LEGS**. I was excited to have him read my memoir and fully expected him to like it, without too much constructive criticism. But alas, he didn't completely love it. Dr. Ken's biggest criticism of the manuscript? He thought that I was perhaps a little too focused on keeping everything lighthearted. He suggested that I dig a little deeper and be willing to talk candidly about a few of my life's big disappointments too. Both me and my book are infinitely better because of him.

Elana & I last saw Dr. Ken about five years ago when he and his wife stayed at our place for a few days. They were on a brief stop-over visit to Vancouver as they vacationed through Oregon and the Pacific Northwest. It doesn't seem all that long ago, though ... as **Mariposa Online** always managed to stay fairly active through the years.

After all, Dr. Ken loved words. He composed countless emails and the vast majority were, at bare minimum, somewhat profound. He was an amazing man with a beautiful mind to the very last.

Dr. Ken Tittle is only two days in heaven and already severely missed. I sincerely hope that his online **Mariposa Ministry** will in some way continue. Even though I know that it will never be the same, not even close.

Until we meet again, Dr. Ken ...



Disabled, according to the dictionary

"Be the change you want to see in the world." ~ Mahatma Gandhi

May 8, 2012

Look up the word **DISABLED** in any dictionary and you will find a laundry list of the following descriptors: *"incapacitated", "broken-down", "decrepit", "worn-out"* and (my personal favorite...) *"wrecked"*. Those words are ugly. Unflattering, to say the least.

Those are just the synonyms. Let's look at a few antonyms, or opposites. Here, we find terms like: *"healthy", "strong"* and *"capable"*. In other words, I, as a physically disabled person, am assumed to be *"unhealthy", "weak"* and *"incapable"*. Pretty ugly, indeed. And yes, my use of oxymoron is deliberate.

I think it's time we had a better definition for **DISABLED**. In my 44 years as a physically disabled man, it's surprising how little has changed. We now have new-age / politically-correct terms like: *"Differently Abled", "Handi-capable"* and *"Physically challenged"* ... but, for me, all of these terms are by some measure inadequate, inappropriate or condescending and in no way properly depict what it truly means to be physically disabled.

Personally, I have absolutely no problem with using the word, **DISABLED**. In my opinion, it really is a far more accurate and honest reflection of serious, life-long physical impairments like my own cerebral palsy or my wife's Arthrogyriposis. So instead of trying to replace the word, I think we just need to start using a different *definition*.

If Webster's dictionaries the world over are supposed to hold up a mirror to our modern-day society, then we need to start thinking a bit more counter-culture to effectively erase all of the old, out-dated definitions that are still being perpetuated onward.

One of the best definitions of **DISABLED** that I have stumbled across so far is this:

"Lacking one or more physical powers, such as the ability to walk or to coordinate one's movements, as from the effects of a disease or accident, or through mental impairment."

Looking above, I like that definition a lot because it focuses on "powers", or empowerment. I, for example, may be lacking one or more physical powers myself (as a result of my CP) but by simple extension, there are many other powers that I **do** have ... a whole lot of things that I can do, and can excel at.

"Differently Abled", "Handi-capable", "Physically challenged" and other terms like these have each tried to replace **DISABLED** - and in my humble opinion, they have all failed.

No more weird & wacky word pairings, please - I don't like it! To me, saying that I am physically disabled is accurate. So yah, use of the word **DISABLED** is perfectly fine. Again, all we need is a better and more powerful definition. To be more counter-culture: to think different, to act different and to behave better towards ourselves and others. Easy, right...?



Meeting a Canadian hero - again.

May 20, 2012

Yesterday (May 19th), Elana & Jake & I took a bus to White Rock to go see [Rick Hansen](#). It was the 25th anniversary of his "*Man In Motion*" around-the-world-in-a-wheelchair stunt ... an unbelievable marathon Hansen completed way back in 1987, the same year I graduated from high school.

I never got the chance to meet Hansen in person back then, at the conclusion of his world tour. I did have a very brief chance encounter with him in a parking lot at the University of British Columbia a few years later, though - an encounter re-told in my book, *Daddy Bent-Legs*. Those who have bought my book will surely remember, as it remains one of my most favorite (and fun to write) chapters.

Rick Hansen is an incredible athlete, still - his upper body looks built like a truck. But more than that, he's an incredible person. A real Canadian hero. To have the chance to meet him in person again was amazing, truly.

I gave him a copy of my book, and he even signed one for me. I have the pictures to prove it. Great day!



Another angel for heaven

May 26, 2012

Elana's dad passed away today after battling lung cancer for the last nine months.

I didn't want to write this blog post. I didn't expect it. All along, I was expecting him to get better, expecting God to heal him until the very end. Maybe it was optimistic, maybe it was denial ... or maybe it was a mix of both.

I will miss him. I miss him already. He was a gentle soul. I'll remember him for his quiet humor. He loved gardening and flowers. He loved art, painting, and choir & classical music. He loved photography. And even though he didn't always understand them, he loved computers.

Most important of all, he loved the Lord and he loved his family. He was an amazing man, husband and father. Married for over 50 years, his relationship to Elana's mom was a shining example, something for all to emulate. I can only hope to be as devoted a partner to Elana for the same amount of time.

I took the photo below at Jake's 3rd birthday in September, only a couple weeks after Dad was diagnosed with cancer. I will remember Dad's strength, courage and smiling eyes always.



Dad's funeral

May 31, 2012

For the past few mornings, I think that I've done most of my crying in the shower. As soon as the warm water hits my face, my eyes open up and the sadness comes flooding out. And after almost two full weeks of summer sun, it seems appropriate that it rained for a bit in the morning yesterday. There were a lot of tears.

Now that Elana's dad is in heaven, everyone else is left to ponder what comes next. I will have no more quality time with Dad holed up in the spare bedroom fixing his computer. No more of his gentle humor and quiet moments. No more of Dad's baked bread and Dutch donuts. No more of him playing the organ and singing carols at Christmas. No more of his prayer and bible reading at family dinners. No more Father's Day or birthdays with him, either. I will miss it - everything.

Death is the great equalizer. It doesn't care about social status, our worldly possessions or other useless stuff. Death doesn't discriminate. The passing of Elana's father has shaken me. Ken Tittle died just a little over a month ago, too - and given everything that has happened in such a short time, I can't help but re-evaluate my life.

More and more, I am beginning to see the things that truly matter. Boil life down to its barest essence and the only things left are God, our family and our friends. It's all about relationship - our connection to God and to other people. Even a happenstance run-in with a complete stranger at a grocery store can be significant. A quick exchange of a few words, a shared smile, whatever.

I've been thinking more about the *quality* of my relationships, each of my connections. To God. My family. My own father. And I realize that I need to be better all-around. In the end, it's about relationships and maintaining positive connections. I am like a stone thrown into a pond, with its splash rings echoing outward. Only God knows how far they stretch out.

It can be easy to take life for granted, sometimes. My friends, my family - and especially my parents - hold a very special place in my life. They are like a permanent fixture: always there, dependable. Alas, this earthly life is not permanent.

I need to remember that.

Here is a post I wrote for Father's Day 2012, to remember Elana's Dad and to honour my own.

Splashes and ripples

June 17, 2012.

Father's Day feels different this year, more empty. The loss of Elana's dad leaves a big hole. It's already three weeks since he passed on, and I've been doing a lot of thinking, remembering and reflecting.

In my previous blog post, I compared myself to a stone thrown in the water with its splash rings reaching out to other people. Leaving a valuable imprint that echoes forward, a legacy. It's something that each of us aspires to, it's something important and it's something we all want in the end.

Except why do we usually wait until the end? Why are legacies only discussed at funerals, and afterward? It's a shame. Legacies should be thought of more often, revealed in. Father's Day is a time to honor our dads and, yes, my mind has been preoccupied with thoughts of Elana's father over the last month.

Even so, I've been thinking a lot about my own dad too. The photo I've included below summarizes my dad's legacy quite nicely, I think. I remember the moment that picture was taken, like it was yesterday. I was around 11 or 12 years old and I had just finished swimming over 100 laps in an Olympic-sized pool. It was a Swim-a-thon, a fundraiser for Easter Seals. Not only did I finish 1st with the most laps but I also collected a lot of generous pledges ... so I ended up raising a fair bit of money too. It was a proud moment for me and I remember my dad raising my arm in victory. It was a totally spontaneous gesture, something truly special.

For me, my dad made a big splash that day. It's a very small part of his overall legacy, and yet its ripples have stayed with me and are still strongly felt, even after 33 years. I've actually inherited many different things from my father. My confidence, persistence, stubbornness and sense of humor all come from him. I may not have inherited his handyman expertise (at all!) but I have every bit of the most important stuff.

Legacies are meant to be shared, carried forward amongst the living. My name, Neil, means "**champion**" ... a name chosen by my dad. Jake's middle name, Tory (short for victory) was my choice, and a very deliberate one.

But again, a picture is worth a thousand words. So thank you, Dad. Thanks for all of your splashes and ripples. I love you.



Musings, mishaps and piss-poor engineering

July 26, 2012

I was planning on blogging something completely different. Initially, my first thought was to write about how my son has become a direct reflection of both me and Elana, combined. At four years old (almost), Jake mirrors and mimics everything we do. My love of computers has become his. Jake has developed a real prowess with technology and the Xbox. He's seriously good at navigating his way around a computer and very proficient at several challenging video games. He also likes to sing and make up songs. Elana and I both do that. He sometimes hums happily while eating. I do that. I love exotic fruit juices like mango and guava and, of course, Jake loves that too.

As well, there's certain favorite phrases that Jake repeats a lot and, at first, Elana & I are like:

"Where is he getting *that* from?"

But then we realize, wow, we do say all of the things he says ... and sound like that ... and act exactly like that. It's equally flattering and scary all at once. Mostly, I love it though. It's especially cool to see my own (or Elana's) personality quirks reflected back. It's weird, but great. Anyway, I **was** going to write about only that today. Instead, I'm ending this post with a little something extra.

I flipped my scooter crossing King George Highway at 68th Avenue yesterday afternoon on my way to the park to meet up with Elana & Jake.

Flipped.

Backward.

Completely.

I love my scooter. It's fast, it goes far on a single battery charge, it's stable and solid and I feel very safe driving it. Nonetheless, I still flipped it. And while it's true that I was feeling a bit tired and sick yesterday (and therefore maybe a little bit distracted), I am not entirely at fault. The cement island that I was trying to ramp up to on the other side of the left-hand turn lane is badly engineered. I mean, seriously piss-poor. So many intersections are like that though - with crossings only designed for people on foot and no consideration given to people in wheelchairs or large scooters. Another intersection a bit further down on 80th actually has the signal/crosswalk button on the *opposite side* of the pole, making it absolutely impossible to reach from my scooter. Anyway, the crossing at 68th & King George always felt a little bit dangerous to me and yesterday I got confirmation of that. The cement island is too small: seriously cramped and badly paved. The incline is too high, for one. Yesterday, my scooter didn't ramp up onto it perfectly and I got stuck, basically hitting a dead-spot. I tried reversing and couldn't. So I drove forward under full power and flipped the scooter completely backwards. The very first thought to enter

my head: *Oh shit.*

My apologies for the bad language, but in the moment it was completely appropriate. So here I am, with the scooter flipped, in shock, thinking what am I going to do now, when I saw four guys bolt across the road to help me. They righted the scooter, checked me over and got me safely across the street.

Amazing. The anti-tip wheels had worked, preventing the scooter from falling on top of me. The extended backrest of the seat protected my head, too. But God is good. Thank you to the men that rushed out to help me and thank you God for your protection and keeping me safe.

I was able to scoot away unscathed, except for a few banged and bloodied toes because I wasn't wearing any socks or shoes. But not wearing shoes is dumb so I probably deserved the bloodied toes. Everything else is piss-poor engineering.

My "Scooter Incident" revisited

October 5, 2012

I haven't blogged anything for almost two and a half months. Right off the bat, I'd like to apologize in advance if any of what follows is a disjointed miss-mash. But please, keep reading.

I've suffered from a bout of bad back & shoulder pain these last two months. However, I have just recently changed to a lower-height, more ergonomic computer desk (with keyboard tray) and bought myself a new recliner. With all of that, I am finally feeling better and on-the-mend. Elana & I used to share a taller desk that helped accommodate her high wheelchair. Over the last year or so, I could tell that my 40+ year-old body was slowly growing less tolerant. So now I have my new computer desk and Elana uses our dining room table re-positioned beside. Not the ideal furniture arrangement perhaps but it works.

Beyond my health issues, our computer is starting to have problems too. I can feel it getting more and more sluggish. I hate it when the PC's not running in tip-top shape. For a techie-geek like me, it's like getting a shovel-full of sand thrown in my face. A major irritant.

Anyway, a lot has happened during my forced two-month hiatus. First though, I wanted to do a quick follow-up on my whole scooter incident back in July. Soon after publishing that post, I also wrote emails to our mayor, Dianne Watts, as well as to the city's engineering department. Within a couple of hours that same day, I received a very nice email from Surrey MLA, Stephanie Cadieux and she thanked me for drawing attention to a serious road safety issue for scooter & wheelchair users and anyone who is physically disabled. A few days after that, I got a phone call from a Surrey roadworks engineer and he thanked me for the heads-up as well. The guy promised to have crews out to fix the pedestrian crossing where I flipped my scooter the very next day. And bless them, they did fix it. But not only that, his road crews also went down the entire corridor of King George Boulevard and leveled out the cement grades at several other crossings and had everything done in about two weeks.

Color me impressed. Now, when traveling down a stretch of King George Boulevard, I can't help but notice all of the wonderful little fixes at the crossings.

Every time I see one, I think to myself: *"I did that - I helped fix this."*

Yes, I was the one who **flipped** a mobility scooter - put my life on the line - for the eventual betterment of society.

You're welcome.

Giving Thanks

October 11, 2012

For the most part, Jake doesn't take naps anymore.

Sometimes, however, on Thursday mornings when Elana has to get up early for work, Jake gets woken up too. At four years-old, Jake still needs a good 12 hours of sleep and him waking up at 7am is too early.

Last Thursday was another one of those days. Jake wouldn't go back to sleep. He watched a bit of TV, had breakfast, played with his toys for awhile and showed no signs of slowing down. Wanting Jake to burn off more energy, I suggested that we go to McDonald's for an ice cream or smoothie. Jake calls it Old McDonald's, it's cute. Anyway, he loves the play area & slide there, so it's an easy sell. But still, it was already two o'clock by the time we left the house fully dressed with coats and socks & shoes. I should have known.

As always, I took the scooter with Jake sitting on my lap and away we went. With my scooter, the whole trip up to McDonald's takes maybe 7 or 8 minutes. Traveling down King George Boulevard, I could see the "Golden Arches" sign-post in the distance. Up until that point, Jake had been happily chatting, singing and debating his choice of smoothie or ice cream. Then, all very suddenly, I saw Jake's eyes close in a fluttering blink.

Loudly, I said: *"Are you falling asleep?"*

In response, Jake protested mildly: *"No, Daddy - Old McDonald's."*

I wasn't taking any chances, however ... and pulled the seatbelt a little tighter. Jake's body went completely limp just a few seconds later, all about 45 seconds away from McDonald's front doors.

I should have known he'd fall asleep. So with Jake slumped over in my lap, I scoot inside McDonald's and order my large cafe mocha as planned. There, in the middle of the restaurant, I sat in my scooter (with the occasional sip of coffee) while Jake napped for the next half-hour.

When Jake was younger (age 1 & 2 & 3), he would fall asleep on my scooter quite regularly. Now that he's four and doesn't usually take naps, it had been awhile. And I have to say, I really enjoyed it. I hugged Jake tight to my chest with both arms and just watched him sleep. A nice quiet daddy moment for sure.

I just sat there watching my son breathe, admiring. I smelt his head and felt the gentle tickle of the hair on Jake's head against my chin. At that moment, I was reminded of a verse from the Bible:

"Are not five sparrows sold for two pennies? Yet not one of them is forgotten by God. Indeed, the very hairs of your head are all numbered. Don't be afraid; you are worth more than many sparrows." (Luke 12, 6-7 NIV)

Those words are so perfectly comforting.

My son. My wife. Family. Friends. Our home. Good health. Finances. My new job. So many reasons to give thanks.

And to think that it all started with a simple trip to McDonald's.



Of course I had absolutely no idea at the time, but Christmas 2012 was to be the final Christmas for our little family: Mommy, Jake & me. By all accounts, Elana seemed quite healthy. Yes, she had the usual struggles related to her auto-immune disorder: the soreness, rashes, swelling & weight-gain etc but she otherwise appeared to be in good health.

Christmas 2012

December 19, 2012

It's been a couple of months since my last blog post and, suddenly, Christmas is right around the corner. We even got our first big dump of snow to prove it.

It's definitely going to be sad & strange not having Elana's dad around. I wish he could be here to see Jake's response to all of the festivities. Now that my son is four, I think it will be the first year that he actually understands and appreciates a lot more of everything.

There is so much I love about Christmas. The colored lights, those little Mandarin oranges & fruitcake & shortbread. Singing carols, attending a candlelight church service, large family gatherings around the dinner table and, of course, the annual viewing of **"It's a Wonderful Life."**

For me, Christmas has always been about a lot more than just Santa Claus and presents. Besides honoring the memory of Elana's dad, I will also remember the birth of baby Jesus. Honoring Jesus is the most important Christmas tradition, by far.



Toddlers & Technology

February 16, 2013

I love technology and always have. I'm a total geek, absolutely.

And it's my parents' fault. You see, my parents knew that I would grow up very differently from other kids my age simply because of my disability. They knew that I'd never play with able-bodied kids in the normal, physical ways: running, bike-riding, and high-energy sports activities. They knew that I would need to hook my friends and neighborhood kids with cool, cutting-edge toys.

I remember getting my first computer when I was fifteen years old. That was 30 years ago. Before that, my parents bought me an [Intellivision](#) video-game console ... and before that, I had several hand-held games powered by a ridiculous number of batteries. Many of them used those big chunky D-cells. I even remember when Dad first brought home [Pong](#) - I was completely floored. Being able to manipulate two rectangles and a square "ball" on a TV screen? Wow!

Today, we live in a world immersed in technology. For Jake, our 46-inch high definition TV, web-connected smartphones, and new touchscreen PC are all nothing special. They just exist. As a responsible dad, the debate about technology has become hyper-relevant. How much TV time is too much? How much Xbox, computer or Nintendo DS? Recently, it seems like Elana & I have been discussing these things on an almost daily basis.

Right now, we have been trying to let Jake regulate himself for the most part. Some days that approach seems to work and sometimes not. But I honestly don't know what the right answer is. Though a couple of days back, Jake only spent about five minutes on technology. He woke up wanting to read a bunch of books and then later played with water & plastic cups in the kitchen sink. Our son also likes hockey & soccer and playing with building blocks & empty cardboard boxes. A rousing game of balloon volleyball with Mommy & Daddy is great fun, too.

In the end, I need to take ownership of my own technological addiction. And if Jake grows up to become a chip-head geek like his dad ...? It's the parents' fault.



Jake with his Angry Birds game

Here is an old email of Elana's from February 2013. She would often cc: "Jake-isms" to me - cute things Jake would say in conversations. Elana would write stuff down right away and save it as a keepsake for herself.

The faith of a child

February 20, 2013

Jake: "Where is Jesus?"

Mommy: "In your heart and in heaven with God."

Jake: "I don't want Jesus in my heart anymore. If Jesus is in my heart I will hit daddy."

Mommy: "Do you mean that if Jesus is in your heart you will be angry?"

Jake: "Mmm hmm."

Mommy: "Why?"

Jake: "I don't want him in my heart."

Mommy: "Are you scared to have him in your heart because you have never seen him?"

Jake: "Yes."

Mommy: "No one can see God or Jesus. We can't touch him or see him, we can only feel him. Just like the wind. Do you know what the wind looks like?"

Jake: "No."

Mommy: "We can't see the wind but we can see what it does and where it goes. When the trees move and the leaves dance we can see the wind. When the wind touches our face we can feel it. It's the same thing with Jesus. We can see him when someone is being kind and loving to someone else. We can see God when we look at the flowers and the trees and the beautiful clouds in the sky because he made them. But we can pray that you will see Jesus like mommy did. I saw his face and it made me very happy and calm. Do you want us to do that?"

Jake: "Yes."

Mommy: "Dear Jesus, we pray that you will show yourself to Jake, in a dream or in another way so that he will see you and not be scared of you anymore. Amen. Do you feel better? Are you still scared?"

Jake: "No. I want Jesus to come into my heart now."

A FEW MORE "JAKE-ISMS"

March 27 2012

"Mommy can I touch your eyebrows? They are soft like a blanket."

March 28, 2012

After a sneezing fit: "Mommy, I told my sneezing to stop and my sneezing said, 'I don't want to!'"

June 20 2012

After pooping on the potty, Mommy says: *"Wow you're such a big boy now!"*

Jakey: "Can I have my happy birthday cake and be 4 now?"

June 22 2012

"Mommy, open your eyes it's wakey-time not moon-time!!"

June 25 2012

"Mommy your yawn is telling you to go to sleep."

March 4, 2013

Mommy says: *"You should go look in the mirror. You have a chocolate face."*

Jakey: *"Mommy don't say that, it's rude!"*

Celebrating Easter and other new things

"Forget the former things;
do not dwell on the past.
See, I am doing a new thing!
Now it springs up; do you not perceive it?"
(Isaiah 43:18-19, NIV)

March 30, 2013

I finally got rid of my old, beat-up pair of crutches. I had been using them for over twenty years, so no doubt there's a bit of stubborn sentiment involved. I was used to them; I was attached to them. After twenty years, I had become comfortable and complacent with the idea that these ancient things were somehow still good enough.

But now that I have my new carbon fiber crutches, I can't believe that I didn't dump the old ones a whole lot sooner. The carbon fiber crutches are just so much better: solid, thin and light-weight. Carbon fiber has a bit of a natural "bounce" to it and I like that too. Walking longer distances with my old crutches made my body tired. And yeah, I've only had this new pair for a few days but I already feel rejuvenated.

This Easter weekend, I encourage everyone to do a new thing. Forget the old and tired tradition of chocolate bunnies & colored eggs. First and foremost, Easter is about a new thing: redemption, rebirth and rejuvenation. Remember what God has done and be blessed.



Here is a poem Elana wrote for her dad on the 1st anniversary of his death. It's a poem filled with deep irony now, given that Elana would be Heaven-bound herself less than three months later.

May 25, 2013

-> <-

DEAR DADDY

here we are,
an unlikely bunch gathered to remember you,
to see your grave,
you lay so still beneath us
while we visit,
share stories, tell jokes, laugh and hide a few tears
We know you are gone
Yet life continues
And quietly you lay, beneath the dirt
Sleeping peacefully
We walk away and the noise fades
Leaving you alone to rest
To dream
To live

*"I know that my redeemer lives,
and that in the end he will stand on the earth."*

Job 19:25

Disabled sex (!) (?)

June 25, 2013

Disabled people are asexual.

Or at least that's what the majority of able-bodied folk believe, it appears.

I know one man in a wheelchair who told me the story of a guy once asking point-blank: "*So you can actually have **SEX**?!?"*"

To which the disabled man replied: "*Loan me your girlfriend for an hour and she'll tell you...*"

Hopefully the tongue-in-cheek humor comes across here. I thought it was hilarious when I first heard it. And yes, that disabled gent is a thoroughly decent Christian man (just as myself), I assure you.

I'm writing this blog post not to be crude but to educate the un-illuminated. When Elana & I are out-and-about with Jake, many people are taken aback.

"*That's your son?!"* they ask.

And if we are out with one of Elana's care-aids, most will assume Jake is **her** (the aide's) son, not ours ... even though my son is an obvious "Mini-me" twin. It's just too much of a leap to think that a disabled married couple is having sex, I guess. Weird.

I remember when we first announced Elana's pregnancy to friends and family over five years ago. There were a lot of dropped jaws. Even though we had been married almost 4 1/2 years at that point, a few couldn't get past the fact that Elana & I were actually **physically** capable of having sex. The un-illuminated assumed that Elana & I were celibate. Disabled people having sexual urges? That can't be right.

Just very recently, Elana had a lunch date with one of her previous / old-hire care aids. At some point in conversation, the care-aid asked how Jake was conceived. *Was it artificial insemination?* She had always been curious but was afraid to ask.

When Elana said that God had blessed us "au naturel", the care-aid was thoroughly confused.

"*No, but really. How did you guys do it?"*

Do it. That's what we did. Except of course that sexual intercourse is never as easy or graceful as it appears in movies or TV. And sure, if you throw a disability or two into the mix it's even less so.

But we did it, simple as all that. Disabled sex is a real thing. Full stop.



Jake, my mini-me !!

To God, on our 10th wedding anniversary

July 12, 2013

I freely admit to being jealous of other people's Facebook status, the ones who post things like:

"Just jetting off to Tofino for a romantic getaway 4 two! 😊"

I hate those. Whenever I read a status like that, I cringe a little - it's true. And I know that I'm being petty but I can't help it. I'm envious of all the able-bodied Facebookers and Tweeters out there who take their able bodies for granted.

Being married 10 years is a pretty big deal. Something worth celebrating for sure. But of course as a couple with a couple of physical disabilities to contend with, life is always a bit more complicated. Things get in the way more readily, it seems. Stuff happens.

Elana & I have been trying to plan something special for the last couple of months. We can't afford anything too fancy, but a few days over on Vancouver Island & in Victoria would be nice. However, *planning* a small trip somewhere - anywhere - has proved extremely challenging. Because of Elana's wheelchair, we need to arrange accessible transportation, accessible accommodation, lug a cumbersome ceiling-track lift for her bed transfers and bring along a full-time careaid (or most probably two) to help out.

If only it were as simple as one call to a travel agent. Elana & I have never been able to go any place spur-of-the-moment. For us, spontaneous just doesn't happen - it has to all be carefully planned & staff-coordinated first. It's times like this when having a disability or two really sucks.

As I've already said, stuff happens. For the past week, Elana has been stuck in bed with health issues over-and-above her usual physical disability (Arthrogyrosis). She has in fact been battling a difficult auto-immune disorder for the past four years or so. At first, the doctor thought it was Sjogren's Syndrome. Later, another doctor thought it was Lymphedema. Now they believe it's Lupus. Irregardless, it all essentially boils down to a compromised immune system and Elana is right now experiencing a particularly bad flare-up ... with nasty rash & painful sores over her whole body.

And so here it is, July 12th, the actual day of our tenth wedding anniversary and my heart is breaking. On the one hand, I am so thankful to God for giving me someone as wonderful as Elana. Still, I feel so truly sad for my wife. Painful rash & sores aren't the least bit romantic. She deserves so much better, especially today.

Let me be selfish for a moment. Please God of Miracles, hear my prayer. I want my wife healed, happy and jetting off to Tofino. Or if not that, I'll gladly accept a few days in Victoria, too. Thank You.



Elana, My Life

For Elana A., in loving memory: December 8, 1974 - August 17, 2013

August 18, 2013

I lost my wife early yesterday morning as she lost her battle with Lupus. She wanted to come home - come home to Jake & me - but has instead gone home to Jesus.

There are no words, really, but I will try nonetheless. Elana was my life. For twelve years (10 married), she was my everything. Now she is gone, at 38 years old. She should have lived another 38 years, at least. Elana was such a strong /spirited / passionate woman in every way possible and, in truth, I expected she would out-live me by a few years easily.

But instead my son will grow up without his mother and I am officially a single dad. I am numb, broken. I will be lost without her. Elana loved being a mother. Between the two of us, Elana was the better parent, by far. I rode on her coattails an awful lot. I always knew she did **a lot** as a mom, for Jake and for our family. In our household, Elana was the brains, the organizer, the master planner. When she first got sick about six weeks back, I immediately felt her loss of support around the home and re-discovered a much fuller appreciation of her.

In spite of her big disability (Arthrogryposis), her motorized wheelchair, all of her physical limitations - and of course her four-year battle with Lupus - Elana loved her life. She would often refer to me & Jake & herself as *"our little family"* or *"our little life"*. And she loved it, she did. She embraced everything and everyone with the true heart of Jesus: open, honest, unbending, driven. Like nobody else I have known or will know. All of the family & friends that knew Elana will confirm this, unanimously. Elana was not without fault, but her heart and thirst for God can never be questioned.

Elana showed me the love of Jesus, too. Elana taught me a lot about love through her own love for me. She encouraged me to share feelings and emotion. Gently pushed me to new territory and experiences. I am a changed man because of Elana and I feel so blessed & privileged to be her husband, and she my wife.

Elana had my wedding ring inscribed with: ***"To my forever knight."***

Now, looking back on the last four years - and her battle with Lupus, specifically - I can't help but feel like I let her down. That I didn't protect her enough. No matter what anyone says, I will always think that, and regret. The whole medical profession let Elana down, in fact ... let her slip through the cracks for four years while not nearly enough was done to adequately address the Lupus and all of her underlying / ongoing health issues. It wasn't until Elana got really sick and got transferred to the excellent ICU medical team at St. Paul's Hospital that she finally got the care & attention she deserved. In her last few days, it looked like Elana might make it through, would turn the corner.

I wanted Elana to come home, so bad, and I remained hopeful until the very end. For her to come home to our "little family", to resume her duties as Mommy & wife. She had gathered an army of prayer warriors and she did fight hard, but it wasn't enough.

Shining bright for 38 years, Elana's little life had such a profound impact on me ... and on the lives of many, many others. I wish she could have stayed longer, but I take comfort knowing she is finally pain-free with a new non-disabled body and that both Jake & I will be reunited with her again someday.

Elana was never given a middle name at birth. When we were first dating, I started referring to her as "**Elana A.**" The "**A.**" was short for "**Amazing**" and it always fit perfectly. Until we all meet again, have fun being amazing in Heaven, my dear sweet Elana.



Elana's Legacy

August 31, 2013

It's been two weeks since my wife's passing. I'm in a fog. Quietly numb, lost.

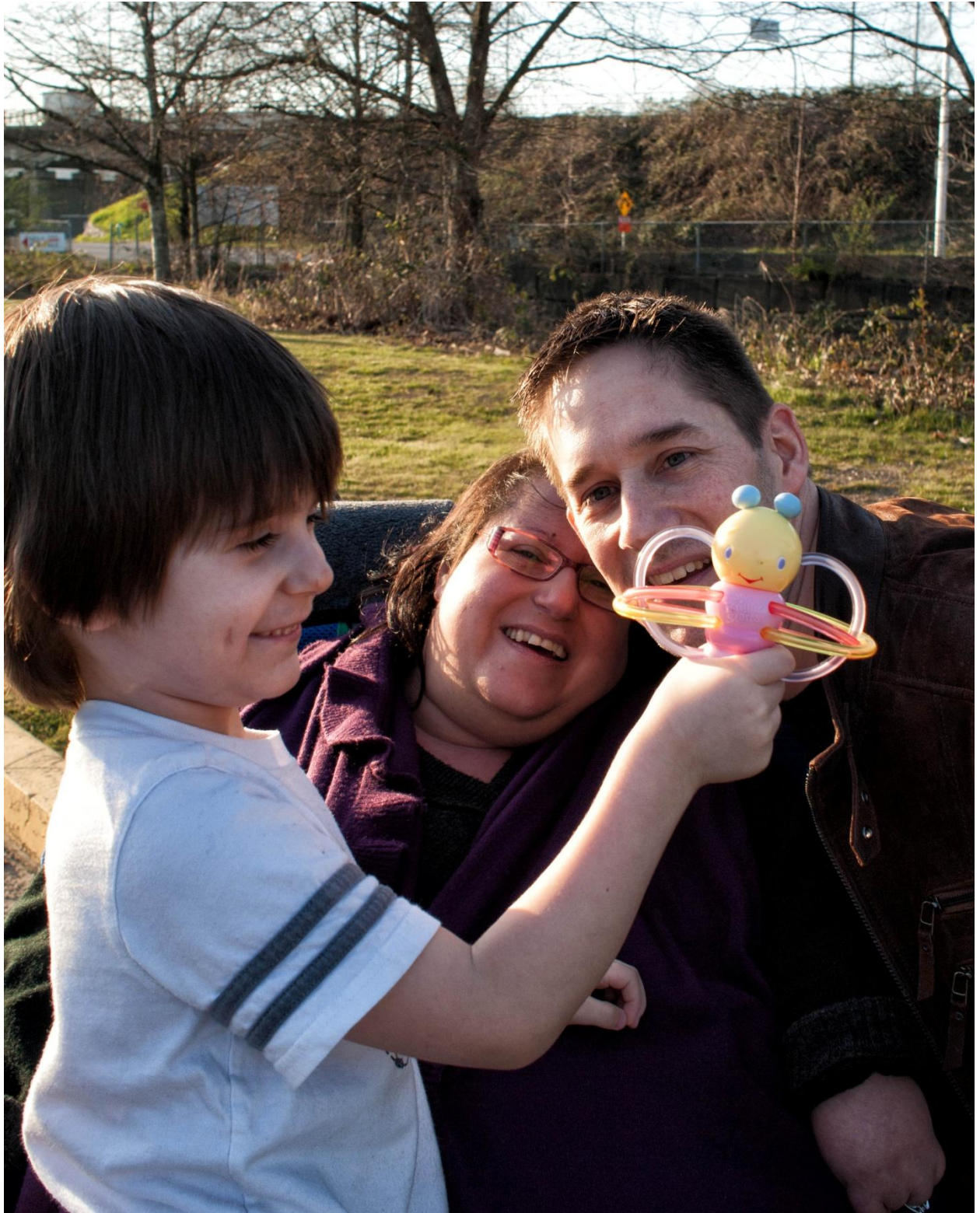
Finding time to grieve has been difficult too. There is so much stuff to do each day, it's overwhelming. First was Elana's burial & memorial and what felt like a very rushed week of planning. Now I'm dealing with life insurance & pension payouts, closing of bank accounts and cancelling her cell phone plan. It's all so very sad & stressful and I don't want to do any of it.

Honestly, it feels like I can't go on. It feels impossible. I want to press **<Pause>**, want to stop, and yet I can't. I want to just grieve but my son won't let me. I have to carry on for him. Jake has been in a much different head-space than me. He is a typical five year-old, after all. His little brain doesn't fully grasp everything. For Jake, these first two weeks have been like any other and he has moved along happy & oblivious. Knowing how much Elana loved being a mommy, it has been hard for me to see that (what appears to be his indifference). But of course I know that Jake loved his Mommy, I know it. When he does ask about her, I've tried to stay simple & consistent. Always saying that Mommy is with God & Jesus & Opa in heaven. That unlike in video games, we all have only one life. That Jake has one life (one body, one brain) and he needs to look after it. That Mommy loved him very much. That she didn't want to leave us. But Mommy had one life, she got sick & she died. And so now she is in heaven.

Just today though (early, about 2am) I got my first glimpse that Jake might actually understand. He woke from a bad dream, sobbing. I calmed & comforted him but then a few minutes later, the crying started again and went on & on. At first, Jake said that he was only sad about losing a ball in his dream. Later, he confessed to feeling sad about Mommy. We talked a lot after that and I cried openly in front of him, telling him how much I miss & loved Mommy too. He finally said: *"Mommy can't ever come back to see us because she's in heaven, right...?"*

Love. If I had to sum Elana up in just one word, that would be it. Elana leaves behind a legacy of love. She touched so many lives in her 38 years. If life is measured by the number of other lives touched, then Elana's time here was definitely well spent. It is my job to carry Elana's legacy forward, to make sure that Jake doesn't ever forget his Mommy. Elana planted many important first seeds. Her love for Jesus, her love of music, her humour, and her love for me & her son. So much love.

Knowing all of this doesn't stop the hurt, however. My faith has not been shaken in the slightest but I do have a new appreciation for how temporary & fleeting this earthly life can be. Elana was my best joy. We were so interwoven together, it was difficult to tell where she began & I ended. Again, my faith is not shaken but (not to be morbid) I can now look forward to my End of Days with confidence. I have a comfortable peace knowing that I will get to spend eternity with Elana, eventually.



This is our last family photo together, taken on Easter Sunday 2013

Survivor's Guilt

September 11, 2013

Jake & I scootered over to Elana's mom's place yesterday to celebrate his 5th birthday. And a couple days before that, we took a bus out to my parents for another celebration. Both times, it didn't feel right that Elana wasn't there.

The whole month my wife was sick in hospital, I kept telling her that she was going to get better for Jake's birthday. That we would throw a big double-party for her & Jake. I also know that if Elana had been in charge of things, she would've for sure had a separate third party planned just for kids / Jake's younger friends.

Alas, there was only two small parties. And while they were nice, again, it felt like Elana should have been there. We definitely all missed her powerful voice, as she was always the only one amongst us capable of singing the "**Happy Birthday Song**" with actual melody. I really missed her *physical* presence. I missed hearing her conversation, her laugh. And I miss coming up behind her wheelchair and wrapping my arms around her neck. Bending my head down to smell her hair, then kiss her forehead and lips. I miss all of that, and more. My heart aches ... feels heavy ... pained.

It doesn't seem right that for every day, week, & month that Elana isn't here, it's a steady stream of moment upon moments that she misses out, doesn't get to see or participate in. It doesn't feel right that she's gone. Of course, part of me wants Elana back here for selfish reasons. I miss her: plain and simple. But even more than that, it just doesn't seem fair to Jake or to Elana herself. Jake misses out on having a mommy, and Elana misses out on continuing to be one. I can't help but think that ten years from now, Jake will have forgotten her ... or at least large parts of her. And that's sad because Elana loved being a mommy. Five years doesn't seem long enough. I mean, sure, Elana gave Jake a good five years and a solid foundation. And as I said in my previous post, Elana planted many very important first seeds for Jake. I know it. I know. But it doesn't seem right that I'm still here and my wife isn't.

My sister says that I'm having "survivor's guilt", and perhaps I am. But Elana was a passionate mother. Between the two of us, she was the better parent. I'm not being humble, merely stating a fact. If God had given me the choice, I would gladly trade places with Elana now. Without the slightest hesitation, I would do it. A friend asked me if I was angry at God. I answered honestly: absolutely not. How could I possibly be angry at God when He was the one who had given me Elana in the first place?

"The Lord gives, and the Lord taketh away." (Job 1:21, KJV)

Mostly, God gives. Any blessing I have ever received comes from Him. Elana was my biggest blessing by far. Yes, my twelve years with her was too short but I am still so thankful for all the time that I *did* have with her. So many people will never experience the love Elana & I shared. It truly was a match made in Heaven. God had chosen for us. It's not what either Elana or I would have picked for ourselves because

we both already knew that dealing with a physical disability every day was hard. Dealing with two was completely impractical. But God knew what we *needed* ... while still giving us everything we ever ***wanted***. In the end, we fell in love in spite of our disabilities. In the end, love trumped all.

So no, I am most definitely not angry at God. I am still sad though. Sad that I don't get to smell Elana's hair anymore. Sad that Jake didn't get to keep his mommy and that he may eventually forget her. And yes, sad that Elana couldn't continue on as a mommy.

Unfortunately, I can't change my reality. I can't change what happened. God is the author of everything, the beginning and the end. All I can do now is move forward. Try to carry on as best I possibly can.

For Elana, for Jake, and for me.

Religion vs. Relationship

September 19, 2013

I love the love story Elana & I had. It's something that I explore quite deeply in my book **DADDY BENT-LEGS**, and those few chapters have always been what I'm most proud of. When Elana first read through an early manuscript, she thought I had perhaps exaggerated my feelings ... had overblown everything a bit with my choice of words in describing our relationship and sharing it with the world. In truth, it was all 100% accurate, every word. If anything, I actually *undersold* or *de-emphasized* certain details. Even so, my wife was a critic. With my blog too, Elana was sometimes afraid to read it.

I can still hear her mild reprimand of my post on disabled sex: *"I can't believe you actually wrote about that. How embarrassing...!"*

So now with all that preamble out of the way, I want to write something that Elana herself would write about. Something that wouldn't embarrass her. Something she would be proud of. The topic: Religion versus relationship. I remember Elana's initial attempt at explaining Christianity to me ... and how she described her faith.

It's like having coffee with God, she said. And I remember thinking how crazy that sounded. At first, I just didn't understand it at all. For Elana, Christianity wasn't about religion or even about going to church. It was about **relationship**: her relationship with God and her faith in Jesus. Other relationships mattered too, of course. Her relationships with family & friends. Even stretching herself out to complete strangers, Elana did that a lot. All relationships mattered to her. Elana had a huge heart and she offered herself up to practically anyone. Through it all, God came first. Jesus had top priority, and relationship ruled all. Elana went to church for relationship, read her bible for relationship, worshipped for relationship.

Before meeting Elana, I never considered myself a true Christian. In my younger years, my exposure to church was limited to the occasional Christmas or Easter service. And yet, despite these brief encounters with Christianity, I do remember always enjoying it, being attracted to it ... and even being jealous of others who had it in abundance!

Looking back, it's almost unbelievable to think it took me thirty-three years to fully commit, to come to God. At age 33, after meeting Elana, I very soon got it. I finally understood that **religion** on its own (as a purely human construct) is utterly fallible.

Since Elana's passing, I have felt my own faith only grow stronger every day. More than ever, I fully comprehend that our earthly life is temporary. Death doesn't scare me anymore. Even as a Christian ... and even knowing how awesome Heaven is going to be ... death used to scare me a little bit. Now I honestly feel invincible, like I could absorb a thousand bullets and walk through a burning inferno

completely unscathed.

I have been very hesitant to share some of these thoughts and feelings openly. Worried that my family & friends will think I'm weird or freaking out. Just the other day, a very dear (but non-Christian) friend of mine of almost forty years said that he's here to support me in any way he can but that he's "*....not big on the religious thing*".

And I totally get it, I do. I used to think exactly like that ... just like tens of millions of other folks out there. Like my friend, I used to think that Christianity was a "*religious thing*". But it's not.

Time to set the record straight. Elana too was quite fond of saying that she wasn't big on religion. At the end of the day, it's *relationship* that matters ... and at the end day, that's what matters most to God also.

That's it, I'm done. Hopefully my wife's not too embarrassed.

A Wedding In Heaven

September 27, 2002. Eleven years ago today I popped the question. I asked Elana to marry me and, just like that, we were engaged. It's the single best and most life-changing decision I've ever made.

It's a moment of serendipity today, also ... as this is my fortieth (40th) blog post, officially. Forty is a number of special significance for me. It's the age I was when we had Jake. And it's a number that appears as part of the subtitle for my book, **DADDY BENT-LEGS**. So yes, it's something that deserves a bit of celebration.

In the thirty-nine blog posts that came before, my wife never contributed any of her own content ... her own words, thoughts, or opinions. She definitely *inspired* lots of what I wrote about, but she unfortunately never got around to submitting a guest piece of her very own. I always wanted us to do some sort of "*He said, she said*" perspective on parenting too. Who knows, there might've even been enough content there to write a whole 2nd book together. I would've loved that.

Back in March 2011, Elana actually started her own blog space (... a couple of months before I launched mine). It was never publicized or really shared with anyone, but it does exist. She only got around to writing four small posts. I know that she definitely wanted to write a lot more entries but my wife was just too busy being a mommy that she never had enough free time to blog. Obviously, I was the more slack / idle parent.

Elana's blog was called, *Wistful writings of a Wheelie Good Mom*. Again, it's just four posts but they are all pretty special. Each one is a tiny piece of her; her own voice.

I want to end with a verse of poetry Elana wrote for me many years ago:

A second wedding, myriads of angel-guests, but I am under your spell. We dance close. You lead me to celestial sheets where, at long last, our love is perfectly known.

It's a vision of us together in Heaven. A second wedding. And I look forward to that day, I do. It gives me great peace and comfort knowing that Elana is already up there, waiting for me.

And so I wait, too. Living a life here on earth, day by day, in 24-hour chunks. I am living for Jake. I am living to carry forward Elana's legacy. But I am also living for eternity and the promise of God's future Kingdom come. So I will continue on, waiting. Until we can all be together again, dancing amongst angels.

Prayer of Thanksgiving

October 11, 2013

Dear Heavenly Father,

Thank you, oh God, for my life.
For Your protection and careful watch over me, always.
Even in my first thirty-three years, You remained faithful.
Patiently waiting for me to come to You.

Thank you for my disabled body,
That I should remain humble in my brokenness.
That I should grow up free of prejudice and have a healthy dose of empathy for others.
With wisdom and respect, I love the life & body You chose for me.

Thank you, because were it not for my physical disability,
I may never have met the love of my life.
Elana was a gift; my very special gift from You.
Of all the rich blessings You have delivered, she was my best.

Thank you for Elana's life and for allowing me to be a part of it.
You used Elana to bring me nearer to salvation, I know it.
It is because of Your gift & grace that
I now have the promise of everlasting life, an eternity in Heaven.

I once told Elana that she was like the sun.
Her beauty & warmth blazed so bright that any imperfections were blotted out, gone.
But she was like Your Son, also.
Being with Elana everyday was like staring into the face of Jesus. So perfect.

I see my life divided into two parts: my life before I met Elana, and my life *after*.
Talking of marriage, Jesus himself said that two shall become one flesh.
That was certainly true of Elana & me.
My dear wife has left me and I am cleaved in half, ever since.

Even so, thank you. Thank you for Elana and for Jesus.
My Lord and Saviour strengthens me, upholds me in my time of grief.
Jesus Christ is the way, the truth and the life.
It is only through Him that I will get to see my sweet Elana again, in glory.

Oh God, thank you for remaining faithful ... for keeping Your promise.

With power, and patience.

With mercy and grace.

For your kingdom to come, amen.

Don't try to squash God ... He is much bigger!!

October 18, 2013

For those that don't know, I'm 45 years old. Not quite caught up to my parents yet, but getting there.

My parents have seen a lot of technological change in their own time, no doubt. But so have the peeps from my younger(!) generation. When I was a kid, rotary dial telephones and black & white TV screens were commonplace. I remember chocolate bars were 25 cents each, too. Ok, chocolate bars aren't exactly *technological*, but it's surprising nonetheless.

Along with all of the advances in science and technology, another significant shift cannot escape notice. Back when I was in public elementary school, we still said the *Lord's Prayer* and sang "*God Save The Queen*" at student assemblies. As well, teachers could freely display posters & decorations of "MERRY CHRISTMAS" without fear of offending anyone. Of course nowadays, it's "Happy Holidays", "Season's Greetings" and "winter festivals". Political correctness rules all. Our modern society has become tepid and watered-down, as a result. God is minimized ... marginalized ... pushed aside. And for many, Jesus has been squashed by a fat guy in a red suit.

I see people ignoring / denying God, and it makes me sad. The evidence of God is everywhere, in plain sight. When I see a tree in beautiful autumn colors, I can't help but acknowledge the master Creator behind it. When I stop to consider all of the incredible intricacies of my human body, divine fingerprints of intelligent design abound. Non-Christians dismiss all examples of worldly creation as pure flukes born out of a million years of evolution, and it makes absolutely no sense to me.

God deserves all of the credit, but a lot of people don't want it that way. Folks that deny God see themselves as governed by a happenstance mix of good & bad luck - that's it. Some people are just so quick to attribute an obvious gifted-wrapped blessing from God as a simple fortunate bounce, nothing more. How frustrating!

In reality - if you **really** pause to think - it's actually quite a challenge to try to dismiss God. Of course people do it all the time, every day ... but the fact is, theories of evolution and faith-systems based on luck alone is an incredibly weak house of cards. It takes some pretty flawed, perverse logic to deny God, and yet people still do it.

Regardless, God is always there. He remains faithful even to those who aren't, those who don't seek Him. God loves us all, but one day His patience will run out. One day soon, Jesus will return to redeem the earth. If Jesus came down from the clouds next week, will you be ready? Would you deny Him, then...?

I sincerely hope not.

*** ADDENDUM, Oct 19, 2013:**

*Evangelism is a tough gig, which is precisely why I don't practice it very often. Still, I hope this post inspires a few people to dig a little deeper and discover the truth for themselves. Jesus Christ **did** walk the earth. His life & teachings have been documented in several sources outside of the bible. And while there are a few translation inconsistencies / errors, the bible has proven itself to be both historically accurate **and** amazingly prophetic. I've been studying the "Book of Revelation" a lot lately, and the upcoming [Blood Moon Tetrad](#) (beginning April 2014) and [specific star-alignment mentioned in Revelation 12](#) are two incredible signs from God.*

Dreams of New Jerusalem

October 29, 2013

I always tell Jake to dream of Mommy. It's part of our nightly bedtime routine.

A few mornings back, as I lie in bed with my son (slowly waking), Jake tells me he had a dream. He saw Mommy. He tells me that Mommy said she misses us. She wishes that she could have stayed with us.

It was all told with such a sweet sincerity. I just broke down in tears, I couldn't help it. Sometimes, I try to hide my crying - but here, I didn't. I sobbed openly.

Jake says, *"Aww, Daddy I know you miss Mommy!!"*

My son was lying in bed behind me and he starts stroking my back, and then reaches both arms around to give me a big hug. It was a tender moment.

I tell Jake that we will see Mommy again. All the time, I tell him. Mommy won't have her wheelchair ... she'll be able to run & jump & dance. Heaven and the new earth is going to be awesome, I know it. I remember before thinking that heaven might be boring. Everyone just standing around singing praises all the time...

I now think much differently. With twelve gates - three on each wall - New Jerusalem will be a bustle of activity, of comings & goings. With lots of fun things to do. It will be like our world is now but unfallen & free from sin.

Jesus has prepared a special place for Elana and me, I'm confident in that. Our "mansion" will probably be a quaint little rancher / cottage by a sun-soaked beach. Elana will have her butterfly garden in the backyard, and maybe I'll have a white wolf as a pet.

One thing I do know for certain: whatever I can possibly envision, it'll be 1000% better. **God is mighty** and He has always over-delivered for me ... going far above & beyond what was expected. Just as God has blessed me with both Elana & with Jake, He is sure to over-deliver yet again.

Meanwhile, back on this earth: birth pangs. In Israel alone, seven earthquakes in seven days. Unprecedented storms worldwide. Beached Oarfish. Comet Ison. Rumors of war. Revelation and prophecy being fulfilled. [The Blood Moon Tetrad](#). And a woman clothed in the sun, with the moon at her feet ([Revelation 12:1, NIV](#)).

Everywhere ... and in everything, **God is mighty!!**

A special gift

November 2, 2013

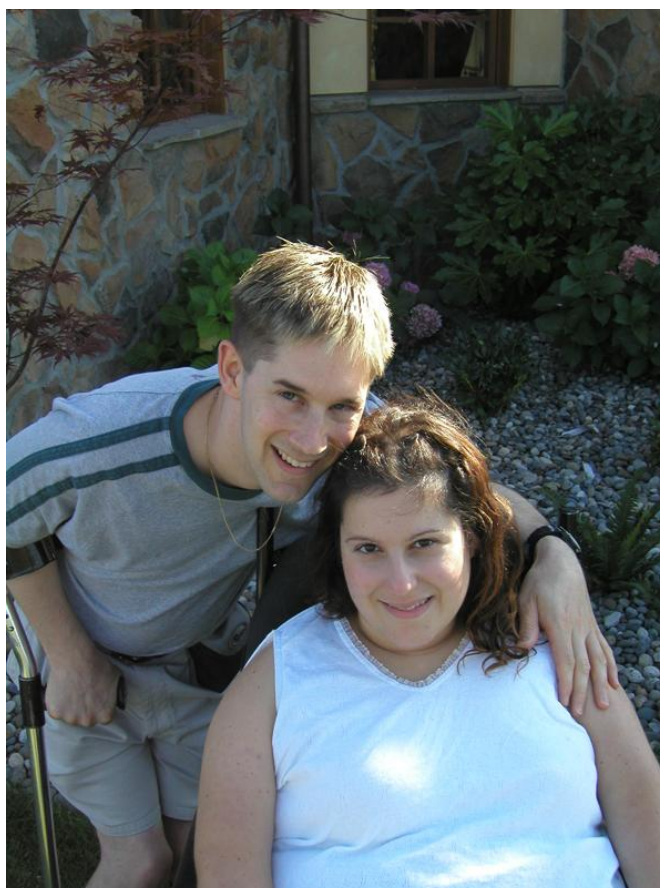
My wife had a beautiful singing voice. She had the voice of an angel, truly.

On our wedding day, Elana surprised me with a song. She had secretly recorded "*Feels Like Home*" and it was playing as she went down the aisle with her dad. I smiled so big as soon as I heard it.

Anyway, that CD of her singing had been AWOL for a couple of years now ... as well as other photo CDs of many treasured pictures of Elana & me. I knew the CDs had to be somewhere, I just didn't know **WHERE!**

Yesterday, the mystery was finally solved. Elana's mom had been storing them at her house. She had packed up a few boxes for us when we de-cluttered a bit to put our condo up for sale. We never did end up selling the condo, and I forgot to take the boxes back...

Re-discovering that song again and all of the photo CDs yesterday was a very special gift. It was a happy, happy day.



92 days

"I can do all things through Christ who strengthens me." (Philippians 4:13)

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November 15, 2013

Dearest Elana,

This Sunday (November 17th) will mark exactly three months since you passed into Heaven.

Three months. A full quarter of a year. Ninety-two days, unbelievable. It is my faith that has kept me going. Only Jesus. Just as the two weeks sick in bed and whole month in hospital with painful sores all over your body were your trials of Job, this is my trial now. A Refiner's fire. But God is good and He draws me close, protects.

Jake & I miss you every day. With every day that passes, I miss you more. The loss hasn't really gotten any easier, I've just become more adept at hiding or ignoring it. Still, that's not to say there haven't been plenty of good days, too. There has in fact been lots.

Besides God, Jake has kept me centered, focussed - and brought me little bits of joy daily. Our son is barely five and he's already developed an incredible sense of humor, truly. He cracks me up and we often laugh uncontrollably together. A wonderful release. If you were here, I know you'd tease me (as always) with how Jake's laugh sounds exactly like mine!

Jake has adjusted well to Kindergarten. The first couple of weeks were hard, but he is actually enjoying himself now and making new friends. Our son is still a very picky eater of course but I am trying to work on that. I got him enrolled in the school lunch program straight away and I think that it's helping. Jake also had his first school portrait taken a few weeks back. I had to use a little gel because his hair was too long but the proofs are very cute. You'll be happy to know that Jake finally let Tita cut his hair again just yesterday.

So I'm trying my best. Struggling at times, yes, but really trying. Not a day goes by that I don't wish you were here to help me. I know that I have God to lean on, as well as the support of much family & friends. But you are my wife and best friend, still. Sure you put me in my place at times but you were also my biggest cheerleader. I miss that. I miss all of it.

I miss you. Absence makes the heart grow fonder. It's true. I miss you, I miss you, I miss you.

Love,

Neil (aka Husb-N)

The Joy of Christmas

*"For God so loved the world that he gave his one and only Son,
that whoever believes in him shall not perish but have eternal life."*

(John 3:16)

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December 7, 2013.

Tomorrow is my wife's birthday. Of course a big part of me is not looking forward to it, simply because she's not here to celebrate with us. I used to always look forward to Elana's birthday. It was kind of the official kick-off to Christmas joy for me.

Long ago, Elana & I started a tradition where every birthday was **HER** day: Elana could do whatever she wanted, go wherever she wanted for dinner, and I would either take Elana to the mall to help her buy a new outfit ... or surprise her with a couple of nice tops or sweaters that I picked out, myself. There will be no new sweater this year, and yes, I'm very sad. I am crying as I'm writing this, in fact.

I loved picking out and buying Elana new clothes, I really did. She was my Barbie doll. My supermodel. My arm candy. I loved showing her off. She was so beautiful. And I was so thankful to have Elana as my wife and so proud to be her husband. Always.

In truth, Elana was **my gift**. A very special gift from God. A gift that I got to unwrap daily: over and over and over again. As a kid, growing up I always loved Christmas. Getting married, becoming a father, and having Elana in my life made me appreciate Christmas all the more.

It goes without saying that Elana absolutely loved everything about Christmas, too. It is a time to celebrate Jesus ... God's biggest gift for the whole world. It is through Christ alone that we all have salvation and life everlasting. Christmas is the only time of year where everyone - people of all nationalities - come together to celebrate in one form or another. Even those who don't call themselves Christians experience joy. Every year, hearts are softened. The gospel is shared anew. And more souls are won over for Jesus Christ.

Elana's birthday. Christmas. Everything will be different this year. For me, everything **feels** so very different. I am immensely sad that Elana isn't here ... and yet I also know that I mustn't ignore the joy of **CHRISTmas**. Jesus **is** the reason for the season, and I feel Him closer like never before.

It is so easy to get buried in the distractions of Christmas. The drunken parties, the shopping, the Black Friday sales frenzy, the lusting after latest-model cell phones & tablets & cameras & Xbox game consoles. A self-confessed techie-geek, I used to be in amongst that crowd. But not this year. This year is going to be very different.

This year, Christmas isn't for me. It's not for me. I'm doing Christmas for my son, Jake. I'm also doing it in remembrance of Elana. But most importantly, I'm doing it to celebrate the joy of Jesus Christ.

This year, I implore everyone to please take time to acknowledge the true gift of Christmas.

First kiss of 2002

January 1, 2014

Those that have read my book, **DADDY BENT-LEGS** already know that Elana & I met on a blind date, December 1st, 2001. Our second date was a couple of weeks later. I remember being distracted pretty much the whole time, thinking about kissing her - wanting to - but also nervous about pushing things too fast.

I would wait until our third date, which happened to be a couple of days after New Years. I told Elana that I was sad because I still hadn't received a New Years kiss from anyone yet. Sure, it was a bit manipulative on my part perhaps, but it was nonetheless true.

I asked for her permission: *"Can I kiss you now...?"*

I had caught her off-guard. *What...? Here? Now?*

Yes.

And so I kissed her. I expected something a bit timid, reserved. A typical first kiss. Though what I got was big, bold & thoroughly amazing! The rest, as they say, is history.

I loved Elana's kisses, her affection, her soft touch. I got to have that first kiss for twelve years straight. I treasured Elana's kisses, and boy did I miss not getting her special kiss this New Years.

The entire last half of 2013 sucked. By default, Year 2014 will most certainly be better. But honestly, I take nothing for granted. For me, everything has become bite-sized. I see others busily planning stuff, chasing the future and a dangled carrot or two while I'm in a far different head space. Elana's death has awakened me, and God has my complete attention.

All of my tomorrows with Elana eventually ran out. That's why each day and every new year matters. I approach 2014 and everything beyond with a true peace & confidence knowing that God has authored my life, my salvation, and my eternity in Heaven.

Better still, Elana will be there, waiting for that first kiss.



Elana & me on our Honeymoon, July 2003

Here is a guest post I did for [Handicap This!](#)

A love born in spite of disabilities

“An excellent wife is the crown of her husband...” Proverbs 12:4 (NKJV)

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February 14, 2014

I was asked to write a guest blog post for **Handicap This!** on Valentine’s Day in honour of my lovely wife Elana, who passed away on August 17th last year. With Elana’s absence, the past six months have been like an eternity. Her loss hasn’t gotten any easier. I’ve just become better at hiding it.

Of course I don’t want my guest post to focus on grief, but on **love** instead. The love Elana and I shared in our 12 years together. Those that have read my book, **Daddy Bent-Legs** and follow my own blog at www.daddybentlegs.com will know a fair bit about my wife and I already. For the folks coming in cold, however, here’s a quick recap.

I was born with cerebral palsy and have been on crutches my whole life. My wife was born with Arthrogryposis, meaning her joints were fused. They never fully developed. As a result of Elana’s limitations, she had to rely on a motorized wheelchair for mobility. Not only that, my wife was also completely dependent on the help of 24/7 care aids for her personal care: dressing, grooming, toileting etc.

Elana’s physical disability was a lot more severe than my CP, obviously. Though in a great many ways, my wife wasn’t limited at all! Anybody meeting Elana for the first time would notice her wheelchair, sure. But the fact is, Elana’s beauty (both inside and out) is what usually garnered the most attention. Whatever Elana could do, she did. Nothing could stop her.

She was a dreamer who believed anything was possible.

The words “can’t” and “no” were never part of her vocabulary. If anybody ever told Elana that she probably couldn’t/shouldn’t do or try something, it simply served as inspiration to prove them wrong. Elana proved herself over and over again. She did it as an elementary school teacher for 16 years, as my wife for 10 years, and as a mother to our son Jake for almost five years.

The last four years of Elana’s life, when she was first diagnosed with lupus, were definitely hard. As if her Arthrogryposis wasn’t challenge enough, her four-year battle with lupus really took its toll on her physically. But just like everything else she had done before, Elana pushed the lupus aside and forged ahead as best she could. For four years Elana carried on as a teacher, wife, and mommy. Unfortunately, the lupus eventually won. If only love and determination alone could have saved her.

Elana was beautiful and sexy, always. Yet right from the opening moments of our very first date back in December 2001, it was her infectious energy and fierce determination that really attracted me. Elana

had a genuine warmth about her; a tender heart. Still, I have to be completely honest. I never thought I would end up with a disabled wife.

In truth, I never wanted to date a disabled woman simply because I thought it would prove to be far too difficult. My own disability was bad enough I thought. *Trying to take on a second, more severe physical disability in someone else?? Pure insanity, surely.*

And yes, for those wondering Elana held the exact same belief/attitude as me. She didn't ever want to date a disabled guy. The full reality was Elana and I fell in love not *because* of our disabilities but, rather, in spite of them.

A lot of people, able-bodied or not, may never experience the love and companionship Elana and I had. Right off the bat let me say that our **"disabled love,"** when compared up against the able-bodied variety, was an entirely different beast. As a disabled couple Elana and I had to work a lot harder for even the simplest of things.

Sometimes the so-called ordinary everyday things were actually impossible for us. The fact is able-bodied couples take their able-bodies for granted. Holding hands while walking. Cuddling together on the sofa, sharing a bath, sex anywhere or anytime, anything spontaneous, spur-of-the-moment Elana and I could do almost none of that.

In a full 10 years of marriage, we were only able to have *TWO* baths together. Believe me, if I had my way, I would have shared well over a thousand bath times with her. And for sure, because of Elana's 24/7 care aids, it was difficult to get true privacy and alone time whenever we wanted.

Nothing could ever be completely spontaneous. Everything had to be carefully planned/scheduled with Elana's care aids first. Also becoming parents five years ago, parents with disabilities, added a whole new layer of challenge to our privacy, alone time, and romance too.

So yes, physical disabilities truly suck sometimes. In spite of all the obstacles and impossibilities though, I can't help but think of Elana and I as a pair of superheroes out to conquer the world. Together we were bold, unstoppable, and unbeatable. A disabled married couple and parents to boot, we were definitely a rare breed indeed.

Going out and about with our son elicited a lot of attention, head-turning, and strange looks in public sometimes. If ever there was to be a magazine cover for "Parents with Disabilities," without a doubt Elana and I would have been on it. We were a rock star family. It was weird and wonderful all at once. Elana used to affectionately call it *"our little family"* and *"our little life."* I miss our little family, intact like was: Elana, Jake, & me.

Oh, how I miss it. I miss Elana, every day. Every hour of every day, I miss her. She was my joy, my daily fun. She was my partner in crime, my trusted sidekick. Particularly anything we did together out of the house and away from care aids, those were treasured moments. Just the three of us: Elana, Jake, and me. Short trips up to the grocery store, a coffee date, a quick lunch at Tim Hortons, or a relaxed family dinner at McDonald's, all precious moments.

As Proverbs 12:4 says, Elana was an excellent wife. She was my crown. It didn't matter to me that she couldn't cook, couldn't clean, and couldn't fulfill the homemaker stereotype. None of her limitations registered with me. Elana had awesome ability where it mattered most. She was beautiful, loving, and amazing.

In the end, her few shortcomings didn't matter. Love happened in spite of disability. At the same time, there's no denying that it was in fact our **disabilities**, our disabled experience that formed and molded both of us. It's what made Elana so determined and made me a little bit humble. Like a refiner's fire, God shaped our persons and personalities and brought us together as one flesh, something inseparable.

Elana once told me of a time back when she was single where an able-bodied guy actually blurted out to her point-blank "Wow, you're really beautiful. It's too bad you're in a wheelchair."

I've also had a couple of experiences like that, myself, of course. But seriously, that guy's loss was definitely my gain. Elana was my biggest blessing, bar none. My dearest Valentine, for all of eternity in heaven.

Reminiscing about love,
-Neil



What Easter means to me: life, death and resurrection

"Behold, I am coming quickly! Hold fast what you have, that no one may take your crown."

(Revelation 3:11, NKJV)

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March 21, 2014

So much of Christian faith can be pinned on Easter: the persecution & death of Jesus and then later, his resurrection and ascension into Heaven.

To be sure, Jesus was pretty radical back in his time. He hung around with lepers, prostitutes and tax collectors. He performed miracles and professed to be God. Yes, Jesus had his followers but he attracted a tremendous number of scoffers also. Bible scholars today have two thousand years of hindsight and a fully transcribed New Testament to lean on. The people of Jesus' time had far less and I can certainly see how scepticism won out.

It's been just over seven months since my wife Elana passed away. Elana's death woke me up and brought me to a whole other level, spiritually. I feel God close always, in everything. It's so intense and personal and I don't expect anyone else to fully understand it. I am forever changed. My eyes & ears are highly tuned, discerning. God speaks to me now in numbers, in music, through scripture, and even technology. I think of Heaven often, too. A few days ago, I had a very powerful vision of my body being translated and raptured up. The idea of dying - of moving on towards a life beyond this one - used to scare me. It doesn't anymore. Still, I realize that all of my religious ramblings and honest talk about death here will definitely offend a few people.

Jesus was offensive too, remember that. His truth came first. Ultimately, Easter represents the promise of life, death and eventual resurrection for anyone who chooses to believe in Him. As for me, I'm holding fast to that promise. I find comfort in it. Christ is coming for his Bride and the whole world's invited to an uber exclusive / inclusive after-party!

I RSVP'd early. My "+1" is Elana, and yes, her dance card is already full. 😊



My beautiful bride!

Mother's Day without Mommy

"And now these three remain: faith, hope and love. But the greatest of these is love."

1 Corinthians 13:13 (NIV)

May 5, 2014

This Mother's Day, Elana will have been gone almost exactly nine months. Nine months. The timing is more than ironic, and yet entirely appropriate.

More than any other day since Elana's passing, I've been dreading the approach of Mother's Day the most. To be sure, Elana has missed a lot: Jake's 5th birthday, his first day of Kindergarten, Thanksgiving & Christmas & Valentine's Day. My 46th birthday too. Still, for me, none of these will match the harsh reality of our first Mother's Day without her.

Jake and I miss Mommy daily. Elana was a wonderful mother. She was naturally gifted; parenting seemed to come easy for her. It never once looked like Elana had to work at it, even though I know she did. Of course Elana had a rather severe physical disability, Arthrogyrosis. Being trapped in a wheelchair and having to depend on the help of 24/7 care-aids did frustrate her, yes. But in spite of it all, Elana was always the mommy: in control, involved, giving instruction, calm, gentle, affectionate.

Being a mommy was Elana's biggest passion. A huge life goal and dream come true, parenthood was it for her. Other than her love for Jesus, nothing else could equal. I remember Elana once asking me what **my** passion was, and I, in stark contrast, struggled to answer. I really fumbled for something. Eventually, I came up with photography & writing.

Kinda lame, looking back. I could've given a much better (more honest) answer. I can say with absolute certainty now that my biggest passion from moment one was Elana, herself: supporting her, building her up, cheering her on. Yah, I didn't always show it. Yah, I faltered and took her for granted sometimes. Nevertheless, it is true: Elana was my passion. Everything good came from her. She gave me so much. I love the life that Elana & I carved out for each other. I love the unique journey we had together as a disabled couple and disabled parents. I love that I got to share the joys & stresses of the everyday with her. I'm so glad it was me who got to co-author her dream of motherhood. I feel so fortunate to have had both a front row seat and VIP backstage pass. Just to be there, tagging along: that was plenty.

Mother's Day is a painful reminder of what was, and what is. Those five years of Elana, Jake & me - of our little family - were the best, by far. A rich blessing. And while Jake and I remain, I can't help but notice a massive hole. Every day, I feel the emptiness. I set my eyes on eternity often now. The bible promises salvation and eternity upon Jesus' return. On that blessed day, ***what was will become what is***, renewed: everything will be as it should be. Our Mommy hole will be a mommy whole once again.

Until then, Mother's Day can stay cruel.



Authors Note:

These next (and last) four entries were posts that I wrote as "Guest Blogs" for another site. That web site has since gone off-line, so I am including them here. A few reflections from Year 2015...

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A NARROW PATH: ONE DISABLED FATHER'S WALK INTO PARENTHOOD

February 15, 2015.

I was born with cerebral palsy and have walked on bent legs and crutches for almost 47 years. And while my physical disability doesn't define all that I am, it has nonetheless shaped me and put me on a very unique path. Even as a young kid, I always thought of my disability as a personal trial. My test from God. A life on crutches and bent legs. If this was my journey, so be it.

Despite my disability, I grew up wanting what most everybody wants. A normal, everyday life. Upon reaching adolescence and early adulthood, I was always trying to push my disability aside in pursuit of a life amongst the able-bodied crowd. Like anyone else, I wanted the entire experience: a girlfriend / life-mate, followed closely by career, marriage and children. Not too much to ask for right...?

In reality, me trying to live exclusively within the able-bodied realm was impossible. I couldn't simply ignore my cerebral palsy. Whenever I pushed my disability to the side, it would push back. Sure, I had my initial successes in school & career and that was fine. I even had a few girlfriends. But trying to dismiss my disability was a tough sled. So eventually, there I was: in my early 30s with still no long-term girlfriend, no marriage & no kids.

But then, near the end of my thirty-third year, I stumbled into something great. Something life-changing. In December 2001, I met Elana (my lovely wife-to-be) and, in an instant, I was heading in a totally new direction. Elana had Arthrogyrosis, a disability far more severe than mine. Her joints were basically fused. Though Elana could use her hands well enough, the overall mobility of her arms and legs was very limited and she needed a motorized wheelchair to get around as well as full-time care-aids to help with basic needs like getting out of bed, dressing, grooming and toileting. Indeed, Elana had her fair share of challenges. On the surface and on first appearances, yes she did. But honestly, I never saw any of her limitations. Right from our first blind date, I saw only her: beautiful & gentle & witty and yet also fearless and fierce. Elana's passion for life is what drove her. It's what made her capable and whole and complete. I fell in love with her almost immediately, I couldn't help it. We got engaged in September 2002 and married ten months later. On our wedding day, it felt like I had finally arrived at the place I was supposed to be. *If this is my journey, so be it!*

Five years on, in September 2008 our son Jake was born: I was a father at 40, wow! With Jake's arrival, we were a fabulous family of three. "Our little family", Elana called it. Having a child of her own was something Elana always wanted. To be a mother: that was her dream, her life's goal. None of our family & friends had expected it though. Turns out, a few people didn't even think Elana & I were physically capable of having real, actual sex. The prevailing misconception is that people with disabilities are asexual, it seems. For some, the idea of Elana's disabled body carrying a baby full-term was mind-blowing. At the time of Jake's birth, Elana & I discovered that we were likely the only true pairing of two PWD parents in all of western Canada. With Jake in tow when out & about for trips to the grocery store or wherever, we turned a lot of heads. We were like a rock star trio and I loved it.

Just after Jake's first birthday, my wife was diagnosed with an auto-immune disorder, Sjogren's syndrome. For the next four years, Elana had to take daily doses of Prednisone pills, a powerful steroid. Elana's auto-immune issues, in combination with her existing and already severe disability, created havoc. It all took a pretty heavy toll on her body, physically. But Elana was an Energizer bunny and for four whole years, she carried on almost as normal. She never stopped being a wife and mother. But then, in July 2013 - in the same week as our tenth wedding anniversary - my wife suffered a particularly bad flare-up of painful rashes. She checked herself into the hospital expecting nothing too serious. But it was. What several doctors had originally diagnosed as Sjogren's syndrome was, in fact, Lupus. Far more serious and brutal. The Lupus aggressively attacked Elana's liver & kidneys. In the end, doctors did everything they could to save her. My wife passed away on August 17, 2013 ... just three weeks shy of Jake's 5th birthday and two weeks ahead of his enrollment into Kindergarten.

Today I find myself on an even narrower path. I am a disabled daddy flying solo, though still finding daily joy & purpose with my son. Elana's been in heaven for eighteen months and she has missed out on a lot of milestones. Jake has celebrated both his 5th & 6th birthdays without Mommy. Jake does occasionally talk about her but for the most part, he has carried on like normal. For me though, normal doesn't really exist anymore. The truth is, I miss my wife every minute of every day. I miss Elana's parenting wisdom and her help with Jake, of course. But it's so much more than that. I miss her like my own flesh. I miss her presence: her voice, her laugh, her singing. I think back to my early years of shoving my disability aside, blazing a trail and striving for equality & everything "Normal" and somehow here I am, again. Pushing myself on in the absence of normalcy, striving forward.

If this is my journey, so be it. My blessed narrow path, let it be.



"OUR LITTLE FAMILY"

March 10, 2015.

In my previous blog post, I told you how my wife used to all of the time affectionately refer to herself & Jake & me as "our little family". We were a fabulous threesome. A triumphant trio. A terrific triad. But my wife's been gone for almost nineteen months. When Elana passed away, it felt like the whole idea of "our little family" had died along with her. It felt like that for me, at least.

My son no longer has a mommy and that's a significant loss. I will never be able to replace Elana's many mommy talents or her special nurturing & way of affection. I am one person ... a single parent, not two ... and I can only be the daddy. When Jake gets an owie, is upset & crying and in need of a hug: for sure, those are the times I try my very best to summon a little bit of Mommy. In reality though, I can only offer up the comforts of me alone. Just me, the dad.

One of the biggest things I miss with not having my wife around anymore is simply not having her as an additional support, encouragement and sounding board to cross-check myself on. Elana & I used to be a pretty good tag-team. Whenever I was growing frustrated or starting to lose my cool with Jake, I could always count on Elana to step in as a relief pitcher to rescue me. And for those times Elana faltered (which didn't happen as often), she could depend on me too. But now with Elana gone, everything falls on me. If I mess up or make a parenting mistake with Jake, there's nobody to tag me out of the wrestler's ring.

Of course, every parent knows that raising a child is a huge responsibility. Doing it solo is even more challenging. Adding my physical disability (cerebral palsy) and a pair of carbon fiber crutches into the mix is the delicious icing on a multi-tiered cake. Being wholly responsible for my son's well-being is daunting. Personally, I liked it so much better when I had the flexibility / option to unload some of my day-to-day parenting stresses, big or small, onto my wife! Spider-man's uncle said that with great power, comes great responsibility. Unfortunately, I'm no Superhero.

Yet for all of my tribulation and constant sense of loss, Jake doesn't care. None of that stuff registers with him. Yes my son does still talk about Mommy occasionally, but it doesn't matter to him in the same way it matters to me. And bless the Lord for that.

A couple of weeks ago, Jake blurted out: *"I think we have the best family."* He's even repeated it a few times since. Out of the mouth of a 6 year-old babe, true wisdom.

As a parent flying solo, it's easy for me to get overwhelmed with Daddy duties. Though sometimes it's important to take a step back to look at the bigger picture. Elana's old label of "Our Little Family" doesn't stick quite the way it used to. But thankfully, labels can be wonderfully stubborn things. Just ask Jake :)



TINY ESSENCE VERSUS REALITY

April 22, 2015.

I haven't written a blog post in over five weeks. I keep getting distracted, which is a little known and under-appreciated side effect of being a widow. My wife's been gone for over twenty months and it's still something I struggle with daily.

When my wife passed away, everything became a whole lot smaller. Job and money stresses were instantly insignificant. Time becomes irrelevant also. I remember Elana used to love to plan things: days or weeks and sometimes even months in advance. But for me, I only deal in 24 hour chunks now. My brain can't handle anything beyond the scope of one day. And that's another thing: my brain has shrunk, too. In the harsh reality of death, everything becomes smaller and more singularly focused. It's simple physics.

When my wife first got sick (about a month before her passing), I kept working. And when Elana was admitted into hospital, I was obviously more distracted of course but I stayed at my job. Even after Elana died, I took a one month leave of absence and then came back for another eight full months before realizing that I just couldn't return back to the way things used to be. Elana's death had forever changed me. My job didn't matter anymore. Stupid stresses didn't matter. Time didn't matter. Going forward, looking after my son Jake is the only thing that matters to me.

Until somebody experiences the loss of a spouse first-hand, they don't understand. Someone may *think* they can empathize or at least partially appreciate its impact, but they can't. The full reality gets lost and all that remains is a much smaller essence. It's like the big digital picture frame I bought shortly after Elana died. I've got that frame loaded with almost one hundred alternating pictures of Elana so that Jake won't forget his Mommy. All those precious photos are only a tiny essence of her.

Jake is my Mini-Me, everybody says so. Jake's brown eyes are about the only physical trait Elana passed along to him. Yet Elana's genetic fingerprints can be found all over the place in Jake's personality, talents and quirks. Jake loves drinking lots of water every day, just like Mommy. I hate plain tap water, it's boring. If it's not a bottle of flavored vitamin water or a Gatorade, I'll skip it. Also Jake loves to sing and is an extremely picky eater ... again, just like his mommy. Jake has so many of Elana's mannerisms, facial expressions and other ticks. I look at him and see Elana's tiny essence everywhere. At 6 1/2 years old, Jake is in Grade One and learning to read. Elana was an elementary school teacher for 17 years and would be absolutely thrilled to see this! My son is turning into an amazing little man and I can't help constantly wishing that Elana was here to enjoy it.

Alas, the full reality is lost and all that remains is a wide assortment of tiny essence.



OUR FATHER, WHO ART IN HEAVEN

June 22, 2016

"He who has begun a good work in you will complete it until the day of Jesus Christ."

Philippians 1:6, NKJV

If there's one thing I've learned being a widow, it's that God's primary focus is on our heart & soul. Life isn't always about being happy, safe and comfortable. God will use whatever means necessary to grab our attention.

There's a overused famous saying that God doesn't give you more than you can handle. I remember my wife used to firmly believe that. And because Elana was born with a significant life-long physical disability (her Arthrogyrosis), she thought that God would go easy on her and pretty much give her a free pass on everything else. Elana's difficult four-year battle with her auto-immune disorder / Lupus drastically changed that opinion. A trial by fire, completely unexpected.

So too is God continuing to refine me, mold me, shake me. The day Elana died, I was paralyzed. I honestly didn't think I'd be able to move forward and carry on with life like normal. But my Father in heaven has started a good work in me and so here I am, still standing.

My son Jake is almost seven years old. Over the last twenty-two months, in my wife's absence, I've somehow managed to hit my groove as a daddy and it feels good. I certainly wasn't always this confident as a parent. Elana was more naturally gifted that way. Me, I had to really work at it. I remember Elana was sometimes frustrated with me and my parenting style. How I would sometimes over-react, lose patience. But having gone through my trial by fire, I'm a whole lot different now. I'm more balanced, more sure-footed. I know all of my son's little quirks and nuances. Jake's emotional buttons? I know when to push and when to back off. I've learned the importance of staying calm and being gentle.

There was a time when I could barely handle Jake, just him alone. But now my son regularly invites two or three kids over at once for a play date and I love it. Too much noise and hubbub used to annoy me, but no longer. And last Sunday, Jake was well-behaved in church even though I had forgotten to bring along the requisite snack-pack of fruit gummies. Jake was hungry and a little disappointed that I forgot the gummies but he still stayed pleasant and huggy with me throughout the whole church service.

It's almost two years on as a widow, a single dad and a disabled parent and I'm actually doing fine. I'm not locked in survival mode: I'm alive, thriving and having fun in spite of everything. My eternal Daddy has begun a good work indeed.



A few last words ~

The death of a spouse hits hard. The only thing to equal it would be the loss of a child, I'm sure. Until you've gone through this, experienced everything firsthand, you have no idea what it feels like. Absolutely no clue. Some of my friends & family say things like: *Hold on to the memories ... stay strong for Jake ... keep focused on the road ahead.* Great advice, and very well-intentioned. But honestly anyone who hasn't been through a profound, deep loss just doesn't understand.

I put this book together as a little keepsake: something for me & Jake to look back on and bring with us, moving forward. I treasure all of my moments with Elana, each one. I remember every last bit of my life with her and the twelve years we spent together.

In the end, it's not about looking back or looking forward. It's not about thinking about the past or trying not to think about it. It's not about distracting myself with work, with Jake, my photography or some other thing. It's not about any of that.

It's about missing someone, a piece of my own flesh. I miss Elana every hour of every day. I miss her physical presence. I miss the smell of her hair. I miss her touch, her voice, her song. I miss her laugh, her comic relief. I miss her daily parenting tips. I miss her help and support with Jake and everything else.

I miss her. That's it. That's all. That's everything.

I miss her.

So I look back. And I look forward. Not because I particularly *like it* or *want to*, but simply because I miss her.

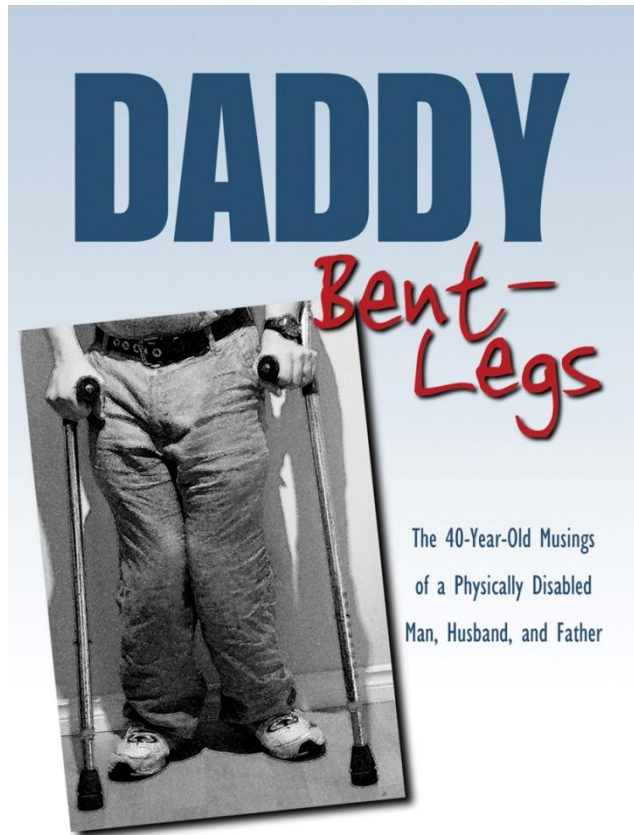
I just miss her.

And so if I could steal Elana away from Heaven, I would. If Jesus came to lift me & Jake up into the clouds, I'd be overjoyed.

Because I miss her.

That's it. That's all. That's everything.

I miss her.



NEIL MATHESON

Did you miss out on my first book, the original **Daddy Bent-Legs**? Grab your copy at Amazon.com, [here](#).

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