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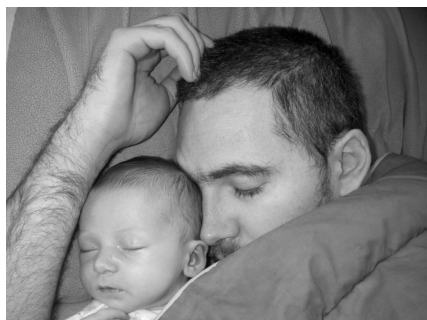
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For Life

April 7, 2014



By Sarah Kilch Gaffney

Sometimes it's tentative and other times it's brazen, but at some point people almost always ask if my husband and I got pregnant on purpose.

When I was twenty-five and my husband Steve was twenty-seven, he was diagnosed with a large brain tumor that we were told would ultimately be terminal. We could treat and hope for the best, but due to the tumor's type and location, there would be no cure.

His doctors optimistically gave him five to ten years because he was so young and the tumor was slow-growing. As he recovered from his first brain surgery, we started talking about whether we wanted to be parents. We did, though we also recognized that it was an enormous responsibility to bring a child into this world knowing that Steve might die at any time, and knowing that he almost certainly would die while they were still young. It's one thing to end up in that situation as a result of fate; it is entirely another to willingly choose that fate.

Steve and I had met five years earlier on a backcountry trail crew and had been married for just over three years. We had always talked about having kids someday (when we both had real jobs with benefits, were more financially stable, etc.) but before that time it had never been a pressing issue. We were young and felt like we had all the time in the world.

One night soon after his diagnosis, we huddled together in front of the wood stove and talked it through. We made our decision and never looked back. Less than two months later, I was pregnant with our daughter. We named her Zoe because it means "life" and we could think of no meaning more fitting for our child.

And so the questions started. Some people were certain she must have been an accident. Why on earth would we get pregnant, knowing Steve was going to die? Others felt similarly to us – it was the best and bravest thing we ever could have done given the situation.

Even after Zoe was born, I was a little quiet about our decision. I would tell people the truth, but I was not always terribly confident. I would watch people start to do the math in their heads and then realize she was born long after he was diagnosed. I could see the moment that the shock unintentionally spread across their faces, and the stunned looks became a predictable conversational theme.

Now, I simply tell people out-right, sometimes before they even get a chance to ask. We decided to have her after he got sick. She was not an accident. We wanted to be parents, wanted Steve to have the opportunity to be a father, wanted to live life with the same options as any other twenty-something couple. We also wanted to be hopeful, optimistic, and have something other than ourselves to live for.

It is an epic understatement to say that the last few years since Zoe's arrival have been challenging. As I write this, she is about to turn three in all her purple-and-princess-loving, world-investigating, temper-tantrum-throwing glory, and Steve started hospice a couple of weeks ago. We had a blissful several months after her birth when there were no treatments, no bad scans, and where other than the faint trace of scar, we felt something like normal parents.

Shortly after Zoe's four-month check-up, the first of many scans showed that Steve's tumor was growing again. Since then, he has had another brain surgery, six weeks of brain radiation, three different chemotherapies, and a proton beam radiation therapy. Nothing has worked. The tumor progressed far faster than anyone could have predicted and the unanticipated severity of radiation side effects caused extensive long-term brain damage. At this point, it is unlikely that he will make it to five

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years post-diagnosis, the short end of his original prognosis.

All that said, we both agree that having Zoe is the best thing we have ever done with our lives. It's a lot harder to fall apart and give up when you have a baby who needs you. It's a lot easier to focus on the positive when you have someone in your life who needs to stomp in every visible puddle, who will sit for hours cutting paper into little tiny pieces, and who has no idea why you wouldn't want her to draw on the television screen with a pen. There also seems to be nothing the folks in a cancer center love more than a babbling baby in the radiation wing or a tutu-and-glitter-bedecked toddler telling everyone how much she likes their pretty wheelchairs.

What I still don't talk about much is our phantom second baby. Just before Steve's second brain surgery and when Zoe was around 18 months old, we decided to try for another child. Though from the beginning Steve insisted I would meet someone else and marry again after he was gone, I didn't want to think about having children with anyone else. I wanted to have another child with him, the love of my life. Steve and I each have a brother, and we both wanted Zoe to get to experience the love, challenge, and companionship of having a sibling.

What I never saw coming was how desperately I would want to have another child. After getting pregnant with Zoe so quickly, I also never anticipated that we would have any trouble conceiving – at the time it seemed like simply making the decision was the hardest part – a thought that is laughable now.

Almost as soon as we started trying for baby number two, we found out that Steve needed to start chemotherapy, a treatment route he was initially not a good candidate for. We went to bank his sperm before he started, only to be told that his counts were extremely low. We banked anyway and then made the difficult decision to try a "mini" IVF therapy. We utilized our tax return and some of our savings. Not our smartest financial decision, but one that felt absolutely necessary. We got to the last step and the eggs didn't fertilize. We had to try, though, otherwise I would have regretted it for the rest of my life.

Down the road we were able to try a couple of times on the rare occasion that Steve got far enough out from a final chemo dose, but never more than a month or two at a time and never with success. All the while I was kicking myself for thinking we had so much time, for thinking we had the luxury to space our babies a couple years apart, for believing that, despite the odds, he was going to make it.

When I finally realized and accepted that we would never have another baby was when I truly admitted to myself that Steve was going to die. For a while, it hit me harder than his impending death itself. And the thought that I might, even for a moment, grieve the loss of a non-existent child more than the loss of my husband (and existent child's father) riddled me with guilt. The double punch of knowing Steve was going to die on top of the possibility that I might never get the chance to be a mother again took the breath from my chest. My heart was broken, and if it weren't for Zoe, I don't know if I would have been able to set my grief aside enough to even function.

When Steve started hospice care, I finally started selling all of the baby stuff. I had held onto everything, even every last little onesie and bib, a physical manifestation of my hope tucked away in grey bins. I made a future grandma extremely happy by selling her almost all of our gear for a fraction of the price. It was devastating to let go, but relieving at the same time. I still can't bring myself to start looking through the baby clothes, but I know someday I'll make an expectant mother very happy with those.

As our days together as a family grow shorter, we're trying to hold onto them as best we can. We take lots of pictures. We put pillows between the hospital bed and our bed so that we can still snuggle as a family. We let Zoe help as much as she can.

In the months before she was born, I started writing letters to Zoe and I continue to this day. Hopefully someday she will read them and learn more about her father and I, and about our love for her and each other. Hopefully someday they will help her understand this path we chose.

Losing her father will affect Zoe for the rest of her life, but I can also see how much his illness has already shaped her in a positive way. There are moments when her intuition into his struggles stops me in my tracks, and I cannot fathom what it would be like to face the future without her by my side.

Author's Note: Steven Gaffney passed away on March 22, 2014 after a 4 1/2 year battle with brain cancer. He was 31 years old. The following day, this piece was accepted for publication.

Sarah Kilch Gaffney lives in rural Maine with her daughter.

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OR SIGN UP WITH DISQUS Name **Kerstin** • 6 years ago

This piece is going to haunt me for a long time. Choosing to fully live out your dreams in the face of sadness is a choice no one should question.

1  |  • Reply • Share**Vanessa** • 5 years ago

This is beautiful. How dare anyone think she was an accident. She was a beautiful light created during a dark time, from pure love. I'm sorry for your loss, but I am also happy that you have a piece of him in your daughter. <3

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I don't understand how anyone could not understand the author and her husband wanting to bring a child into this world even under their dire circumstances. A child is love, and her father lives on in her. Makes sense to me. Hugs to this Mama <3

 |  • Reply • Share**jr** • 5 years ago

My mother made the same choice to have me, and my father died of brain cancer when I was six months old. She is an amazing mother. I certainly could not have blamed her if she made the decision not to have me (literally) but its always your choice and whatever it is, you've got to make the most of the life you chose. Here's to you and your daughter. Also, my life is great and I've always missed my dad but it never held me back.

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I, too, decided to have children with my husband who has a terminal illness. I see bits of him in each of my children and I know with everything in me that they will sustain me when he is gone.

We chose to not wait and have our son right after our daughter was born. Well... we chose to see what would happen and he arrived 16 months she did! He is so much like his dad already at only five months old.

Thank you for sharing what I always knew in my heart was the right decision...

 |  • Reply • Share**Allyson** • 6 years ago

Hi Sarah,

Such a beautiful story. Thank you for sharing. My husband and I too decided to try to have a child knowing that he was terminally ill with brain cancer. We just figured if it was meant to be it was meant to be, so like you we made the decision to start a family and I got pregnant very quickly. My husband died from his tumor in April, 2013, at the age of 33, and our son Isaac was born in July 2013. As he approaches his first birthday, Isaac has been a ray of light for so many people, and deciding to start a family remains the most difficult and rewarding decision we every made. I am on the other side of the country from you, but I would love to connect, as our stories are so similiar.

-Allyson

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