

MICHELLE HUGHES MILLER

Grandmothering in Remission

Xander, your Grandma is really sorry, but right now I can't concentrate on this upcoming milestone in your life, your first birthday, because today I'm having my two year scans.

In this personal narrative I explore grandmothering from a position of uncertainty—in this case cancer in remission. Using the framework of letters to my young grandson, I unpack my expectations for and experiences of the role of grandmothering, contextualized by my simultaneous effort to understand myself as a cancer survivor and the liminality of that particular status. How do I develop a relationship with my grandchild when he may not even have the memories of our interactions? How do I grandmother authentically while masking the health worries that sometimes threaten to consume me? How do I care for my daughter who has become a mother from a position of strength and confidence when the very ground I walk on feels unsettled and the future unclear? Considering issues of temporality, relationship directionality, caregiving, and authenticity, I place my musings as a grandmother and cancer survivor from my cancer journal, half-written letters, poetry, and reflective narrative into interaction.

I've been doing various writings, journaling, reflective musings, poetry, and letters since I was diagnosed with breast cancer in 2014. In this work, I focus on the writings that help me understand the intersection of what it has meant to me to be in remission—that liminal state of noncure but nonpresence of cancer I currently embody—and the simultaneous becoming of a grandmother for the first time. So, here are some of my very personal thoughts on being a grandmother in remission.

I was alone when I got the phone call that the biopsy was malignant. But I already knew. Since the moment I found the ridge in my left breast that couldn't be anything else. Since the ultrasound technician stopped mid-exam and said you're going to want to get this biopsied. I knew, I think, when the phone rang even before I answered it. It was January 2014. Happy New Year.

During my first conversation with my surgeon, she looked at me very seriously and told me that cancer was not a crisis; it was chronic. I didn't understand, and expressed frustration that it was taking weeks to make a plan for my treatment. I could not understand why she didn't have the same sense of urgency to get this tumour, this 4.5 cm ridge of hardness living in my breast, out of my body before it spread (spoiler alert: it already had).

Two more times during that conversation she used the word "chronic." We didn't have to hurry, her demeanour implied. Speed wouldn't cure me. She was preparing me: I would have to deal with cancer the rest of my life.

20 Oct 2016—twelve days until your first birthday

Xander, I have to tell you something, although I'm pretty sure you're not going to understand, seeing as you're not really talking yet. Your Grandma is really sorry, but right now I can't concentrate on this upcoming milestone in your life because today I'm having my two year scans. What that essentially means is that from 9:00 a.m. to 2:00 p.m. today I will be lying on various tables after various concoctions have been pumped and/or drunk into my system while big machines take pictures of what is inside of me. "Something suspicious" is what they will find if the cancer has come back—and sometimes even if it hasn't and they need to run additional tests. So far, the second set of tests has always come back negative.

Anyway, I want to celebrate with you, I really do, as you take this next "step" into toddlerhood (we both know you've been walking for a while so all this is old hat), but frankly today is only midway in my semiannual worry fest (because my scans are twice a year, of course). Two weeks before the scans I start envisioning what would happen if they found something. If the cancer was back. Tears spring to my eyes unbidden, and I cough and claim a cold so no one notices. I meticulously soap my body in the shower and feel for any lumps or difference that may be a sign of what they will find. Any ache gets reconsidered in light of a potential discovery. I become convinced that this time around I won't get good news, and it gets harder and harder to concentrate on work, or even on you and the upcoming celebration.

The worry builds, and by the day before my scans I am practically incoherent. You and your mommy Skyped me that day, if you remember. That was only yesterday, but when you're almost one, your perception of time, I think, is a bit sketchy. Mine, on the other hand, is almost visceral, with each minute clicking off as the scans and their potentially bad news get closer.

Because we are flying up to be with you on your first birthday, we discussed the particulars of our trip—we fly to you the day after I get the official results from the scans—and for a moment I couldn't breathe as I considered having to tell your mommy a few days before your birthday that my cancer had returned. Yes, that was when I excused myself because I had something in my throat and needed a drink of water.

I'm actually not sure what made me cry right then. Maybe the thought of telling your mommy—my daughter!—that they found something or the overwhelming worry that this will never be over, and as much as I want to celebrate your birthday, I can't get away from this chronic disease that has me by the . . . well, I was going to say breast but that's gone now so maybe by the brain? That appears to be where all the hubbub is coming from right now anyway.

5/21/14, journal entry

I've been thinking about attitude. My ruminations started when my friend Ray—who has just gone through chemo for bladder cancer and been declared, finally, cancer-free—told me with glee in his eyes that I needed to be “aggressively optimistic.” That's the trick, he assured me, to a full recovery. Believe, over-believe, that everything would be okay and eventually it is. Be so aggressive about it that you annoy people with your optimism.

I'm not sure how to do that. Pollyanna is not a role to which I've ever ascribed, nor one I've actually rehearsed. How is one aggressively optimistic about their cancer diagnosis?

43 percent.

I am not a math hater but odds of winning a lottery intimidate me and chance of rain annoys me and the tax forms have to be double and triple checked because numbers move when they shouldn't.

I am not a math hater but I would like to burn the piece of paper you gave me that said even with chemo and radiation and five years of tamoxifen I have a 43 percent chance of recurrence over ten years.

I'm fifty-two years old. I just became a Grandma. Nine years left.

Spring Break 2015, only a few months after I finish treatment, I get the news: a positive pregnancy test! A beaming daughter. A plea in her eyes to be happy, to see the future, to believe that 2015 was going to be a much better year. I was going to be a Grandma! I felt such an inhale of joy it permeated my body and emptied me of any stale breath of cancer fear I'd been holding onto.

I tried to be there for some of the major pregnancy events. I drove the fifteen

hours for the baby shower. I helped my daughter with the registry, painted the nursery with my son-in-law, and tried to provide support and encouragement to my daughter that it was ok to sit down, to put her feet up, to claim her own needs, and to relax. I tried to give care, whatever she needed, and I tried to encourage self-care. I thought the latter even more important, as I remembered clearly how little I cared for myself after I became a mother and I did not want that same fate for my daughter.

But the mom in me worried about her health (the mom in remission, that is). I worried because worry—railing against the unknown future because of exceedingly knowable possibilities of risk and danger (god bless the Internet)—seemed like one of the few things I could do because I was already doing it.

Throughout the pregnancy I kept getting called back to cancer; the joy air (tempered with worry) was forced to make room for breaths of doubt. Sometimes the worry and doubt, fuelled by doctor visits and scans, left little room for joy, and they merged into a generalized fear that I wouldn't be there, I couldn't help her, something would go wrong, and all my planning wouldn't be good enough. It didn't help that Xander's due date was almost a year to the day from when I finished my cancer treatments—an annual reminder of how long I've been in remission.

Xander—I take one step toward you, toward the future, and then I'm back in the present, in my body, for the quarterly search for where the cancer went. I wish it'd left a forwarding address so we could stop looking.

I went back to the doctors again and again ... my list of appointments seemed endless, divided between my surgeon's PA, my oncologist's PA, my radiation oncologist, my scans. Blood tests every three months made me decide to keep my port in—a constant reminder that it wasn't over. Each person felt my scar, then my remaining breast, then my lymph nodes; each said I was doing fine and sent me on my way ... with another appointment slip.

Dear Xander—I don't like playing hide and seek. I mean, I love playing hide and seek, but sometimes I feel like it's too real, you know. Something hides. Someone seeks (in my case using really expensive technology). Finding the something means you win. I'm not so sure.

My daughter watches me, sometimes. I don't know if she's watching me for the same reason the doctors are, or if she's watching me because she can tell how vulnerable I am sometimes around Xander.

Or maybe she's just watching to see what kind of grandmother I am. I'm pretty sure she has an idea about what kind of grandmother I should be. I wonder if

our ideas align. I want to be loving and fun and someone my grandkids want to talk to and hang out with (sometimes). I want to say “yes” more than their parents can but still teach them values important to me. I want to be someone who matters to them. I want to be someone they remember. I want them to have Grandma stories to tell.

I bought this book called *The Invisible String* before Xander was born. The story is a simple one: the mom explains to her children that they are never alone in the world because they are connected to everyone they know by an invisible string stretching everywhere. I'd read this book to Xander the day before heading home from a visit. I'd put him on my lap and we'd share a moment where I would read the story, and then tell him how special he is to me and how I'm never far away.

My daughter makes this happen; sometimes she asks me to read to Xander before bed on my last night, as she knows I'll take the opportunity to read our special book. Sometimes, she watches me read to him on the baby monitor. Does she worry I won't be here, too?

When I bought the book I was thinking about distance. Fifteen hours away. That is so far. If I could only wiggle my nose like Samantha on *Bewitched*, I could be where I want to be anytime. I could help my daughter mother. I could help my daughter by being her mother. I could help my daughter be the mother she wants to be.

But it's not really the distance that is the problem.

Xander—I do so much to try to create memories for you, even though you're just now two and chances are you won't remember anything.

Our weekly Skype ritual? So you don't forget me. PopPop gets annoyed that you seem to think the Skype call is passé—you're more interested in your toys than us most of the time. But I don't care. If I'm passé that means it's because you know me, and you are comfortable with me—I'm a presence in your life.

Sometimes, I play a game I secretly call “What does Grandma like?” Does Grandma like books or puzzles? What is Grandma's favourite colour? What does Grandma like to do? These are educational questions I can ease into the conversation anytime, like when I told you I liked when dinosaurs danced rather than stomped, and then we danced around the living room. I do this a lot, Xander. Maybe some of what Grandma likes, or what Grandma is like, will stay with you.

I sing to you every chance I get, even in the car when we're just driving some place. I know I don't have a great voice, but for some reason it's important you hear the songs I sang my children when they were little. I want you to hear some songs and think of me.

I write stories for you in my head. Some I record, some I write down, some I bring to you. You're so little! How will you ever know that you inspired me to write?

When you're older, and you read this, you'll probably feel like I was trying to imprint

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on you— to make you subconsciously remember my voice, my smell, my laugh, my songs. And honestly, if I knew how to do that I probably would, even though that sounds a bit creepy. But I will do what I have to do so that years from now when you're talking about your "Ga-ma," you will have something to say. Just in case the cancer comes back.

I'm crying while I write this. I'm sorry. The need for you to know me is so intense. And it doesn't feel grandmotherly at all.

* * *

7/12/2014

The other night I found myself in a conversation with casual friends about my cancer. I didn't intend to be in this conversation, but it seems like that's all I get to talk about with casual friends these days. In the midst of this conversation, one woman claimed that I was soon going to discover that cancer was the best thing that ever happened to me. To explain this, she discussed her own lupus diagnosis from ten years ago, which gave her the ability to just say "no" to things that weren't working in her life. You'll see, she told me, you'll be better off now.

I let that thought percolate in my head. Cancer is the best thing that ever happened to me. Really?

Probably correctly reading the incredulity on my face, another woman in the conversation tried to temper the comment. Maybe your husband is the best thing, and cancer is just in the top five, she suggested. Maybe my children are somewhere above cancer in their importance in my life, I join in. I then have this surreal out of body experience in the middle of this conversation as I realize the three of us are trying to rank cancer in terms of its positive effect on my life.

March 2017

Dear Xander—

I hope I never have to talk with you about cancer. But Xander, I had cancer. (Is that the right tense?) In 2014, before you were even conceived. And I'm still dealing with the chronic part of this chronic disease. I just had another scan last week! I still worry I won't be there as you grow up—that I won't see you play your first ball game, or graduate from college. I want you to remember me as the woman who played with you, read to you, sang to you, laughed with you. I want to be present in your life. I want you to not just remember me, but to know me, as I'm getting to know you.

But there's something you need to know: the Grandma you know isn't the woman I was before you were born. I'm different. I feel different. The difference isn't in my missing flesh, although when you curl up against my prosthesis I wonder how it feels to you, this fake pillow under your cheek.

The difference is in me, my heart, my brain, my sense of self. And especially in my

sense of time. There's so little time, really, even in long lives. And the uncertainty of how much time and what kind of time makes me want to hold on tightly to time with you.

You never met the Grandma before cancer, the Grandma who worked, and loved, and partied, and mothered your mother, because throughout your whole life I've been in remission, wondering if the cancer will come back. Wondering when it will come back.

* * *

On one level, grandparenting is so much better than parenting. It's like eating cheesecake without the calories, or seeing a Broadway performance from the front row for free. You get to watch one of the loves of your life love and care for another, and your only real responsibility is to enjoy—although helping is pretty fun, too.

But grandparenting is also more tenuous because your own aging takes you further from your grandchild's future. That's the natural order of things, and I actually take comfort in knowing that I'm supposed to, I must, I will go first. It makes the time together sweeter.

At least it should—if it wasn't for the damn cancer, messing with my sense of self, screwing up the timeline, encouraging me to think of myself as an unwitting passenger on the chronic cancer journey, and pulling me constantly back into my body with the search for mutations.

I do not know this Grandma, this woman who thinks about herself as vulnerable. I do not like this Grandma, who worries about everything and sees life as fragile and dangerous. I do not want to be this Grandma, whose joy is constrained by what-ifs. I want to exhale all the fear, and only have joy left to breathe.