

*“Guilty Or Not” first appeared in On The Move (April 2015, Vol.11), the e-zine published by the Parkinson’s Movement, under the umbrella of the Cure Parkinson’s Trust. It was then published in Viewpoints, the quarterly newsletter of the Parkinson’s Society of British Columbia.*

Guilty Or Not

April, 2015

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Our house is for sale and we are moving to be near our children and grandchildren. I have just finished cleaning out the little building at the end of our driveway. It isn’t a garage but more of a shed or shop, complete with a workbench and an ancient wood-burning stove. It has been a catch-all for our active family’s outdoor stuff - gardening implements, sports equipment, woodworking tools, and camping gear, all in multiples, because my husband, Lincoln, never threw away anything. When a ski pole broke he kept its partner, “just in case”. In with a new bike did not mean out with the old. Ever. The same applied to skis, snowboards, backpacks, snowshoes, kayaks, paddles, wet suits, lifejackets, camping gear, tarpaulins, chains, rope, lawn chairs, air mattresses, tennis racquets, bocce balls, croquet mallets and hockey sticks. Lincoln never met a bungee cord he didn’t love or a broken tool that he could bear to toss. In my husband’s world, duct tape fixed everything. But some things are not fixable and Lincoln has no idea that his shed is being readied for the stuff of another family’s life. He lives in a cottage in a long-term care residence along with 13 other advanced dementia patients. Though I have long

grumbled about the state of that shed, I found the act of culling its 34 years' worth of accumulated contents incredibly difficult.

"Lincoln would be so upset if he could see all this being given away," I told a friend. "I feel so guilty".

I expected her response to be empathetic and reassuring. She is that kind of person. However, she did not say, "He would understand" or "This must be very difficult for you."

"Hmmm," she mused. "What do you think guilt is?"

I didn't know how to respond. She rephrased her question.

"You say it makes you feel guilty to have cleaned out the shed. I wonder how you define guilt? That's all."

After thinking about it for a moment, I told her I thought guilt was an emotion experienced when we have wronged another and know it. It was what my mother would have called "your conscience talking."

My friend then wondered aloud if guilt was of any use. I suggested that if it leads to a sincere apology and an attempt at making it right, followed by a heartfelt promise not to

repeat the action, it is useful. It's a simple drill I told her. If you screw up, say you're sorry and mean it. Then, try to fix it and don't do it again.

“And so why is it wrong to be clearing out the shed?” she asked.

My turn to “hmmm.”

As a caregiver, I have been, by my own definition, guilty of any number of things, mostly impatience. Wrapped up in my own despair, I know I failed to understand the devastating effects that his dementia was having on Lincoln's ability to feel safe or at ease in the world. It was his grace and patience that taught me hard lessons about compassion and acceptance. The Parkinson's Disease beast had lessons for me, too. I fed it on stress and fatigue and it grew quickly. I started vomiting up my meds and was too weary to exercise. I looked in the mirror and I could not recognize the haggard old woman looking back at me. I shook and wobbled and made the good people in our lives anxious on my behalf. If I wanted to be the caregiver that Lincoln deserved, I needed to be strong and healthy, resilient. I needed to ask for help. And so I did. Guilt had served its purpose.

“What if they find a cure for Lewy-Body dementia tomorrow,” I worried, “and I get to bring Lincoln home. What is he going to do when he sees what I have done to his shed?”

It was an image both cringe-worthy and joyous. It made us laugh, the kind of laughter that lives one breath away from tears. However, I am not going to be bringing Lincoln

home but my feelings about the culling of the shed did not seem to quite fit my notion of guilt. There would be no easily recited “drill” for getting through this.

I told myself that it was just stuff in that shed, possessions, objects, all replaceable, but it was stuff that spoke about our whole family. It was stuff that represented how enriched my life and our children’s lives had been because of Lincoln’s passion for the outdoors and his willingness to share it with the people he loved. It was the stuff of memories.

Cleaning out the shed, even with the help of our supportive tribe of friends, meant that I was now on my own, alone in a way I have never been before, responsible for every decision affecting us both. I was forced into an independence I never wanted and that, if I am honest, frightened me. It still does. Feeling guilty was a whole lot easier than plumbing the depths of sadness that clearing out the stuff of our lives evoked in me. Feeling guilty meant I did not have to acknowledge the many joys of my life, when all I wanted to do was howl. It wasn’t just guilt at all, but a complex tangle of emotion, painted the colour of sorrow, in which guilt was just one tiny thread.

“You have to look after your self!”

I hear that once a week, if not more. I know the truth of that assertion. I get that it comes from a place of kindness and caring. But sometimes it makes me want to explode with frustration.

“Don’t you think I know that!?” I want to shout. “Why do you think my husband is in a long-term care facility? Do you have any idea how that feels? Please don’t tell me what to do.”

How can anyone else know, for me, where necessary self-care ends and selfishness begins, when I hardly know it for myself?

My friend is wise and she has spoken with many caregivers. She tells me I am not alone in my frustration and confusion. She knows how consuming a misplaced sense of guilt can be when we fail to manage the unmanageable. She understands how disloyal we feel when making the hard decisions, hopefully in our loved one’s best interests, and our own. She tells me we are all of us trying to figure out how to tease out, from a huge tangle of emotions, the ones that are best to guide us, the ones that will hold us together as our worlds shift and crack. Empathy and reassurance. She is that kind of person. And we agree that guilt has its place in our emotional lives but it is place we too easily find. If we permit guilt to suspend our experience of our most profound pain, do we also allow it to diminish our capacity for joy?

And so I don’t shout. I smile and nod and carry on. It isn’t courage nor is it a lie. I am the only face of the twosome that once was Lincoln and Leslie, before Parkinson’s, before dementia, that most people ever see now. I try to see their concern for me as concern for us both. Our lives have changed and people care. That’s what “Look after yourself” infers. No, they don’t know what I am going through... any more than I am privy to the

hard truths of their lives. And so I don't shout. I dig into that tangle of emotion and I find, along with the anger and the regret, the grief and the guilt, a bright thread of gratitude. I cling to that. I have that choice.