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FIRST PERSON ACCOUNT

On Loneliness

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I've sat down several times over the past few weeks attempting to work out what I would tell you about loneliness and being a mental health family carer of someone with severe mental illness. You see; I'm not used to telling my story because mine is an invisible one, I have obligations to meet at work, and also at home caring for my husband and family. I have many roles and responsibilities to others.

I think often me as a child and as a young woman, and I look back over the past, often. I see something got lost along the way, somehow. Something is missing. Naming it, sharing it, asking that my needs are also important, showing that I'm also vulnerable, brings with it unintended consequences that will be all about the mental illness that invades our life too much already, that will only make my husband feel distressed, and that I will have to ultimately fix. But keeping it unsaid will also have consequences, reminding me that I'm alone in this dilemma; either way I lose. So, I remain stoic, to keep unspeakable things to myself, alone, to accept that intimacy in my most important relationship has rules and limits. So, I'm protective of the fragments that are still me, they're private, for me alone. I hold them close and continue to put on my "public" face as I go about my day.

I live in 2 worlds. There is the one where I'm keeping myself busy. . . . And then more busy, always busy. . . . Filling up my day, each minute accounted for with my lists of tasks, the next jobs, and errands to fulfill, the next deadlines to meet, the many routines that I've managed to accumulate to fill up my life, the plans for the next week, the schedules of appointments for my husband that I know are coming up over the coming days, weeks, and months, the reviews, the dinner to cook when I get home, the chores to achieve on the weekend, the perpetual "list," the obligatory "social" life that I must try to fit in around this ever-forward pace of movement just to remind myself that I'm here, that there is more to life out there, somewhere. The scramble of time in this life, the urgency

to fit it all in, to not lose a moment, to make it count, to keep looking for meaning, to hold onto some sense of future, where this all might be different.

Then there is the other world, where I sit in the quiet moments, thinking about how I got to this point, thinking will it change, will there be a time for me, thinking how I'll get up tomorrow and do it all over again, walking into the office "Good morning, how are you today. Fine thanks, and you?" It's the evening. They have all gone to bed, early (thanks goodness). I'm here again sitting on my own, watching some predictable UK crime, switching off, escaping, giving myself permission to stop, accepting my lot, appreciating my small moments. This is my time, my only time . . . to be me . . . now.

I'm striving for the relationship, hanging on to the parts of our life that aren't about mental illness, that don't pull me too close to the edge of utter loneliness. Mental illness takes up more than enough space in my life, in our life together. I'm valuing the moments more and more, the song I remember on the radio, the day we met, the glance across to each other as we walk holding hands through the busy shopping center each weekend. The compulsion to share the moment. "I love you." Or when we are out driving on an open country road, heading somewhere, anywhere, being just here now with the radio on, laughing, thinking, and telling him in jest "That song is my memory; I was a 70s girl going to the pub listening to it when you were just in primary school back then, you 80s boy." Deliberately, fiercely pushing the mental health carer role away. Through this misplaced humor, we gain intimacy, love, connectedness to something that is not about mental illness, not about me being his carer, not being alone.

I'm not sure if any of this is loneliness as defined by the "experts." I know it feels that way, sometimes. My two worlds have become so surreal that sometimes, it is being acted out in front of me. I'm behind a sheet of glass watching that girl who I vaguely recognize as myself. It's hard to unravel it from loss, grief, frustration,

bound up in my duty as a carer. I'm moving in and out of social interactions, I'm looking outward from my mind, from the image of that girl sitting in silence looking out the window to the world, watching the perpetual movement of people living life around me, wondering "Are they just like me? What do they think life means? How do any of us create purpose? Is here the arrival point for meaningful existence? Is this as good as it gets?"

I cannot say I feel robbed of some other life that could have been, of the constraints that now mean my path is subsumed in the needs and responsibilities and commitment to care for another. I push that thought aside, quickly; I know it serves not good, that it will make me feel sad, trapped, more lost; more lonely. Though I know that my push forward in advocacy for my husband's needs is also about me, about all the mental health family carers out there, somewhere. When I meet them, we don't need to explain ourselves. Loneliness, but behind it fierce commitment and love for our family member, is written on their faces as assuredly as it is on mine. We share a bond;

our sense of the surreal life that we lead as mental health family carers.

So, I'm moving in and out and through each day, mindful to hold onto some contentment and happiness. Otherwise, I'm privately, quietly standing on the edge, being fiercely determined not to be lost in mental illness altogether, of losing me altogether. This is it. I am many opaque and translucent things. This is me.

Acknowledgments

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