

Notes for "Hold On": This was written almost 3 years ago. Lincoln's diagnosis has changed from Alzheimer's Disease to probable Lewy-Body Dementia. That is not better or worse but different. It explains so many things. There is another grandbaby. That makes three. Lincoln is in longterm care and I visit him twice a day. I live in our condo, near our children and grandchildren. We are okay. We are home.

Hold On

January, 2013

*I am bound to my man of the hills
And he is bound to me.
We lurch and bump over stones and stumps
Craggs and meadows alike to greet
Wrestle the marmot for his whistling rock
I cling to the moss
He scales the peaks
But we are tethered to we.*

My husband has Alzheimer's Disease. At least we think he does, though we cannot peer into his brain to see if the telltale tangles of errant proteins are present. But we are losing him, our daughters and I, we are losing him to a disease that steals his memory, erodes his reason, and silences his voice.

My father died of Alzheimer's and so did my father-in-law... good, smart, hardworking men whom we loved very much.

I thought that taught us how to bear heartbreak.

I want to go home, my father would say.

Dad, you're home, I told him. You're home.

But the familiar room, with its books, including the two he had written, the paintings he and my mother collected over their 60 years together, and the family photos, was no longer a haven of peace and comfort.

I thought at the time that it was just his inability to connect to the externals of his environment that so disoriented him.

And my father-in-law would pore over tiny photographs mounted in leather-bound booklets tied with fraying laces. These moments, from a life almost 70 years gone, before the war, before Canada, before kids, seemed to hold more meaning than his wife, his son and daughter, or even our two girls, his only grandchildren and the light of his life no longer.

He would point to a sepia street scene, brick row houses with front steps leading down to cobblestones, and he would whisper to himself in his soft Lancashire speech.

Oppenshaw.

He could not have told you his own name.

I wonder now if our fathers were trying to tell us, not so much that they couldn't make sense of what they were seeing, but that they could no longer make sense

of what they were feeling and needed to find something to cling to, something that meant “It’s okay. I know this. I’m home”.

I know my husband struggles that way, sometimes.

I am all mixed up, he says.

Our dads were both in their early 80’s when their symptoms presented themselves. Lincoln was only 66 years old when he first started experiencing episodes of confusion in the middle of the night. I look back and see the signs. What could we have done differently had we known?

We had settled into a retirement in which we were fulfilling the promises made when we were young, promises to always welcome adventure into our lives and to never hold each other back. So Lincoln climbed Mt. Kilimanjaro and then rode his bike from Paris to Istanbul. We walked across England, from the Irish Sea to the North Sea. I plunked myself down in front of the computer and wrote and wrote and wrote. Together we picked up the travelling life we had willingly abandoned 30 years before, a life we had exchanged for the joys of living and raising our children in a little town ringed by mountains and beribboned by two perfect rivers.

*I wander along side my travelling man
And he wanders along side me
A winding road, sirens' laments
Valleys and vistas and Berber tents
Cactus and cedar, eclipse of the moon
To a slip of a child with a wink of a smile
We speak with our hands, a nod, a grin
He wants to keep roaming
I want to be homing
He wanders along with me.*

Once again we loaded the Volkswagen camper and headed out, with no clear plan and no timeline. Several winters in a row we wandered to the southern tip of the Baja peninsula and up the windswept, eastern cape. We free camped in palm-sheltered bays, paddling our kayak to the sound of dolphin breath and the cranky bark of seal colonies. We rocked in a small wooden boat while grey whale momma's and their babies slipped and rolled around us. We puttered up and down the west coast of Canada and the US, clambering down cliffs to reach isolated beaches, finding humility among giant redwoods and Douglas firs. We hiked the slickrock canyons of Colorado and Utah, sat in solitude beside lakeshore campfires, and traced the shorelines of tiny, mountain-ringed lakes in British Columbia's stunning Chilcotin country. We poked about in northern rainforests where eagles filled the sky in numbers too large to count and made plans to return and perhaps carry on to the Yukon and Alaska.

Then life slid sideways.

I developed a tremor in my left hand and arm. It only occurred when I was using it, extending it, not a rest. Therefore, according to Dr. Google, not Parkinson's Disease. I breathed a sigh of relief. My husband's sister had recently died of the complications of young onset Parkinson's.

I thought that had taught us how to bear heartbreak.

My left leg began to drag. My left arm did not swing when I walked. I started to stumble. My shoulders became excruciatingly painful. Exhaustion plagued my days and sleeplessness my nights.

My GP ordered a scan of my brain. He thought maybe I'd had a stroke. I was hoping for a nice, little, benign tumour, something they would safely remove and my brain, and my life, would return to normal. You know you are in trouble when you find yourself wishing for a growth of riotous cells a-bloom among the neurons. The scan results came back negative.

I waited to see a neurologist who, after a series of physical tests, told me that I had Parkinson's Disease. What? Dr. Google is not always right? The medication helped right away. That was the good news and the bad. You see, if the medication mitigates symptoms, a Parkinson's Disease diagnosis is confirmed.

My first waking thought the morning after my diagnosis?

I want to go home.

And I think instantly of my dad, and of Lincoln's.

Home. Not a physical place but a place of being, a sanctuary of the self, inhabited by confidence and hope, in which the world, or at least one's own small corner of it, makes sense. In an imagined future of walkers and wheelchairs, a frozen gait, a frozen face, and a Swiss cheese brain, there is little hope and no confidence.

*I share a canoe with old river man
And he shares a canoe with me
Whitewater foam becomes his home
A tranquil shore with sand for my toes
Onward his paddle
While backwards I dig
That moose in the lilies is much too big!
But we share our boat
We stay afloat
Old river man and me.*

Despair can become familiar territory but it is not a groove I want worn into my brain. And so, because I am loved and lucky woman, I learn, in time, to be grateful once again for the abundant joy in my life, the staunchness of our friends and extended family, the good man by my side, and the strong, compassionate young women our daughters have grown to be. I go

adventuring inside my head, on the computer screen, in my notebooks, finding inspiration in memory, in a wonderful book, in a chance remark, or a trick of the light on a late winter's evening.

And now it is Lincoln's turn. Denial can hold the truth at bay for only so long. Nighttime confusion, panicked awakenings...distressing dreams, critters in the the bed, strangers in the house. Our new car flummoxes him. Our closest friends express concern. His doctor prescribes medication. Lincoln tries. He tries so hard. The pills leave him depressed for the first time in his life and they make him physically ill. And no one can assure us that, in the end, they will make one bit of difference.

We make a choice to be as open about Lincoln's illness as we had been about mine, to not close ourselves off or pretend all is right in our world. I know it will be hard news for people to hear. And we are, along with almost everyone we know, mourning the loss of a beloved friend, one of a small group of outdoor-loving men, including Lincoln, we call the "Lost Boys". There is now, for me, such poignant irony in the name.

I stumble sideways and he catches me in his arms and turns it into a clumsy waltz. I dump my first glass of wine and burst into tears. The second glass spills and this time I laugh and wonder aloud if I can't pour it, should I be drinking it?

We call ourselves “Shake and Baked”.

I tell him how much I enjoy the hallucinated “others” in our house, the benign strangers who begin to appear in the daytime, in only Lincoln’s vision. They never want a meal or leave the toilet seat up. He sets extra places at the table and makes them tea. He waits for them to catch up when we hike.

Oh, you would have to know him to see the humour in that.

This is one of the oft-repeated stories of my life: Lincoln miles ahead on a cross-country ski or hiking trail, finally thinks that maybe he should stop and wait for me. I puff up to him, exhausted, a little annoyed.

Great. You’re here! he says, as he readjusts his pack and immediately strides off.

Those of us who have hiked, skied or biked with him shake our heads at the attentiveness paid these new companions. But they become part of our lives; I find myself asking them to watch over him, over us.

We make a new acquaintance, by chance or fate, a talented sculptor of wood and stone, a storyteller, a kind, strong man whose world is as naturally inhabited

by spirits as our little town is by garden-marauding, white-tail deer. Lincoln's hallucinations are nothing out of the ordinary to him. He sees them as blessings and tells me the old ones he sees around my husband enjoy his company very much. This helps enormously.

And just when I think I am doing really well, feeling at home within this new reality or, rather, this new sur-reality, Lincoln begins to be confused about who I am.

Do you have a twin? he asks me. You look like my wife.

Who was that who hopped into my bed last night?

And then with such kindness, he peers into my face.

Why are you crying?

I have not yet learned how to bear heartbreak.

*We make a home in the heart of the town
In mountain shadow, at river's edge
We lose our days in children's play
Hills are tamed by small ones' steps
River calmed by small ones' fears
Our hearts near burst to watch them grow
I hold them close; he lets them go*

*We play our part, love harbours we
My gentle man and me.*

Our girls live in a pretty little mountain town, five hours away. They have both found admirable young men with whom to share their lives. And there are grandbabies, two of them, beautiful little boys, one for each family. We have bought a small apartment there... a grandchild just one block this way, another two blocks that-a-way. It is perfect. This is what my brain tells me.

We are in the middle of our first long visit in the new place, a month over Christmas. There is a lot of snow in the valley, and not much sun, but the town is beautiful and everyone we have met in our new building has been kind and welcoming. We go so easily, so happily between the kids' houses and our apartment and I am grateful for this time. I know that a permanent move here makes sense, for so many reasons, the biggest of which is the opportunity to be part of our grandchildren's lives. My heart cannot call this home. Not yet.

An e-mail comes from a dear friend. She references Barack Obama's tribute to Nelson Mandela and the Nguni-Bantu word "Ubuntu".

She writes: "... we'll all continue to be connected by the invisible threads that bind us, even after you move... we are all bound together in ways that can be invisible to the eye; that there is a oneness to humanity; that we achieve ourselves by sharing ourselves with others, and caring for those around us."

These words come at the right moment, on a day when I am weary, when nightmare thinking threatens to undermine my sense of joy-no-matter-what. I struggle to put into words why this means so much to me, at the year's end, when displacement seems the theme of our present and future lives. This is where I will find home, sanctuary, refuge from the ghouls of despair, this connection to those we love, those we like, and even those we find it impossible to understand. If the day comes when Lincoln or I lose the ability to know who it is that loves us or whom we love, I know there will be someone, some gentle soul who remembers for us, who feels for us even if we cannot feel for ourselves. They will wipe the drool, and because I've made them promise, pluck a few wayward facial hairs. They will hold our hands and share their stories and please, there must be laughter.

In the meantime, I awake to a morning that holds the first bright sun in weeks. I fill the little camera I bought with air-mile points with picture after picture. Golden light spills slowly over mountain tops and I stand, coffee mug in hand, shivering on a balcony that gives view to a beauty I cannot attempt to describe. Lincoln joins me.

I need a better camera, I say.

Why? he says. It's all right here.

*I will be bound to my man of the hills
I'll watch his stars from a lower ridge
The canoe will carry us both ashore
The road will bear us onward still
His eyes will shine in a small boy's face
And tender sunset blessings grace
This bittersweet will be will be
And tethered are we to we.*