
Reflections on life and death

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INTRODUCTION

Patrick began writing a journal in 1998 just before he retired from paid work as a result of effects of Multiple Sclerosis. He continued to write irregularly over the subsequent 5 years until he moved into a long-term care facility. He used the journal as a writing exercise, but lived with the frustrations of having to rely upon the computer first to translate his spoken words into written text and then to speak those words back to him. Although Patrick was legally blind, a wheelchair user, and lived with debilitating fatigue, he never let himself be defined by those features. Rather it was his imagination, humor, and quality of thought that captured those around him. These journal excerpts document his reflections on “life, the universe, and everything” in the words of Douglas Adams, a favorite author. The poems were written with the assistance of scribes while Patrick lived in a care facility. Patrick died on January 11, 2004 of pneumonia, having embraced the process of dying as he had his living over the previous 45 years. His family, including his research and life partner, Deborah Stienstra, and their children Rebecca and Cailum, celebrate his life and contributions.

April 12, 1999

Today started in a blanket of small-scale discomfort but somehow worked itself into a productive effort. Supper was made and laundry done thanks to an efficient homecare worker, phone calls were made and homecare supplies were requested and received, and now a moment or two with which to write. If nothing else, I have a varied and sometimes hectic life.

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I have had a headache as a result of too much computer screen viewing and too much television watching. Of the two activities, I’d much prefer computer screen viewing because of the satisfaction provided by my writing, so if a choice has to be made, television will just have to go. I have given up Scotch, sex, and my sight. I do not think giving up watching television will be much by comparison. It is strange that pleasurable vices have been slowly taken from me. Not that I think there is a moral by half. Or one that I would want to promulgate.

April 14, 1999

It would appear as if my disability will restrict my writing in the morning. It is really only until after my nap that I feel well enough to write. Today I listened to Milton Acorn reciting a poem on the radio. There was some delightful discussion about “voice.” In Milton Acorn’s case, the words leapt out of the radio with such depth and had obviously been chosen with such care. I don’t know if I will ever have the strength to put such effort into my words. I imagine I will have to find my own voice, even if it turns out to be a sparse and lazy one. Who knows? Maybe there are people who want to read lazy voices and lazy books.

If you wanted to lie on the beach, you should have been a grain of sand. For me, this says a lot about doing nothing vs. doing something. I prefer to be doing something, however badly.

April 23, 1999

Carol Shields is being treated for cancer. The vitality of the woman has been greatly diminished. The threat of that disease to her life makes me more aware of the precious nature of my own time. It is scarce and not to be wasted. If there is a grand design, perhaps the purpose of disease and death would be to acquaint the other people around us

with the value of their lives. Perhaps the entire planet is one big organism with its various parts learning about their place in its organization through the lives and deaths of others.

April 27, 1999

Today was difficult. I did not feel well and my homecare worker worked badly as a result of allergies. I only have a few minutes to write before Deborah comes home with Rebecca. Yesterday was a frustrating comedy of errors. I erased my morning's work accidentally and then caused my computer to malfunction in an interesting way. It began writing spontaneously by itself. I rather enjoyed that, even though the writing was incoherent. It was understandable but did not make any sense. It did, however, almost rhyme.

May 6, 1999

I spent the day reorganizing files and reading the 23rd chapter of *Moby Dick*. The chapter is titled "The Lee Shore" and is a description of why a man called Bulkington would choose to return to the sea again quickly following a long sea voyage. In this short passage, Melville describes Bulkington by describing his reasons for going to sea. He does not describe the physical characteristics of the man but rather an idea that the man embodies. The metaphor of the ship at peril from the wilds of the open ocean is used to describe human longing for something beyond comfort. Melville gives flesh to an idea of struggle and choice and endeavor and opposition. Melville applauds Bulkington and Bulkington's endeavor. It is a brilliant description and a clever means of making the transition from the ship leaving harbor moving to open sea.

Last night while watching television, I saw myself reflected in society's mirror. I watched a fairly sensitive portrayal of a MS mainstay and even there I did not enjoy what I saw. I am now a stereotype. I am the "MS guy." Frustrating but inevitable. Some people make careers from this stereotype and the super crip[ple] misconception. I didn't and don't want to do that. I am attempting to be something beyond a stereotype of myself. Like Bulkington, I prefer the open seas of just attempting to be myself.

July 5, 1999

The last six days have been spent in the hospital. I had another urinary tract infection. Not pleasant,

but I had the opportunity of having consults with a neurologist and a choking specialist. I was advised that my choking was being handled appropriately, and that I should take my anti-spasm medications. I was satisfied with the business, although I regret time spent in hospital. It is a necessary waste. I also learned that I have been missing meeting new people, which was an opportunity provided by the hospital visit. I enjoy meeting new people—even though what I have been reluctant to admit to is the vulnerability exposed by my need to meet them.

November 9, 2000

Today, my VON nurse, Sonya, told me that a 40 year old friend of hers who had MS died unexpectedly. Sonya has been visiting me once a week for the past couple of years. She seemed very disturbed about the sudden death of her friend. Apparently, her friend aspirated on her own vomit while in bed. She had been living with a rapidly progressing condition and possibly had been suffering from pneumonia as well. Sonya used the opportunity to suggest, once again, that I should get a pneumonia vaccination. My choice about quality of life over quantity of life takes on more serious implications at times like these. The bravado of a young man now has to become an older man living with the courage of his convictions. It was easy to be courageous when I was foolhardy. I still believe in my convictions. It is not that we wish to remain alive because we fear death. We wish to remain alive because we do not wish to leave the only thing we know. That, and that we are disturbed by the absolutism and the immovability of death. So I am left with my convictions and my choice not to get a vaccination.

September 10, 2001

Last Saturday night, Deborah and I went to a "dance" party. I was introduced to a woman named Michelle. Seven weeks ago, Michelle was diagnosed as having MS. She lost vision in her left eye, and was short listed for an MRI. Her story in short is relocating from Toronto in order to take a position at a university, the breakup of a long-term relationship, and, hardly coincidentally, her being diagnosed. She is currently in the shell shocked but still "phoney war" stage. I wish I could offer more than an ear and information, but that is all anyone actually can. I do not think she realizes how difficult it may become for her. A network of family and/or friends is crucial. She may be able to make a go of it, but it will be incredibly more difficult.

Four Battered Angels

*Four battered angels by night came searching,
A tiny flickering candle each held in one hand,
In the other her love for a sad friend,
Whose certainty vanished before cold remorseless
quicksand.*

*Disguised in appearance as women,
Each came privately to my quiet island's lee
Asking questions of responsibility and duty
Unfortunately, they asked them of me.*

*So I spouted some platitudes and truisms,
Silly nonsense that all of us should know,
How to take heart, how to give heart, where to
find comfort,
When to hold tight, when to stand back, when
to let go.*

*Perhaps I said something that helped still their
nightmares,
Perhaps I said something from which they took
hope,
Perhaps I said something wise despite my
misgivings,
Most likely, though, I just helped them cope.*

December 18, 2001

The last few days have been difficult ones for me. Excessive fatigue has combined with boredom to depress me during the day. As well, I watch Deborah coping with very young children [2 and 7] without a break either physically or emotionally. As a result, she is exhausted and I have to address my frustration with the kids and my guilt over not being any help to her. Same old complaint and same old refrain. There had better be some change found in our lives.

Life in a state of nature can be nasty, brutish, and short. Perhaps so, but the process of death can be lengthy and painful. Over the past two weeks, we have all been the unwilling witnesses of one of our guppies killing another. For no reason but that the weaker boys of a different species with different colouration, the aggressor relentlessly chewed off the dorsal fin of the weaker. It was a cruel and painful death and it was a kindness when the tortured victim finally rolled over and floated to the surface. Perhaps the knowledge that life is nasty, brutish and short provides some people justification for being cruel to each other and the planet around us. Fear is the justification for what they do.

April 27, 2002

My best time of the day is the middle of the night. At 4 a.m., after six hours of sleep, I lie awake, a body rested and cramp-free, and dream dreams of fantasy and desire and longing and reflection. These are the moments when I am most myself, when I do that thing which I am best able to do and which no one is capable of doing in that way which is unique to me and, of all things I can do, most satisfying to myself. These moments I would take into my day if I could, but only seldom can I even glimpse the monuments I earlier stood atop. The concrete hurly-burly of the day sweeps aside these fragile less than nothings and I am left with disquiet and frustration and the necessity of inadequacy.

Little surprise that I write. Little surprise that I dislike my writing. The painful selection of words and phrases and punctuation and cadence trying to replace the inspiration of thought! What a folly, what a weakness, what a trial is this!

August 30, 2002**[Patrick's final journal entry]**

This morning, I am convinced that if the aliens arrived today and spoke to me, I would tell them, "The human race is only a slight evolutionary step beyond a rodent—in fact, hardly not even a step at all, beyond the creation of machines in order to better manipulate our environment, which has eroded our planetary environment to the detriment of every form of life on the planet." I ought to know better. It's not that I believe in these words, it's just that I'm only repeating them again to myself because I'm unhappy. Probably, I am depressed, or my body hurts, or I'm unhappy because of the way I treat my family, or for some other reasons. Stupid. Futile to waste my precious few brain cells on such folly. Neither the human race nor my family will be bettered by my unhappiness. More reasonable is to remember the prayer: God, give me the wisdom to recognize where change is needed, the strength to make better what I can, the ability to ignore what I cannot make better and the wisdom to recognize the difference (or whatever that prayer is, anyway).

My eyes are bothering me. I may be going blind. I hope not. At the same time, I have to admit difficulty holding and manipulating my mouse. Some day, if my children need to find out about me after my death, they can turn to these journal entries. Would that I had strength enough to write them long, richly beautiful entries which gave them life lessons, which made their existence richer by far more than paltry dollars. Given that I do not have sufficient paltry dollars to give them, perhaps wasting my few dol-

lars on them will be enough. Unfortunately, it isn't. I wonder if it is better to die unknown and leave the gentle mists of memory shadow you into a figure more beautiful than you really were? Probably, but a life without legacy is a life unlived.

The Price of Admission

*Writers write about things that they're scared of,
At least, according to the author, Margaret Atwood.
Well she ought to know what she's saying,
She's written a lot of novels,
I've even read one or two of them myself.*

*W.O. Mitchell was never scared of the subjects
of his stories,
He was a small town prairie humourist who made
everybody laugh
Unless he was actually afraid that someone would
stop to
Accuse him of being small town stupid,
Woo, this is getting heavy,
Better watch out before I strain my back.*

*There are lots of things that scare me,
There's a hole in the ozone layer,*

*There's environmental degradation,
There's everything American,
And now there's SARS.
Because I know I can't protect my children,
I can't even romp around with my children,
If that SARS ever comes a'calling,
I'll be the first one dead and gone.*

*Now I'm not afraid of dying,
Any fool born can do the other,
I have a different deep and darkest that I'm
ashamed to drag into the light,
I always thought that life was just for living,
Maybe I should have climbed out and just started
pushing.
That way now I may have more satisfaction,
That I was of a little more use.*

*Because I want to be remembered
Beyond the memories of friends and family.
I want to be remembered even by
The people who haven't met me yet.
So, in this you can do me a little favor,
Should I happen to predecease you,
Hold this moment in your memory,
Think of this as a little poetic kiss goodbye.*