



By:
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*Includes "The Tao of MS"
cartoons by author*

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Introduction

So, just what is **Essays and Other Musings** anyway?

This is a collection of essays about life with multiple sclerosis. But, more than a mere compilation on subjects, this is a collection of thoughts and concepts of mine, as I wade through life with a major chronic illness.

The main purpose of this book is to highlight both the differences and similarities in life experiences between those of us who have MS and those of us who don't.

There are some striking differences between those of us who live every day with multiple sclerosis and those of us who don't. For instance, those who don't have to worry about whether they will be able to walk next week will see walking and mobility in a different light than I would. Consequently, few would really understand just how grateful I am to be able to walk a couple of kilometres. I have no idea whether or not I will be in a wheelchair next week and while outside circumstances, such as motor vehicle accidents, can change one's life drastically and quite suddenly, the chances of that happening to any one person are profoundly small compared to that part of the MS population that faces the prospect of having to get around with a cane, walker or wheelchair.

We joke about the virtual illegible scrawling that physicians (and not a few professors) have mastered early in their careers (pharmacists have to demonstrate their mastery of deciphering scribbles before they receive their diploma – seriously, it's on their final exam); but for many of us who have MS, our ability to communicate in writing is usually permanently compromised and often to the point where we cannot write at all! For me, personally, this has had a major impact as I also draw cartoons! I'm teaching myself to write with my right hand (I'm a leftie) but, so far, my scribbings with either hand are just that – scribbings.

Yet, for all the myriad of challenges and difficulties we who have multiple sclerosis face, our life experiences are nearly identical to yours. Double vision does not change the fact that the driveway needs to be shovelled (I actually enjoy doing that) or that I still had final exams to write a couple of years back (I closed one eye during a relapse when I had to write about insolation, plutons and subsolar points on Earth during my Geography exam). Having a limp will not ever change the way the garbage truck driver lovingly flings our garbage can half way down the street every Thursday when I must (sometimes) hobble my way to extract the lid from the neighbour's marigolds. Extreme fatigue doesn't change the price of gas (actually, nobody really knows what the logic behind gas prices is anyway – assuming there is logic in the first place) or that I still have to scoop the cat's box.

There is a third aspect to living with Multiple Sclerosis; the fact that it is, in some ways, a gift in disguise. We have written and been forced (sometimes at

gunpoint) to listen to sappy drivelly tunes sung by crooners with bad teeth, big noses or even both, wailing about our mad pursuit of living in eternity with our loved one. In my case, with the diagnosis of MS I was thrust into eternity. A vast spiritual re-awakening took place within me and I found myself living in eternity... the everpresent moment. We cannot alter an already braided past nor can we predict an unknown and unknowable future! We don't have to pour out our hearts onto a music sheet and slobber about eternity (while collecting royalties as well) – it's right at the end of our noses, even the big ones! The only eternity we really have is the everpresent moment and this book contains much that promotes our living in that realm. This isn't as fatalistic as it may sound. I still make plans for the future and even knowing that plans may have to be changed, I still cherish the very present moment as best as I can.

It is my hope to be able to promote the *living* aspect of MS, rather than the *disabling* aspect of it. Thankfully, we don't need to have a major chronic illness to come to that conclusion. There is much to smile about, much to laugh at, including (if not especially) ourselves.

Periodically, my essays acquire a sort of angry whining sound to them; you gotta take the not-good days with the good ones, I suppose. However, you, the gentle reader, will note that I never remain in that angry whining mode...whew! Sometimes, they may even appear somewhat contradictory; just like a lot of our lives in general tend to be.

As for me, well, I'm still hanging in there.

I'm not as robust as I used to be, but I'm not fighting to get back to that place either. I am simply me, living as well as I can with the limits that I have but also with the understanding that the limits I have are merely relative, for as my ability to withstand excessive heat may not be as good as before, my ability to withstand moronic Ottawa drivers has more than made up for that deficiency.

My returning to my inner spiritual self has been catalyzed by my MS. I still have to undertake the journey but I'll succeed there, too – even if I have to do that from a wheelchair!

Ruth A. Merkis-Hunt, B.A.*

*Bravely Altruistic

Essays and Other Musings

Living Day to Day with Multiple Sclerosis

Ruth A. Merkis-Hunt



Critical Praise for *Essays & Other Musings*

“Jared! Put that thing back! You don’t know where it’s been!”

-Wanda F.

“It is the apocalypse!”

-John P.

“It is the apocalypso!”

-Harry B.

“Two bums up!”

-Roger E.

Essays and Other Musings

Oh no! It's Analogy time!

I was lying on the table in the examining room at the hospital in Red Deer, Alberta, some time in mid-August of 1999 when the neurologist came in and told me that, after having examined the CT scan they had just done, that it really looked like I had multiple sclerosis.

Me?

MS?

Me?

This is a very common reaction to news like this – utter shock and disbelief. It didn't take me a very long time before I started to process the information. I badgered the doctor for information about MS. I had certainly heard of it but knew virtually nothing about the disease itself. Would it kill me? No. Was my life over? Shrug. It shouldn't be. Would I be able to walk again? Unknown.

That was the really scary part – not knowing if I would walk again. I had a flashback to the time long ago when I had actually run a half-marathon...and now I could hardly walk a half metre. The certainty of my being able to walk again was in some doubt!

Adam and I had only been married for a little over three months and this was not at all what we had in mind for ourselves. We were in the middle of developing our counselling practice, with me working full time on that while he was working long (and generally uneventful) shifts as an air ambulance helicopter pilot in Shilo, Manitoba. How would I ever be able to resume the practice if I couldn't even walk, see straight or write anything?

Not knowing if I would ever walk again...

did that mean a wheelchair for me...

no hope for graduating from university...

assuming I would even be able to finish my degree...

was my life over...

All these kinds of questions hung heavily on me even as I was being admitted to the hospital for further tests. The garlicky taste in the back of my mouth from the dyes they had injected into me for my CT scan was still present as a nurse helped me to the bathroom one last time before getting some badly needed sleep. Once the lights were out, my thoughts began to wind up and run faster than I had ever known in my 35 years! The variety and strength of my thoughts were far too numerous and so I eventually fell asleep – the last sound having been the gentle humming of nearby hospital equipment, or was it a vending machine? A solid night's sleep later, and a nurse who had awakened me had informed me that Dr. Scott Wilson, the neurologist who had gently broken the news to me, would be in shortly to do a lumbar puncture. I didn't know why this would be done but I was still smart enough to know that the word "puncture" meant "sharp" and "lumbar" meant "lower back".

Being the dull intellectual type, once we had determined that I wasn't going to die, I went on an information hunt. I was bound and determined to educate myself as much as possible about this disease. Here is what I found out.

Multiple sclerosis is a neurological disease of the central nervous system in which the body's immune system mistakes the protective covering on the nerve cells (myelin) for something that shouldn't be there. The immune cells launch an unwarranted attack and begin to attempt to destroy the mistaken enemy in a sort of "mutiny on the myelin" manner. The process unfolds like this:

In the first stage of an "attack" (relapse), there is inflammation as the psychotic immune system tries to rid the body of what it thinks is some kind of enemy. During this phase, symptoms arise and continue to get worse.

In the second stage, the symptoms (anything ranging from vision problems to dyscoordination to outright paralysis and even beginning to believe that you understand rap music) appear to stabilize over time as the immune response moderates somewhat.

In the last stage, the body attempts to repair the damage inflicted by the out-of-control immune reaction. It generally does a good job, but, eventually, the body's ability to repair itself completely is outstripped (excuse the pun) by the damage, hence increased and permanent disability. Oh, and, after awhile, the actual nerves themselves become permanently damaged. Yuk!
There – that's MS in a nutshell...sort of...have a nice day and don't forget to turn off the lights when you leave.

I can also recall having been asked by a few people what an MS episode (exacerbation) is like. I resorted to my tried and trusted method of explaining...the analogy!

The analogy I like to use is the "getting to work from home" image. The Dramatis Personae look like this:

You = the initial thought

Car = the nerve impulse, presumably to bring said idea to fruition

Road = (white matter) nerve cells, complete with insulation (okay, we'll call them axons covered with myelin)

Construction crews = your body's immune system cells

Munched up road = the damage your immune system does to an otherwise perfectly innocent roll of myelin

Picture yourself at home and you are getting ready to go to work. You hop into your car and drive away expecting to take the same old route to the office. As you drive, however, you discover that the road you are on is being torn up for no known reason and is either reduced to one lane or else closed entirely. You now have to find some other way to get to your destination. Sure, it can be done (usually) but it does involve being delayed and it does involve taking detours. You do get to your work, but it has taken you a lot longer and you are somewhat worn out from the venture.

In multiple sclerosis, it is the white matter in the brain that is affected; the road in my above analogy. As the immune system targets healthy myelin, so do the city construction crews target the ordinarily quite "healthy" road you are on (let's call it "Bank Street in the Glebe" or "Deerfoot Trail" near Calgary, both of which are almost always being torn up for no discernible reason!). The result is the same, you have to take some kind of detour to get to where you are going. Or, if the road you are on is somewhat passable, then you may be in for a bit of a rough ride as you negotiate the lumps and bumps of shredded asphalt hoping like mad the suspension in your car

doesn't give in before you can find a parking spot (an impossibility in Ottawa). During an MS relapse, you may want to reach for an object only to find that you can only sort of clumsily paw at it...or sometimes not at all! As the symptoms go into remission, this is akin to the road the construction crews have torn up being recovered. The result may be patchy and it still won't really be as smooth a ride as it had been previously; but you can at least take your old favourite route once again...for now anyway!

Armed with this new kind of understanding, the real task at hand would not be just for my central nervous system to reconstruct itself as best it could but for me to reconstruct myself. Images of lost hopes and dashed dreams played in my addled mind, even as I was turned onto my left side so that the neurologist could do this lumbar puncture (read: sharp lower back) while a nurse held me down.

A part of the problem with MS is that its course is unpredictable, in much the same way that no one can tell if the highway 403 cutoff from highway 401 heading west out of Toronto will exit from the right or left lane. It is possible that months or years may pass in between relapses and relapses themselves may not really be all that horrendous. The one I experienced in 1999, the one which got me in the hospital in the first place, was quite bad. Subsequent ones, though troublesome and at times debilitating, have been substantially less horrendous, but the recovery has also been somewhat less complete, too.

So, what's it like living with a major chronic illness whose course and manifestations are totally unpredictable in nature? It's like living with the sword of Damocles hovering above your head. There is just no way to know when it will strike, how it will strike and what the damage will be.

The Reader's Digest Version...the first few lessons!

As soon as was possible, Adam sprung me from the hospital in Red Deer and brought me back to Shilo, Manitoba where he was working as an air ambulance helicopter pilot. There, he would literally nurse me back to health over the course of the next seven weeks. As nasty a relapse as this was, I simply could not believe that I would never walk again or see straight or be able to write. It took 3 of the hardest weeks of my life up to that point before I was, once again able to sort of walk for a bit (a bit being half a block with assistance and with lots of breaks – I had been a regular 5-10k runner). Yes, I looked like Igor or someone who was intoxicated, but I didn't care about that. When you are struggling to walk, you don't care what anyone else thinks of your efforts. But, it took only another 4 weeks before I was running up and down fields, waving my arms to the gloriously blue skies of late summer southern Manitoba and laughing out loud. Nobody except Adam could really understand what being able to run freely meant to me. So, in October, after the work in Shilo was done, we flew home (it was the first time I had ever been in a helicopter) and spent a few days trying to get our lives back together.

Except that our lives were now and forever completely different from what we had envisioned, a reality that came home to us when I had my first MRI in Edmonton. By early November, the diagnosis of multiple sclerosis was confirmed. The next step, it was felt by the neurologist, was to get me on medication.

But the real next step was for us to try and resurrect our practice, which we had to close for the time I was in Manitoba. Tried as we did, however, we just couldn't get it to work out. We were rapidly running out of money and options, so it was a timely job offer for Adam to work in Ottawa, Ontario that made the decision for us. It would mean selling our house (the one we designed and had built) at Sunbreaker Cove (a summer village nestled on the northwest corner of Sylvan Lake), closing down our practice and moving to Ottawa. Here was the first real lesson in my journey through this disease; *just because you had plans for your life did not mean life didn't have plans for you.*

All was going well, so far, and I experienced no relapses of any kind until a very small one in 2002. That's when I had my first taste of only double vision and my very second opportunity to put the value of persistence into action. The only consequence I had experienced with this minor relapse was that I couldn't drive or ride my bicycle. Thankfully, living in Ottawa with our fabulous transit system, getting around was not a problem. I was still fully able to do anything else, including finishing my school year and writing final exams...in a non-airconditioned classroom with no windows...in +30C weather...while covering one eye. Luckily, there were no other students who were writing at the time I was so I didn't have to worry about looking too silly half squinting while wading through acres of exam material. I was still able to walk and, as the weeks went by and my vision returned to normal, I would only experience a temporary worsening of things after a particularly long run. This was my first taste of what is called "Uhthoff's phenomena"; a temporary worsening of symptoms as a result of exposure to excessive heat.

But the point was: that I could still do it and adopting an 'I can conquer all' attitude would prove to be a huge mistake for me. Lesson number 2 was this: *adopting a combative posture will result in you getting bitten by it.* It is easy to adopt either fervent denial of the diagnosis or else a raging battle-mentality. I did not ever *outwardly* deny my illness (there were enough test results to convince anyone) but I was rather proud of my ability to survive even this. I was still living off the fact that I had made a full recovery from my initial 1999 attack that I was beginning to assume that I would, somehow, be able to "beat" MS. It would not get *me* down – no way. Wrong, wrong, wrong, I would find out. In fact, adopting a warrior-like stance is really a form of denial, not so much of the *reality* of the disease but of the *implications* of the disease. Taking up arms against multiple sclerosis is a little like wedging yourself in a trench armed only with your will, opinions

and wits. You know the enemy is out there with a good complement of weaponry and could strike at any time but you'll be ready for anything, you'll beat it (again) and it won't affect you. The problem there is that whether you think that maybe someone switched your test results with someone else's or that you can somehow outsmart the disease the fact remains that you are not living your life. You may have made all the accommodations in the world to your work and home environment but that all amounts to naught if you haven't first made accommodations in your mindset.

Lesson 3 is, perhaps, the hardest one of all; *your point of view must become a lot more present-focused*. This means that pining for a past (real or imagined and probably mostly imagined) you miss and desperately want to recreate or scrambling for a future you presume will fix all your problems is a complete waste of time. MS means "no ability to predict", so that only leaves the everpresent moment. Here then, is the very first gift that multiple sclerosis has given to me – even if I didn't recognize it at first – welcome to eternity. You have forever to live so, as the Nike ads all say, "Just do it".

The Empty Vessel – or, don't look a gift horse in the mouth!

There is a time in everyone's lives when some brutal self-reckoning is called for. We don't always heed the call (some of us actively avoid even thinking about it), but it can be a life altering time when we actually do!

For me, that time was 2003. At the end of May, I graduated from university, a goal which had been one I had had since I was a young girl! It was only at the end of June when the vessel that is me began to spill its contents.

It all began with a relapse. Just one week after I began my Avonex therapy (30mcg injected IM once per week – I picked Fridays), I drove from Ottawa to Trenton to pick up my kids for their “two weeks with Mom and Adam”. I noted that my left leg seemed a bit rubbery, but I had no real difficulties walking or changing gears in our Tracker. I semi-shrugged it off as fatigue from a gruelling six months of finishing school, grad prep, volunteering and just life in general...the whole bit.

But, the next day and with my kids with me, I found I was having increasing difficulty walking. Now I knew it was an MS relapse but I didn't feel that it was as bad as it had been in 1999. This time, though it was an unpleasant time, this relapse lacked that mind-numbing fatigue or extreme paralysis. In other words, it was mostly very annoying and I soon worked through it. Even by mid August, I still got kinda shaky legged and a bit wobbly if I had been walking for about 3 or 4 kilometres non-stop but that's okay. It really is...

That particular summer, though, saw more than me merely coping with MS. It saw a large number of external stressors that more than simply taxed my abilities; it got to the point where any and all social interaction with anyone other than Adam actually physically drained me dry. I felt like a rapidly emptying vessel. But, here is where it got interesting for me – an empty vessel is still a vessel.

Wicca teaches us that an empty mind is devoid of preconceptions and prejudices. Buddhism and Taoism teach that also. As empty vessels, we are thus free to receive the gifts of love and caring that are truly out there. It's a little like starting again from scratch! So, by that reasoning, my having felt utterly depleted and, I admit, despondent and totally empty meant that a lot of garbage must have accumulated in my very soul. Now that it is empty, can I assume that I can be “re-born”, as it were? Does this mean that I am now ready to learn how really and truly to cope with a major chronic illness? If so, does this mean that, until this point, I had been in complete denial as to the implications of having and living with this frightening though thankfully non-fatal (for me) illness? How does one reconcile illness with wellness? Are these two concepts mutually exclusive?

I spent quite a bit of time attempting to answer my own questions.

- Question: Am I “re-born”? I wasn't aware of having died in the first place. Yet, every moment of our lives is a chance to experience a sort of (re)awakening. Maybe that's a better term to use – reawakening.
- Question: Am I really ready to learn to cope with a major chronic illness like MS? Again, I sure hope so. It is my hope to finally shake off these shackles of ill-chosen reactivity and replace them with a more measured and more calm response to emotional stressors. But, more importantly, coping with a chronic illness like MS is a dynamic process. You don't “graduate” from despair to enlightenment; it's a lifelong process which each one of us owes to ourselves to undergo.

- Question: Had I been in denial regarding what MS is and that I have it? I think so, to a point. It's a difficult balance between self-pity with all its connotations of resignation and misery and adopting a highly combative posture (ie 'This won't do me in!!'). I'm far more inclined to conclude that while I had altered my surroundings to accommodate my illness, I hadn't altered my mind-set to accommodate my illness. That takes awhile, at least a whole lifetime.
- The last two questions I felt were two sides of the same issue. How does one reconcile illness with wellness and are these two concepts mutually exclusive? These are common questions to ask but I am uncertain that they are useful ones. The ideas put forth in these two questions tend to suggest that illness and wellness are specific points that reside at opposite ends of some spectrum, but that would be a fallacy to believe. Illness defined by one person is wellness by someone else's definition.

So, how to I even approach these questions? Well, I suppose I could start by looking at my ultimate goal vis a vis MS. This is a simple goal to state but probably the most difficult goal to attain (not to mention maintain) and it is this:

My goal in living with multiple sclerosis is to transcend the whole thing in the first place.

Control – when to take it and when to leave it!

“Get a hold of yourself,” we often hear. The message there is simple: don’t let your emotions rule you; don’t let them take control of you. We’re supposed to squeeze ourselves into rigid little emotional molds and anyone who doesn’t is some sort of weak thing deserving our pity at best and our scorn at worst.

Lovely dramatics but completely harmful to our psyches. We’re conditioned by our culture not ever to express any extreme emotion. That doesn’t mean we don’t feel it (and we generally do) but we’re not to do anything about it and that’s wrong. If we lose a loved one (ie death, divorce, splitting up, et cetera) we’re “allowed” a small amount of time to “feel bad” but we’re then told to “get over it” ...whatever that looks like.

In grief counselling, we have the client talk and, hopefully, help them to identify and exorcise the barriers we all have to expressing our feelings. For some of us, we intellectualize a loss. In my case, *someone* has to develop MS so it may as well be me. If you examine the typical profile of the person most likely to develop multiple sclerosis it is...bla...bla...bla... Yes, I know the typical MS patient because I’m it. My life consists of, but is not defined by, regular visits with neurologists, prescription medication and various therapies to help me work and live with an illness that does everything it can to remove any and all control I may have over my own life...

Or does it? Well, the answer is ‘yes’ and ‘no’. I know that I’m a “regular” in the waiting room of my doctor(s). To that extent, my ability to control my whereabouts and my own body’s insane need to inflict chaos on my nervous system is beyond my control. But, there is also another side to this: the question of whether or not there is anything to control. I have found, though with increasing difficulty from time to time, that sometimes relinquishing control over certain aspects of my life has brought to me the gift of inner peace. Here, then, is another gift from multiple sclerosis in disguise.

For example, I have problems with food. Food and I have a very strange relationship which I fully recognize to be highly dysfunctional: I eat as little food and as infrequently as I can possibly get away with and, in return, food promises to occupy my mind as much and as often as it can possibly get away with. The less I eat, the more it nags me – it’s an inverse relationship. This is a power struggle that I have fought for almost my entire life. Yet, I now find myself increasingly unoccupied with food. I eat and consciously tell myself that it’s really okay; that weight control is a process and not a product and that if I eat poorly one day then I will eat better the next day but that the general trend line is not ballooning into morbid obesity or shrinking into some shrivelled skeleton. So, having multiple sclerosis is “forcing” me to relinquish control over a lifelong issue of perfectionism. This, too, is a little gift from the disease!

Yet, it is an incredibly scary thing sometimes when it feels that you have absolutely no control over anything in your life. Travel is a good example. Adam and I can go away somewhere, as long as I can get back to the house in time to take my weekly Avonex shot. To that extent, the medicine controls me. Sure, I can bring the stuff with me – unconstituted, it remains effective at room temperature for up to a month – wow - but that isn’t the point. The point is that this is something I would *have* to do if I wanted to be away for longer than a week. It is something that must be done. So, I take control of that situation by taking trips that don’t last more than a week, which suits me fine. I enjoy travelling a great deal and there’s no reason why I can’t go places but, after a few days, I long to have a home cooked meal and to sleep in my own bed. At the same time, however, I don’t fuss or worry about the situation. Taking medication is all part of living with MS and, at this point, I don’t care what I have to take and for what reason. I have my little 7 day pill box that I use daily. Sure, I feel like a sick person sometimes, but I don’t wish to control how I feel. I can let go of my need to emotionally restrain myself, to “get a hold of” myself

and simply allow my feelings to come forth, unrestrained. Sometimes it's anger and sadness. Sometimes it's fear but sometimes it's utter joy. I like feeling joy.

How Many Balls can I Juggle?

One of the first signs of “emotional spring”, I think, is that I am becoming a bit more aware of the number of balls I am juggling. Under the advice of my neurologist, my GP, and Adam, I am keeping the number of balls down to a bare minimum. The intention there is not to simply catch my breath, juggle what few issues are present and then slowly increase them until I go bananas. Rather, the intention is to keep the number of balls I can juggle to a set number – no more and no fewer.

But, to do that, I need to be aware of what those balls are. We often feel that we’re juggling things like “family”, “friends”, “work”, “health” and “hobbies” (to name a few) yet we don’t generally define these issues in any concrete way. For instance, if someone says they’re juggling “family”, what precisely do they mean? Do they have a family member who is ill and needs our extra attention? If so, are we feeling anxious about it? Do we have a family member who is starting a new job and their schedule conflicts with our own? Or that maybe we’re feeling a little afraid that any conflicting schedules will mean that we never see each other again? By juggling “friends” are we dealing with a change in a dear friend’s behaviour which leaves us worried? Do we have too many friends who are all demanding our active participation in some activity (this is related to “hobbies”)? What’s going on at work that makes us conclude that we are juggling it?

Of course, we’re all juggling particular issues but my point is that we rarely, if ever, define those issues. Many parents face difficulties with emotionally volatile adolescent children who are mired in the tumult of puberty. I have three children and they live far from me, so the issue of all of us being able to get together becomes a “ball” to juggle. That’s a pretty big ball to juggle by itself but I’m doing it with necessary help. We each have our own anxieties about how our children are coping and, in my case, how my children are coping with their mother having MS! Someone else with an emotionally volatile 13 year old daughter, for example, may have other particular worries but we could each then claim that we are juggling “family”. Another issue I have is the difficulties with seeing my children as pertains to my disability and driving. This is another “family” issue..or is it a “health” issue?

I could go on, but the point is clear – I’ve got to keep the number of balls I juggle down to the very barest minimum and (here’s the tricky part) *keep them there*.

Have you tried the Internet?”

This is a common response we hear when we ask someone a question about some information we need. For instance, if we wish to know the latest information about some diet plan, the cost of admission for an upcoming seminar or trade show or a new type of social program that you heard about on the news, you will invariably be directed to a website.

I shudder imperceptibly whenever someone suggests that I try the internet. I smile and hold my tongue but, truth be told, I want to throttle the dolt who suggests that I try the internet. Does this person think I'm too stupid or lazy to try the internet? Sometimes, I quietly reply that I have already tried the internet – in fact, the chances are certain that I have not only tried the internet but have sometimes spent countless hours on the internet looking for answers to my questions. Thus, if I am asking you, a trusted authority, for information it is only because you are my last resort. So, the next time someone asks you a question and your answer is that they should try the internet, don't be surprised if you get a quietly hostile, barely restrained, “I did already. That's why I'm asking you.”

Now, to be fair, there are enough people out there whose blatant stupidity would annoy a Zen Buddhist monk. These are the people who have no problem e-mailing someone for information and then engaging the respondent in a venerable chess game of question and response. If you don't respond within the next half second, they will then phone you and blabber on forever about anything other than the subject of the original question and prevent you from getting any work done. I wonder how these people can be smart enough to know how to use an e-mail program, like Outlook Express or Eudora but can't figure out how Google works. These are the people who should be tied to anthills and have sugar sprinkled on them.

But that's not my complaint. I'm talking about the throwaway, default answer to every question

“Do you have any information on depression?”

“Try the internet.”

“Do you have any information on the history of the Tibetans?”

“Try the internet.”

“What time is it?”

“Try the internet.”

The problem is that the once revered internet-as-a-research-tool is gone. It's been replaced by pop up ads, and dire warnings that your computer may not be up to the task of actually doing what it is you asked it to do. Here's an example from my life.

I wanted to find some information on the Goth people. So, I went on the internet, called up the browser and typed “History of Goth” into the search bar. What I got at the time was a history of some rock band “Goth”, a history of Goth fashions (including a sale on thigh high Goth black BDSM boots with silver buckles – the kind that “real” Goths wear...) and Goth make-up. There were also several personal web pages written by depressed, illiterate twenty-somethings ranting on about what's wrong with the world, why they like to wear black and how they like to pierce body parts until metal detectors several provinces away go off randomly and that the schedule of the latest “Goth” punk band includes a stop in their town. Most of these sites featured out of focus self-portraits of drug ravaged, pin pricked anorectic self-indulgent depressed teens “just hanging out”.

This wasn't what I was looking for. I was looking for some actual, genuine history of the Goth people – that band of disorganized Germanic tribes who lived throughout Europe, conquering all that they saw (Alaric sacked Rome in CE410) and who were under constant threat from the Huns, the Vandals and other disparate nomadic groups and, most importantly, who were really looking for a homeland; not thigh high black boots.

Eventually (okay, it was seven days) I found a reference to the book "The Goths" by Herwig Wolfram. So, I followed that thread and, after sifting through on-line bookshops, more pop up ads featuring opportunities to flatten my belly, find the right partner, or learn Swahili in my spare time on line, I managed to find out that the book was likely available at most libraries also. Problem solved...right? Nope.

I then tracked down the website for the library and, through Herculean efforts, managed to discover that Wolfram's book had been known to actually be visible at the library, right next to the 6 volume series on how to talk to your goldfish so that it understands. Day eight, I shuffled out to the main branch downtown. Wiggling past the turnstile, I entered the library and, having been there numerous times before, knew that I would need to head upstairs where the reference books would be. It would only be a matter of finding the right section and I should be able to track down and borrow Wolfram's book.

Except that I foolishly assumed that the library's internal computer would point me in the right direction. After finding a free terminal (there weren't many), I typed in the author's name...and was told he didn't exist in this time/space continuum and to try again at some other epoch. My spelling was correct so I tried typing in the name of the book and was told the same thing, the book was only a reality to me and had I taken my medication? Well, to make a painfully long story short, I did manage to find the book. The library's computer had lied to me and I despised its very existence. The total time it took for me to find the answer to my question was eight (expletive deleted in the gerund form) days. That's what I get when I "try the internet". It's no wonder people phone to look for answers because the internet doesn't have any. Unless you're willing and able to forcibly extract the information you need, then you're out of luck.

Incidentally, it took Google.com a whole 0.0028 seconds to find the Goth punk band's website.

Dreams, prophetic metaphors or random synapse firings?

One of the more fascinating side-effects to bupropion hydrochloride (Wellbutrin – an antidepressant) is that I am invariably treated to a whole night of stories and images flashing in my already addled mind – dreams, in other words. Lately, these dreams have become a highly organized pseudo-miniseries featuring multicoloured rabbits, books, people I know (except that they have different hair) or other symbols. I feel that many of these dreams actually mean something. There is no doubt that dreams are significant – the problem is that some people ascribe a higher level of significance to dreams than others and some don't think dreams mean anything at all! For these people, dreams are merely the random firings of synapses. Yet, given the nature of antidepressants, I'd have to give some weight to the idea that the source of these wacky and only marginally sensible images comes from some of the work that the medicine does.

Antidepressants like bupropion hydrochloride work because they change how some neurotransmitters are taken back into the neuron. Some neurotransmitters like serotonin and norepinephrine (to name two) don't hang around long enough before they are taken back up into the nerve cell from whence they came and the result can be depression. Bupropion hydrochloride and other selective serotonin reuptake inhibitors, SSRIs, inhibit or slow down the reuptake of norepinephrine, though the second "S" refers to serotonin. The result is that this happy little neurotransmitter gets to hang about a bit longer and exert its effect.

But, I still get these weird and awesome dreams. They're not frightening per se, although the one I had last night made me really happy it had only been a dream. The question is whether dreams mean something significant or are merely random firings of neurons resulting in a sort of cobbled together set of images and ideas that beg to be made sense of? A classic "dream" features us trying desperately to scream for help, only to have a choking gurgle emanate from our dried throats. Perhaps some psychologists or dream interpreters would suggest that this was the brain's way of telling us that we are afraid to speak up for ourselves. Another classic "dream" includes trying to run from the monster that is chasing us, but we find our legs won't move or that we find ourselves trying to run through mud or molasses. A psychologist or dream interpreter may offer that we are perhaps trying to run from something unpleasant but don't know how to do so.

Personally, I don't think dreams are quite that prophetic, although I have been able to glean some interesting insights from some of the recurring dreams I have had. A particularly interesting one has me sitting on some invented little mobile device resembling a skateboard but with a seat. I am sitting on this skateboard and I am controlling a sail on a windy day. It's big, tall, white and very unwieldy. My goal is to get moving down the road before the phalanx of cars which I can hear coming up behind me runs me over. But, I can only get the mobile device going in fits and starts; I can't ever seem to get it to work in any consistent manner. This is a recurring dream and I'm wondering now if this is a metaphor for how I feel about where my life is going. I can get going sporadically but can't seem to make any genuine and steady progress...and there's that phalanx of cars. I can hear them and I know they're there, but they never quite seem to get me, and perhaps that's the best part of all. I never get run over by this cluster of killer cars...

...or maybe it's my neurons having a bit of fun at my expense.

So, what is it about dreams that fascinate us anyway? I like to think that dreams represent the starting point of human imagination. We have sometimes heard people say that they had a dream about themselves floating in the air, only to have them become astronauts. I can remember having a dream about being tumbled on the space shuttle – the next morning, I had labyrinthitis – an 8 hour (likely or at least suggested) "masked MS" event characterized by endless vomiting and perpetual motion sickness. The eyes tumble and the only way to stop the scene from flipping furiously like a runaway horizontal hold on a television set is to keep your eyes shut tightly. The

eyes still tumble, but you have no visual input which disagrees with what your semi-circular canals are telling your brain.

Under fused eyelids, my eyeballs rolled and tumbled, just like they do during REM sleep (where we dream, incidentally) but I would have to open them just long enough to grab the bucket and barf uncontrollably. The last two times I developed this charming feature, I wound up in the hospital getting IVs because I couldn't even keep water down and I was becoming rather dehydrated. Thankfully, labyrinthitis doesn't last long (although you wish you were dead after about 4 hours of unending barfing) but the point is that it was from a dream that I discovered I was developing this terror. In other words, it just seemed as though the dream my brain was concocting was directly interacting with the labyrinthitis.

So, what does this have to do with dreams? Well, I'm not certain but it does tend to mean that encroaching illness or actual bodily movement can (and will) insinuate themselves into your dreams. Dreams of movement can mean that your inner ear is signalling your brain that it's being rocked and rolled around...in which case, don't make any plans for tomorrow because you aren't going anywhere!

How to be thoroughly Ignored

This isn't as bad as it sounds, actually. At least, from where I'm standing I would like to be ignored by a lot of people, except Adam. Other than he, I would like to be a little more ignored these days, thanks. Besides, cutting back as many distressing situations would be in my best mental health interest. I can't disagree there.

One of the main features of this depressive period for me is just how little contact I actually want with nearly anyone else. That doesn't mean I can't cope with grocery store clerks; just don't ask me to do anything for you. I do know that as the depression lifts, thanks to journals like this, as well as the medication, I will be better able to deal with the demands made by others.

I guess the only real way to be ignored is to ask to be left alone. The key lies in not being rude or hostile in your request – a simple, "I'm not any good around people right now. Can you call me later?" will suffice. In wishing to be ignored, it is not meant that I wish to become a hermit – I thoroughly enjoy the company of others and wish to continue doing so. It is simply that I sometimes need time for myself and if that means I don't go anywhere for a while, then please don't take it personally. Part of the problem, however, is that some people just can't seem to understand what needing to be alone is. Too many people take such requests as personal slights and will (over)react accordingly. They may feign concern, disguising their uncooperativeness as worry. Or, they may decide that not only is your request for downtime unreasonable, but is the source of their own distress and that you ought to learn to think about someone else besides yourself...bla...bla...bla...

About the only thing anyone can do in that case is to accurately reflect the other person's statements and then reassert. For instance,

"I'm not really up to going out for a java with you; thanks for the invitation."

"No? What's wrong?"

"Nothing, really. I just need to spend some quiet time by myself."

"Nonsense; you really need to be out and doing things. Spending time by yourself only makes it too easy to start feeling sorry for yourself."

(reflective statements here) "So, you think my desire to spend time by myself is a way for me to get stuck in self-pity. Did I hear you correctly?"

"You can't just stay at home and do nothing. You need to get out and learn to relax."

(another reflective statement goes here) "Sounds like you think that going out will help me to relax."

"Yeah, you can't relax if you're stuck in your own head."

"Spending time by myself isn't good for me, is that what you mean?"

"Come on, stop this counselling crap! Do you want to come out for a java?"

"I'm not really up to going out for a java with you; thanks for the invitation."

...and so on. Invariably, this exchange will be repeated in some way shape or form, but the message is the same: if I'm not up to going somewhere, then please don't persist.

And don't take it too personally, either. It isn't that I don't want to spend any time with you, it is just that I need to spend some of my time alone.

Just ignore me, please.

What's really important

It is fairly often that we read about or hear about someone whose entire life had changed dramatically after some life-altering event. Whether a near-death experience, natural disaster, finding a really good parking spot or some brand of existential crisis, the question which begs to be answered is what is really important. Oh, we don't always have to be in the midst of some terrible crisis in order to wonder about what's really important – it's just that our lives are generally far too crowded to be able to sit ourselves down and spend...actually *spend* ...some time asking ourselves what really matters.

This is precisely what I have been doing with myself over the past several months, especially when I really just needed to be left alone. There, inside my mind was this swirling ball of anxieties I recognized (even then) to be nothing more than petty annoyances which I was allowing to get under my skin. My ego's need to be always and forever "engaged" and "productive" prevented me from doing any genuine spiritual growing. I could have blamed MS and my relapse, but that would be a lie. The truth was that I was still clinging to this mad premise (hope?) that I could "beat" and "overcome" the intricacies of this disease. Buddhists would call this "distraction", Wiccans just call it a waste but whatever name you use, it will suck the life out of you if you let it...and I freely admit that I did let it get so far.

The Taoist approach to living is to live as much in harmony with the ebb and flow of the universe. Far from being merely lofty and complex pedantry, this approach has its practical uses. For one thing, it prevents one from engaging in self-pity or self-punishment. It also, however, puts a swift end to the nagging wondering of why things happen. The answer is that they just do. This isn't a subscription to the "shit happens" attitude, even if it sounds a bit like that. It is more of a call for each of us, especially me, to just yield and flex with the comings and goings of whatever life has to offer, rather than adopting the role of "victim" or "warrior". Even my neurologist's advice to me in '03 when I was having a relapse was for me to just "ride it out". If that isn't a Taoist prescription, then I don't know what is.

Then, the first signs of depression began to settle onto me; partly due to the MS itself partly due to the medication I was taking for my MS but also due to the fact that I was just feeling extremely psychologically exhausted. When one's cup is full, it must be emptied before one is ready to receive again! Perhaps this is what Dr. Stotts meant when he told me to "ride it through".

Cause and Effect

When I received my diagnosis back in 1999, we had to make the inevitable phone calls to relatives to let them know the tragic news. Adam got to make all the phone calls because I was lying in bed partially paralyzed and likely asleep when he made the calls. Sure, there was the shock and horror of finding out that someone you love and/or care about has a major illness whose course is unknowable although thankfully not fatal in my case. But, it was the response we got from family that shocked and, at times, appalled us – but it didn't surprise us.

I never sought sympathy (“Oh, you poor thing...”). Sympathy is useless. However, I found that I was given what so many of us get but so few of us actually need....advice and opinion as to cause.

We heard things ranging from the fact that I was so thin (according to them at least) to the suggestion that I should eat more fish or that I wouldn't have developed MS if I hadn't gone out running in the cold weather and that I really need a television so I can watch teleplays. The effect of such expressions ranged also, from eye-rolling restraint (barely) to feeling completely to blame for all this. There were two related psychological concepts at work here.

The first was what is known as the just world hypothesis. This belief simply states that bad things happen to those people who, somehow, deserve it. If you are mugged, then you must have done something to warrant the attack, like walking alone at night in a dangerous part of town, and so deserve to be mugged. This is “justice” at work. If I cross-country ski or go running in cool weather, then my health will suffer and so it would only stand to reason that I would develop MS. This is the same theory that lets people with Type II diabetes (adult onset) know that their fat bodies and sedentary lifestyles are what did them in. Nobody who took care of themselves would develop Type II diabetes. “Justice” (presumably social or even religious) is served by these consequences.

Related to the just world hypothesis is the concept known as blaming the victim. This is the sort of thinking that permeates too many police stations and why too few women report having been sexually assaulted. Surely, they must have dressed provocatively or said something to encourage the attacker and so we should blame the victim for their plight. It's a treacherous way of distancing ourselves from the plight of the victim – as we delude ourselves into believing that we would never be victimized. So, in my case, it was something I “did” (walking outside in the cold) or didn't “do” (not eating enough fish) that resulted in my developing MS. This is the consequence (justice) of my transgressions and so therefore I should not be surprised at all this.

In other words, it's my fault.

I have a problem with this. If the just world hypothesis is correct and that transgression will result in corrective or “just” consequences, then how come more of us who exercise outside in the winter don't develop MS? If the just world hypothesis is correct, then the fact that I dislike fish should also result in MS but it should also mean that anyone else who didn't like fish would also develop MS, too. I can't stand television – any bright video screen is too much stimulation for my brain and, after about half an hour, I wind up extremely agitated and seeking a calm and QUIET place. If watching television is “the answer” then scientists would have figured this out long ago.

But that simply isn't the case. If I had to ascribe blame anywhere (not that it's a useful exercise), I would have to blame my parents for the rotten genes they passed onto me. There, see how that sounds!!

Reflections

One of the most amazing things I can recall ever doing happened when I was six. I had gone into the bathroom at our house and, after using it, noticed a hand held mirror on the counter. My mother was downstairs and my other siblings were elsewhere. Having nobody banging on the bathroom door, a rarity, I took it upon myself to investigate this hand held mirror a bit. I picked it up and peered into it. I saw my own reflection and then I glanced at the bathroom mirror on the wall. I immediately noticed that the image was both the same and not the same at all. It was the perspective which had changed and this idea intrigued me. In fact, it intrigued me enough to want to investigate further; so I stood before the bathroom mirror and took the handheld mirror and aimed it at the first mirror. The results utterly awed me.

For the very first time, I was actually able to glimpse into the merest hint of infinity as the reflections bounced back and forth interminably. I could plainly see my own outline with the hand held mirror perched against my chest but it was the sheer vastness of vision that amazed me. I was utterly transfixed. I didn't even blink for a good long while. I noted that the endlessly repetitive images turned a slight green the further into this brand new world I delved but that didn't diminish my profound awe at this effect. And all it took was placing one mirror in front of another.

I felt as if I had made a profound discovery; a new portal into a dimension nobody else had ever heard of. I found my eyes unfocusing slightly and my imagination kicking into high gear. I concentrated on one of the reflections and imagined a person's head just appearing over the top. The person is nobody in particular, just an individual who is trying to leap out of the neverending dimension and get back into this world. Like an athlete running the hurdle race on a track, this person leaps and grasps for the next one...but he never quite gets to this world. If I remove the mirror, he is trapped in some sort of extra-dimensional matrix – but if I hold onto the mirror, his efforts remain futile. He can never escape that world and enter into my world because he is not of my world and so has no place in it...or does he?

So, what do I do? Do I remove the mirror and sentence this hapless soul to an eternity frozen in some invisible but quite real time/space or do I hold the mirror steady and, somehow, manage to rescue this person from his predicament so he can return to the here and now? The answer isn't that simple. Suppose this "person" is really some terror who is hell-bent on destroying the human race? Would it be immoral of me to "allow" this creature entrance to our world? If that were so and given that mine was not likely the first to discover this neat trick with mirrors, then it is just as likely that this "person" would have gained ready access to our world aeons ago. Of course, if he hadn't, then maybe I was tempting fate too much and I should really remove the mirror and save the world from this monster...

...Time passed and I found myself not just astounded at the leaping runner seemingly aching to escape, but growing quite frightened at my own imaginings. Didn't my mother tell me I had too vivid an imagination already?

But if I simply remove the mirror and leave the poor guy "stuck", is that the moral thing to do as well? Suppose this "person" really did belong in this world after all and my initial assessment of his "right" place had been in error? Maybe he was supposed to be successful in his re-entry into our world and that my actions were designed to facilitate it? Suppose this "person" would come into our world in order to solve all the problems afflicting us, including that rotten kid in my class who kept beating me up after school? If that were the case, then I should really be encouraging him to leap again so that he could be one dimension closer to emerging from the mirror in front of me.

Ach, such thinking for a 6 year old. I really should have just put the mirror down, marvelled at the science of it and then gone back outside to look at the clouds. In the end, I did just that but that event so etched itself into my mind that variations of it occasionally visit me today.

A variation on this theme happened on the late afternoon of December 31, 1998. Adam and I were living in Central Alberta and we were heading to a friend's place some distance away. We travelled on a single lane highway. The skies were that dull overcast that washed away any and all colour from the skies. While the clouds were not thick enough to completely block out the sun, they were thick enough to render the sky a featureless "thing". As it was Central Alberta and as it was December 31, it was bloody cold. In fact, the earlier freezing drizzle that had made many roads dangerous to travel on had hardened into perennially floating ice prisms. Adam was driving and I soon became aware that there was what looked like a thin and rather faded line starting at the horizon directly in front of us and stretching upward. The only way I could really see it was to use averted vision (where you look just slightly askance of the object in question so you can actually see more of it. It's an old astronomy trick and it works beautifully!) and when I pointed out to Adam what I was seeing, he replied that what I was, in fact, looking at was a reflection of the road itself on the ice prisms far above...

The feeling that coursed through me was not too unlike what I had seen when I was six. This time, however, I felt very scared. Actually, I didn't feel scared so much as very very small – that something as ordinarily playful as light waves could render me humbled and so utterly speechless. It is something I sometimes feel when I spy a rainbow – I love rainbows and especially moreso for the glimpse into infinity they give to me. They are the honest manifestations of sunlight – "pure" white light stripped of any of its pretense and turned into the artist's palette of rich and equally pure colours. I have heard some people refer to rainbows as "pretty optical illusions" but I scoff at such dismissive definitions. Rainbows are as real as the strip of road reflected in the clouds above and as real as the infinite I first saw when I was six!

Process versus Product

I am forever amazed at the effort some people put into sculpting the perfect body, earning the perfect grade, drawing up elaborate plans for places or plotting the perfect revenge. What amazes me is not the sheer number of people who are embroiled in such endeavours but the fact that anyone is embroiled at all.

What I'm referring to is this silly idea of emphasizing the process of doing or becoming or emphasizing the final product. I say this is silly because the process of any worthwhile venture is the product and vice versa. Here's a common example of the silliness of splitting this entity: go into a grocery store (it doesn't matter which one or at what time of year). Invariably, you will find some rag expounding the latest "diet" which promises to "melt fat", "pep up your metabolism" or "fix your trouble spots". What do you notice about these "promises" apart from the fact that they're boldface lies – they're *products* which are being sold to you. In other words, a finished work of art can be yours if you buy the magazine and learn the latest diet secrets (eyes rolling upwards). They all talk about getting the perfect abs or the perfect hair for the holidays...all of them products and not a single shred of process. These rags don't tell you how to *keep* those perfect abs do they? Do they talk about what it is you really need to do to get into shape? To lose weight? To gain muscle mass? And, most importantly, do any of these rags tell you that it takes time and genuine effort – process – to acquire *and maintain* your goals?

We are so used to having instant solutions provided to us for free which require no effort that the very idea of process is alien to our collective psyche. We wake up one morning, conclude that we're hopelessly overweight and out of shape that we're going to do something about it...except that what we usually wind up doing is buying some super quick "zap that fat" *product* or load up on low-fat non-food and expect miracles to happen. When the miracle of "lose 25 pounds by next week" doesn't materialize, we become despondent, assume we ourselves are total failures and try the next "fad" – the next product...all without process.

Conversely, aimless action does nothing for us either. Take university, for instance. We can go through the motions of applying to university, choosing our courses, declaring our major and arguing endlessly with bookstore staff who can't seem to understand that textbooks are an integral part of university and that they really ought to stock them...but if all we do is undergo a process of doing school without having some plan as to what the goal or product will be then our efforts will be wasted. We'll wind up graduating with some kind of degree (maybe) and no goal for ourselves. What is it that we are trying to accomplish for ourselves anyway?

Again, we are so used to assuming that the application of a process is sufficient to meet our needs that we miss the point entirely – unless we know what our needs are, then no amount of effort will bring about the desired results. We need a goal and we need a method, or plan, in place to help us meet our goal.

This is why I find it amazing and utterly ridiculous that we would put a serious effort into focusing on one side of this entity at the expense of the other. We can't "get rid of unwanted lard" overnight simply by resorting to some quick "fix" method (none of them work and some of them are downright dangerous – I'm thinking of ephedra); nor can we accomplish our goals if we don't have a plan to bring our success about.

The solution as I see it is to reunite these sides of the one coin and actually really and fully understand that separating process from product is both pointless and unbalanced. If you want to lose any excess weight, the first thing you need to do is visit with your doctor and talk about what you want to do. The next step will be to sit down with a nutritionist and thoroughly analyze your eating habits. Then, devise a sensible plan of proper nutrition and proper and regular exercise and, most importantly, *stick to it!!* Here is the process described – the product will be a healthier weight, improved health overall and, most importantly, permanent changes.

As for those stuck on process only, you really need to sit down and write out what it is you actually want to accomplish. If you have a plan, check it over with someone who can better guide you along the way. In the university example above, go and visit with the guidance counsellor (they're not all mindless dolts) and talk about where you want to go. Then, the two of you can work out a solid plan of action. You not only have a plan, but a goal in mind.

Both of these corrective measures call for some self-examination. Perhaps you won't be able to lose 25 pounds by next week, but you won't care if you apply careful nutrition and exercise methods. The excess weight will come off, and probably as quickly as it was put on! Perhaps the potential physician would be better off taking an extra year of physics, biology and organic chemistry before tackling primate physiology and advanced zoology.

This is confrontation with ourselves in the highest form. In my own case, I had had dreams of helping others with some of their emotional challenges and obstacles to psychological growth, but those dreams included working full time (and full bore) as a counsellor. Those dreams were dashed when the diagnosis of MS came through and I now had to reorganize not just my ambitions but my very lifestyle. Thankfully, I am flexible enough and lucky enough, to do all this. For me, the process of living with (and working with) multiple sclerosis has resulted in a product – me!

The Value of Sleep

For the first time in a very long time, I actually got a really good night's sleep last night. How much of it was due to the antidepressants I can't know – but what I can say is that, whatever it is, it is resulting in my feeling ambitious enough to re-explore coping strategies.

Getting a good night's sleep is necessary for anyone but especially for those of us who are living with a major chronic illness, a good night's sleep is crucial for even the merest functioning. When I began to sink into a genuine depression, one of the first things I noticed was that it was becoming incredibly difficult to even get to sleep. It was quite typical for me to toss and turn for upwards of 5 hours after turning off the light before any sleep would set in and those 5 hours were usually spent ruminating and worrying about (insert a noun here). I would be lying there, trying to relax and keeping my eyes closed yet my heart would be thundering at breakneck speed and my mind would be whirling just as quickly. Then, after about 3-6 hours of restless sleep, my eyes would pop wide open and I would drag my exhausted butt out of bed to begin yet another day. This is no way to be!

As a dull intellectual type, I tend to prepare myself for any undertaking by reading as much as I can about the subject matter and charging full bore into it!

...but not this time...at least...not quite...

Instead, I have tried to surrender control of things somewhat. You might think that would be dangerous given how depressed people already tend to believe that they have no control over life (external locus of control) – but this feels different, actually. I'm not talking about some wave-like epiphany. In fact, I can't really describe what it feels like – except that it feels like a good night's sleep for once. I had just finished reading *The Method of Zen* by (the late) Eugen Herrigel, author of *Zen in the Art of Archery*. Frankly, Herrigel's *Zen in the Art of Archery* was an "okay" book which didn't really speak to my heart; but it was a quick read and I zoomed through it anyway, translation errors and all (the original text was in German). But in *The Method of Zen*, Herrigel makes a bit more sense, I thought, and the chapter on breathing really helped me tremendously. The technique of proper breathing is really quite simple – breathe deeply into all of your lungs (not just the upper portion) and then exhale firmly and fairly rapidly. There were dire warnings that "dozing off" was likely, but this is what I wanted to accomplish! Still, skeptic that I am, I remained unconvinced that a simple breathing technique would allow my body and, more importantly, my mind to relax. But, I figured it wouldn't hurt and so gave it a try. Lo! It was not long before I must have drifted into sleep – I saw 11:30 pm go by but not 1:30 am which is more typical for me in my state! I awoke this morning at 6:30 am and, though this is typical for me, felt quite refreshed. I lay in bed for a little while longer before getting up to take care of the sundry things, like feeding the cat and putting the kettle on.

But, it was more than that. I felt renewed and quite invigorated and, gasp, significantly happier than I had felt in a few months. Hell, I didn't even feel guilty for jettisoning a lot of dysfunctional relationships (qv most of this book). I am slowly (but steadily) feeling able to better cope with the difficulties that friends (I still have some) present to me, but here is a crucial point to make; *the fact that I feel more able does not mean I am fully able*. I am still finding myself turning more inward but it is what I am finding there that fills me with hope and that alone will go far in helping me get another good night's sleep!!

Empty your Cup

There is a story told in Zen in which a well-educated man claims that he is seeking enlightenment. This man goes to a Zen Master and describes what it is he seeks but it is not long before the Master has discerned that this man does not really wish to be enlightened. Instead, what this man truly wants is simply to pass on his own egocentric and pompous thoughts and opinions on Zen Buddhism. Eventually, the Master invites this well-educated man to tea and while pouring the man a cup of tea allows the cup to overflow and to spill everywhere. When the man points out to the Master that his tea cup is overflowing with tea, the Master replies that it is the man himself who is overflowing. He then asks the man how it is possible to seek enlightenment when his cup is already overfull of his own thoughts and opinions.

It's a simple parable, but the point is well made in its simplicity – how can we even begin to travel the path to enlightenment when our own “cups” are overfull? In other words, to even begin the path to enlightenment, we need to empty our cups. This is precisely what happened to me in the summer of 2003.

I am ordinarily a very cheery and upbeat person. I much prefer to laugh at the sheer absurdity of life than to sigh and weep. I deal with events by writing, drawing silly cartoons and, when life gets too heavy, do a serious fast paced walk or light jog. I especially enjoy jogging because I get that runner's high – that charming cascade of endorphins that leaves me with a calm and even mindset. But, this summer, with my MS relapse, I was not able to go for a run. Walking was a struggle enough even though I was able to do it only slowly. When I had recovered sufficiently that I could walk at close to my usual pace, I had learned that a young 27 year old woman had disappeared from one of the NCC bike paths. Her body was found a few days later. Frankly, those facts alone left me with a perpetually creepy feeling and so I wound up abandoning my daily runs. Even now, I generally don't walk while wearing my walkman; I am looking behind me a bit more often and I stay where there are other people.

...my cup begins to drain as my own sense of what is important, that is, my abilities changes...

As it was the left side of my body which was experiencing difficulties, and I am left-handed, drawing cartoons would have to be put on hold also. Word-processing became a fairly arduous task.

...my cup continues to drain...

Once I was able to walk without assistance (even if that meant taking more breaks to re-energize my batteries) I found that it didn't help my sinking spirits. Finally, the demands placed on me by others finished off what little was left in my cup.

...my cup is nearly empty...

I should point out that the emptying of one's cup (assumptions, desires, aspirations, opinions, abilities and talents) is indiscriminate. You don't always get to choose what gets jettisoned from your soul. My ability to play music, to draw pictures, to write stories and to take my children out to the museum or library came to a halt. The reason nobody else was there to help me, is because they couldn't help me.

...besides, it is my job to help me, not anyone else's!

Recognizing this as a necessary situation, I kicked my cup over (with my good leg) so that the very last of things could drain completely. As scary as that may sound, it's really not. In fact, it's a

good thing because I can now choose what goes back into my cup. So, with my cup nearly dry, I am choosing to fill it once again with life-affirming influences and experiences.

My relationship with Adam, which was always wonderful, has improved that much more. The necessary limits I have had to impose on the behaviour of others are actually quite effective. The fact that I am screening phone calls and not returning ones from life-drainers is also working. I have always said that 2003 would be the year for me – I had no idea how right I would be! But, there are times when I wonder if I am doing the right thing, for the right reasons and in the right way. I am quite certain that I am doing the right thing, or, rather, that the right thing is being done through me. I am also certain that I am doing the right thing for the right reasons; to purge all that binds, drags down and stunts but I sometimes wonder if I am doing the right thing in the right way.

Is it a good thing, I ask, to get rid of absolutely everything that defines me? I appear to be cleaning out my personal attic, cobwebs (that is outmoded thinking and relating styles) and all but is it necessary to incinerate everything there just because a few items are useless to have? If I don't like the way the bathroom looks, do I torch the whole house? The answer there is a firm "no" – I don't destroy the whole place, I simply clean up. I allow my cup to be emptied and there is nothing quite as empowering as tipping over your own overfull cup. It is the most life-affirming thing I can ever do, perhaps even more than sex, though not by much!

Now, the choice is mine what I put back into my cup, but with the wisdom of my years (all 40 of them), my experience and my education, I can make much better choices. I am not as bound by a shaky and insecure self-esteem as I had been when I was much younger. The void is not so much a vacuum as a potential and I still call the shots. I think every 40 year old should tip over her or his own cup; it's a wonderful feeling.

“You need a television”

This was something my mother insisted I needed when I spoke with her from my bed during my first MS episode back in '99.

“You can watch teleplays while you're recovering.”

“But mom...” I replied, “I don't like television and I don't want a tv. They turn your brain to mush...”

“Nonsense. You can get news and other information from the television.”

My mother, the master of irrelevant remarks, had completely missed my point. I could have argued that what is on the screen is completely irrelevant to the mere existence of the screen itself. Whether I am watching John Cleese play Petruchio in a teleplay of Shakespeare's *The Taming of the Shrew* or Peter Mansbridge giving us a detailed tally of the day's carnage with all the feeling and compassion of your average ice cube, the effect is the same: it's painful on the eyes.

I've never really liked television. There never seemed to be anything worth stopping whatever it was that I was doing just to watch it for very long. Oh, sure, I watched my fair share of *Gilligan's Island* or *Get Smart* but I could never really “get” television. This isn't just intellectual snobbery on my part either, even though I much prefer science books (my mother rolls her eyes audibly at this) to *Spongebob SquarePants*. It's simply that television hurts my eyes to watch for too long, meaning, more than an hour is what I can take before I simply must go and do something else.

Yet, in early June of 2003, my neurologist had sent me for an evoked potentials test. This is a series of tests in which the speed of neurological impulses is measured. At least, this is what they tell you. What they don't tell you is what's actually involved!

An evoked potentials test involves mostly being covered with thick, gelatinous goop where one end of the spaghetti of wires and probes will be attached to you and that the glop itself won't wash out of your hair in under a dozen shampoos. By the time I had been “prepared” (that is, having several metres of wires crazy glued to various body parts which, themselves, had been lovingly prepared with a small sharp instrument) I resembled the inside of a motherboard that was bleeding in certain spots behind my knees. I can recall wearing only a little hospital gown (standard fare for humiliating patients), carrying my clothes and my bicycle helmet in one hand and this cluster of wires in the other and walking into a tiny little room (unaccompanied by any member of any clergy reading me my last rites) which contained a single chair (the electric chair, I jokingly mused but not out loud – technicians can be so sensitive) and several chunks of equipment that looked as though they had been stolen from the Science Centre just north of Toronto and would be returned soon.

Okay, the 13 milliamps the technician zapped through my wrists and ankles (one at a time, of course) was only mildly painful...but it was the visual test that reminded me of why I didn't want a television.

“Okay, I'm going to have an image on the screen and there will be a target in the centre. Your job is to cover one eye and, with the other eye, stare at the target. Don't move anything else, okay?” said the technician. The good patient that I was that day, I complied. Then, he switched on the screen.

The screen consisted of a checkerboard pattern of black and white squares of equal size that alternated their colour at a particular sequence while the target itself consisted of two concentric circles fixed at the centre. If all I had to do was keep my (in this case) left eye on the target, then I figured that it wouldn't be too awful...I was wrong. It wasn't long before the target began to blur around the edges. After the next thirty seconds of this nightmare I wanted to scream. True, it was boring, though it wasn't supposed to be exciting, but I found that it was hurting my eyes just to watch, and I still had my right eye to go! Ack! Then, to make matters more interesting, the technician decided to change the size of those damnable squares and so I had to, essentially, repeat the whole thing. Although he did say that if I absolutely had to stop I just had to call out, I didn't do that for two reasons; I'm a big girl and can handle this exceedingly irritating but otherwise painless test and, more importantly, I would have to do it all over again if I said a single word. So, I held my own and survived the visual test. The blinking squares would have amused the cat but at least she would have had the choice to look away. I didn't!

I don't know what loony dreams up these sorts of tests. I understand their purpose – but do they have to include blindingly awful tests like the visual test? This is why I hate television. I'm no philistine – I enjoy all manner of art and culture and all things visual...I just can't tolerate television because there is excruciatingly little that could be called "cultural" or "artistic". Even working on this computer, upon which I am typing this essay, I find that I'm good for about an hour, after which I simply have to get up and do something else or else I go bananas...and that's the last thing I need!

The futility/utility of Categories

Throughout my day to day activities, and especially having worked as a counsellor, I have found that there are far too many divisions between groups of people. Most of the time, these divisions are arbitrary and chock full of value statements about the group we're in and the groups "they're" in. This is known in psychology as "in-group out-group bias" and we are all quite guilty of partaking in this tendency. Well, this essay promises/threatens to do just that...placing some people in one group and others in a different group. But, before I do that, I will explore the reasons why we categorize in the first place.

The simple reason we categorize everything in our environment is so that we can predict things. If I say the word "tree", I can predict with certainty that it won't pull out a gun and shoot me – whereas the word "soldier" will conjure up a different image altogether. Making predictions isn't merely some sort of intellectual exercise. We predict things so that we can behave accordingly. So, we can predict that if we make a running jump at a tree, it won't shoot us, whereas a soldier probably will. Categorization of objects in our environment can mean the difference between life and death.

On a more mundane level, categorizing objects can allow us to not just make assumptions about said object but can, in a darker sense, maintain any incorrect assumptions we make. We tend to do this around people whom we have summarily excluded from our own "in group". Many groups of men may conclude that women are illogical and overly emotional and so will make sure that women are excluded from doing things that "guys" do. I'm thinking about the woman who will be overlooked for any overseas military posting in a combat zone, regardless of her qualifications, solely because she's a woman and would simply break down emotionally and cry every time someone got killed. Some women may just do that, but some men may do that, too. Thus, the dissolution of these "us versus them" categories based on erroneous assumptions often results in social disarray (some would even argue, social breakdown!). I can think of my time as a student pilot. See, women don't command aircraft, even light aircraft; that's a man's job, a "guy thing" and the existence of a woman as a pilot will surely draw (unwanted) attention. My very position as a student pilot who was also a woman was a complete violation of expectation. People could no longer predict the socially approved conclusion that men and men alone could ever have the cognitive where-with-all to fly a plane; nor could they ever predict whether any so-called "pilot" talk would be offensive to me. Again, some women can fly planes while some men cannot but the point is that the criteria for inclusion in a group (and, ergo, exclusion from another group) is a purely arbitrary one. Religious tyrants would argue that the separation of the sexes is some sort of divine order and that humanity would be out of bounds to even challenge it, let alone successfully.

So that, in a very tiny nutshell, is why we tend to categorize objects in our world. But, we also tend to ascribe a certain value to the categories we create. Take sexual orientation as an example. The term "heterosexual" has as a value some sense of "normal" or "good" whereas the term "homosexual" directly implies the opposite (Alan Watts would be so proud of me!). If heterosexuals are "normal" or "good", then homosexuals must be "abnormal" and "bad". Since we are trained from birth (or sooner) to shun all that is "abnormal" or "bad" then we wind up avoiding anyone who is homosexual, even though the only difference between a homosexual and a heterosexual is that the homosexual is attracted to persons of the same sex. A homosexual won't try to "convert" others to "their lifestyle" either. This is a ridiculous thought and one borne of ignorance and intolerance. You couldn't "convert" anyone from one sexual orientation to another any more than you could "convert" a Black man to an Oriental man. But, because we place value judgements on criteria for categorization, we seem to feel the need to deify our own group and vilify "the other" group.

Don't get me wrong – categories are a useful way of making sense of our world and of allowing us to make some predictions about cause and effect (the tree/soldier example I gave is a good one); but it is in making judgements that concerns me.

I know a number of people whose lives have been touched by chronic illness (not just MS but diabetes to name one) and they have experienced some less than helpful events when dealing with many of the so-called “disease organizations” who all claim to be desirous of helping those who have the disease in question. Too often, these well-meaning sorts merely dispense useless advice. They genuinely believe that they are being helpful but too many of them are not! The reality is that such cursory advice amounts to nothing more than insults to the intelligence of the person who is living with the “disease” in question. Many of us wind up asking ourselves if these administrators think we're so cognitively impaired that we couldn't possibly know the most basic of information? As if we don't have doctors who tell us about what we have, or that we know how to look up information ourselves? The problem here lies along two distinct dimensions: firstly, that almost nobody who works at these “disease of the day” societies actually has the illness itself, an important distinction in having a better idea of how best to deliver services to those of us who are living with an illness. Secondly, these are the same people whose behaviour tends to reflect the socially prescribed value that people with the illness are necessarily and only ever “sick” (read: helpless and unreliable) and who are deserving of pity at best, but nothing more and often lots less! Here we are categorizing “us” as the “healthy helpers of these poor unfortunate victims of this (enter dramatics here) terrible and awful disease” and “them” as “those poor sick people who can never have a real life ever again (enter a ‘sympathetic’ sigh or three here for the camera) and who desperately need our help.” This is pure melodrama, but it makes it a lot easier for us to predict things if we can both pigeonhole people and actually construct those pigeonholes in the first place.

Is there a use for categories? In a word, yes. We categorize ourselves in many ways. For example, I'm a woman and I'm in my 40s so I place myself in the category of “female” and “between the ages of 40 and 50”; but I do much more. I categorize myself as “adult”, “owner of a cat” and “enjoys baking bread”. This is a very simple example but it does help me whenever I try to define myself in any meaningful way. If I own a cat, it stands to reason that some of my behaviours will include taking the cat to the veterinarian periodically. If I still bake bread, then I will likely buy a lot more flour than someone who doesn't bake as much. So, these behaviours I demonstrate are manifestations of my own self-schema, in much the same way that my buying flour and taking the cat to the vet annually are also manifestations of the categories I occupy.

So, categorization is a fundamental tendency of people though it is a dangerous one at that if only because of the values we place on categories. Should we assume that all men are “Male Chauvinist Pigs” and that a woman who demonstrates sexism is only being “assertive”? Is it fair to presume that a young, Black male is a drug pusher and high school dropout just because he's Black? Is it right to assume that a person who has a major chronic illness like multiple sclerosis is this helpless wretch of a creature who needs the heroic assistance of a society whose organizers don't even know anyone who has the illness itself? Does “disability” mean the same thing as “inability”? Does this sound like the best way to utilize our very real human tendency to categorize things in our environment? I think not!

Self possession and self obsession

The two terms are often used interchangeably but that is as much an error as equating childlike with childish.

By self-possession, I refer to that person who displays a degree of confidence and comfort in one's own skin. The self-possessed person seeks and generally finds reassurance and self-esteem from within and is satisfied with the answer he or she finds there. The self-possessed person has high yet realistic standards for her or himself yet recognizes that there are some days when meeting those standards comes more easily than others. The self-possessed person can readily apologize to another for any harm done with the knowledge that his or her own self-respect will remain intact. The self-possessed person does not seek to dominate a situation nor to shy from opportunities to contribute. The self-possessed person understands that the true value in all of living lies within the process of living and not the product because they're one and the same. The self-possessed person lives each day to its fullest while ever mindful that she or he had a past and has a future but that the past cannot be changed and the future cannot be known. The self-possessed person knows that the only real certainty is the present moment and not only lives there fully but takes full responsibility for being there in the first place.

By contrast, the self-obsessed person is the one who is always uncertain about anything and everything and exudes that uncertainty in many ways. These range from self-destructive habits such as drinking alcoholically or eating very poorly, to ensuring that one always fails at every endeavour. The self-obsessed person is the one with the eating disorder, who systematically starves him or herself (usually herself) out of some feigned sense of disinterest. Delving a bit deeper, though, the eating-disordered person genuinely feels entitled to be loved but can only seem to gain that love and attention by frightening others. Sometimes, the eating disordered self-obsessed person simply makes sure that she or he does not turn out like everyone else, as if life were really about how one *doesn't* want to be. The self-obsessed is the one who uses "moods" to gain compliance; to wrest absolute control over a situation aggressively. Generally, these are the people who have tried over and over to make themselves heard and understood, only to have their words fall on the deaf ears of the other self-obsessed caretakers, colleagues or friends.

On seeking Irrationality

The Macmillan Contemporary Dictionary we have defines “rational” as, “1. *conformable to reason...*3. *endowed with the ability to reason...*4. *of, relating to, or based on reason...*”, the word “reason” as, “3. *power or faculty to think logically...*” and the word “irrational” as, essentially, absurd or devoid of reason. Generally, we are told to behave rationally and to use logic and reasonableness in our thinking and acting; but I don’t always believe that to be the best case. I especially don’t see the place for rationality in realms of spirituality. In fact, I don’t think that spirituality is actually rational at all; I think it’s irrational.

Spirituality has historically been a divisive feature of human existence. In most “modern” (meaning anything younger than about 2000 years) religions, there is the physical, corporeal human dimension to existence and the ethereal, distinctly non-corporeal and very non-human dimension to existence and never the twain shall meet except in only very exceptional circumstances (like being in a grocery store lineup that actually moves). These are the religions that insist on splitting the universe into the here and now and the not here and not now (or at least not yet), where we occupy the earthly realm and where some deity occupies the spiritual realm “up there”. We are lead to believe that the ideal goal is to gain acceptance and entrance to this “heavenly” domain and that the only way to do that is to suffer horribly here on Earth so that we are duly rewarded in much the same way that eating our boiled liver and turnip souffle surprise will net us the piece of chocolate cake we really want.

Yuk!

This “thinking” came from the opportunistic power mongers in the ancient world. These men (yes, they were all men) did everything they could to devalue women and in the most amazing ways, too. Women bled monthly and so were “unclean” and to be shunned. Women were the temptresses, consumed by demonic forces which they themselves somehow managed to invite, who would as easily ensnare any unwitting man from his religious studies as cause him to have uncontrollable erections as a result. We’re an evil lot we are, and we soon became equated with all matters earthly. Women represented life, yes, but we also represented death, decay, blood and all manner of bodily and, thus “ikky” things. Men, on the other hand, were equated with all matters spiritual, of higher order and of that which is desirable. Even the very word “evil” sounds much like the name “Eve” who was presumably the one who had tempted Adam and had got humanity kicked out of paradise – he could have listened to Nancy Reagan and said “no” but didn’t.

Thus, through a profoundly complex set of thought patterns, assumptions and conclusions, men became the ones with all the power. God is almost always depicted as an old man (God the father – right?), only men can become priests or rabbis and, socially, men occupy the vast majority of positions of power. Even Aristotle had argued that women were incapable of reason because we are “biologically inferior”; that our brains are constructed so totally differently from men that we are, thus, illogical and irrational. Today, our language is replete with references to women being the “weaker sex” or the “fairer sex”...

I shall try to present my argument:

Premise 1. rational thinking is a human invention

Premise 2. rational thought is only possible in men, according to Aristotle and many others

Sub-conclusion: only men are humans

Premise 3. “human” means having a body which can die and decompose

Premise 4. all matters bodily are seen as of the realm of women

Premise 5. bodily matters are not spiritual matters

Premise 6. spiritual attainment is desirous

Premise 7. the spiritual realm is the male preserve

Sub-conclusion: women have no true access to the spiritual realm because theirs is the earthly realm

Sub-conclusion: men have no true access to the spiritual realm either because they're human

But, if we take the first sub-conclusion to be correct (which it isn't, but let's pretend here), then the second sub-conclusion is only partially correct because if "human" = "earthly" and if "earthly" does not equal "spiritual" and if "men" = "human" then nobody would have access to the spiritual realm.

Alan Watts (1915-1973) argued that the existence of one implies its direct opposite. If that were true, then the existence of rational thought, as invented by bodily (of this flesh and blood born) men must mean that the spiritual realm, being the presumed opposite of the earthly one, must be irrational.

Many others would argue similarly, stating that if women are the "opposite" of men, and if men are rational, then women must be irrational – which makes women the perfect brand of being to occupy the divine realm where everything there is ostensibly just as irrational because it was not human made. The divine realm preexisted all and never really came into being, or so the story goes.

By refusing to discourse in any logical, or, rational argument over the value of or even the existence (or not) of any deity, I have rejected rational thinking and, consequently, my place in a society that purports to value rational thought. By being a woman, I am, according to Aristotle, incapable of reasoning logically and rationally because I am biologically inferior; yet it is the very biologically constructed men who invented rational thinking in the first place. And since mainstream religions seek to divide the blessed from the damned, the white from black, the right from wrong, the women from men, the earthly from the spiritual and the rational from irrational, then rationality being a human invention must be an earthly one. We are left to conclude, therefore, that if these premises are correct, then the spiritual realm must be governed by irrationality.

Yet, so many of us seek some kind of (re)connection to a spiritual "leader" or "guide"; so does this mean that there are scores of us who are desirous of abandoning rationality? Does this mean that we have to abandon rational thinking in order to meet our goal?

I don't doubt that there are several logical fallacies in my aforementioned argument and it is not my intention to necessarily present a perfect and watertight argument. Rather, my point is that I found myself fussing and fretting for a good long while over all this and I'm uncertain if that is a sign that my depression is lifting or not.

What's for supper?

Living for the moment...living in the moment...

We hear a great deal about living for the moment. The idea there is that the past is gone and the future is an unknown and so we should just kick up our heels and savour the immediate. Well, that's a really nice idea but that isn't usually how it all plays out.

Living for the moment, despite its implications, is really an excuse for not living responsibly. Rather, living for the moment is about the imposition of one's own ego wants onto a desired outcome which we can then salivate over. For example, I can save my money and then head out to the nearest coffee shop and indulge myself in the finest caramel something latte I can find. Then, after inhaling the delicious and intoxicating aroma, I can immerse myself in the second most sensuous wonder in all the universe. After all, I'm living for the moment – right? Well, perhaps, but it isn't really living responsibly, is it? Ignoring for the moment the reality that a lot of lattes are both fattening and not especially heart healthy (especially those really huge sized ones), the realization of my caffeine adventures is really only the culmination of having planned and imposed my own will onto a *desired* present. What I have really done is planned the present by living in the future – by making sure that my actions *will* result in a present (and a present) for myself. This is not true living by my definition and, though I used to fail often I do try to shun such plots and plans.

Living in the moment, by contrast, is the culmination of that which simply is. There is no imposition of ego onto a circumstance in order to bring about a desired outcome. I don't deprive myself of something I truly enjoy just so I can enjoy something else in some as-yet-to-be "present". Living in the moment means truly being in the present state. The present state is the real point of infinity, that forever moving, instant moment from which all paths radiate, all choices possible and all outcomes just as likely. The past is a finite realm which is unchangeable. The future is a product of what we do now and which will pass into the past.

Living in the moment means to truly experience yourself as both a being and a continually evolving manifestation of the universe itself. We are creatures of sense and sensuality. We can taste the most exquisite foods, listen to the most beautiful music (not always professionally composed) and smell the most ecstatic roses ever known. We can plan for these events to happen, such as listening to slender chimes while gargling Belgian chocolate in the rose garden and truly enjoy those times; but they aren't nearly as precious as the simple confluence of these elements purely as a matter of chance. The first is an example of living "for" the moment (in other words, our very activities are solely "for" the rewards of sensual bliss) whereas the second is an example of living "in" the moment (where we simply find ourselves surrounded by the sound of delicate chimes tinkling lightly in a breeze which carries with it the creamy scent of roses; our eyes closed quietly while tonguing the perfect latte truffle...). The (in)famous power outage of August, 2003 provides a perfect example of living "in" the moment.

Luckily (?) for us, the day was warm and clear when the lights flickered once...twice...and then simply went out. That was interesting itself but when it was certain that this was going to be a long blackout, we busied ourselves by preparing to have to "survive" without power. But, when the sun melted below the horizon and the first stars bled into view, I stopped whatever it was I was doing (mostly berating myself for trying to inject cold medicine into my leg and thinking it was a good idea – long and dumb story) and simply went outside. The moment (not to mention the view) was utterly breathtaking. I am an avid amateur astronomer and have been for over 30 years. So, the issue of dark skies and the preservation therein is a big one for me...but not on that night. Instead, the thick spine of the galaxy lay, sprawled out for everyone to enjoy if not to actually notice for the first time ever! I merely stood and let the sheer magic of the constellations and the brightly glowing Mars lift me up and move me into dimensions and realms I hadn't seen in a frightfully long time. Now, I compare that experience (the recollection of which still sends shivers of rapture up and down my spine) to the "activities" of packing up the telescope, inserting it strategically into the back seat of our truck so no damage is done to the delicate optics and

driving many kilometres just to find a similar kind of space. Oh, it can be done and I most thoroughly enjoy skywatching from our little spot but all of those activities, as laudable as they are, are simply me imposing my own desires to re-connect with the universe at a certain time of my own convenience so that I can “live for the moment”. The power outage of 14 August, 2003 brought the present moment to me.

Another example occurred a couple of weeks later. Adam and I had gone camping at Sandbanks Provincial Park, a wonderful little hideaway located south of Belleville, Ontario and about a three hour drive from our home in Ottawa. When we say “camping”, we’re not talking about some fifth-wheel or trailer or some such contrivance. We camp in a tent, our only source of cooking is a Coleman stove (and a fire pit, too, if there isn’t a ban in effect) and we bring our bicycles with us to go and explore the place. We’re fairly rugged people who are regularly dressed in MEC gear. (MEC stands for Mountain Equipment Co-op and the name says it all; it’s a store for wilderness activities and most of our wardrobe comes from there. What I like is that the clothes themselves are virtually indestructible!)

So, there we were, camping on the night that the planet Mars was at its closest approach to Earth since some 56,000 years or so. Adam awoke in the middle of the night partly because he had to go pee but also because that pumpkin coloured gem was so bright that its fiery light had penetrated his closed eyelids. He woke me up to show me Mars but I was too sleepy to get a really good look at it. I could not, therefore, live for the moment that local newspaper science journalists and other astronomers had been calling upon us to do. My moment was about getting back to blissful sleep before the reality of my own full bladder became too compelling. Within a few minutes, Adam was back in the tent and we were both back asleep.

The real joy of living in the moment came the next night, however, after Mars’ close approach and, presumably, after we had “missed” the show of a lifetime. We had gone to the beach well after sunset. We were both instantly and fully immersed in that thickening charcoal of imminent night. It was only by the grace of a small flashlight that we were able to find our way from the parking lot to the beach itself. It was damned cold, it being late August and all, it being dark and all, it being incredibly windy and all but we trickled onto the sandy beach where the southern skies were spread out for, it seemed, only we two to see and experience. Mars was still too low on the horizon to get a really good look at but that fact wasn’t important. What was important was the sheer immense beauty of the nighttime skies. Knowing the constellations (in the northern hemisphere) as well as I do, it was too easy to pick out Scorpius, Sagittarius and, yes, even Corona Australis. The summer triangle, consisting of three stars, Vega, Altair and Deneb in the constellations Lyra, Aquila and Cygnus respectively glowed unobtrusively, asking only that we enjoy their presence. But, it was a collection of stars known as “The Coathanger” (technically in Vulpecula but it’s close enough to Sagitta that the latter constellation is a better starting point to find this celestial treasure) that so enraptured us both. We, in our own individual ways, simply fused with this paradise. Yet, collectively, we were both in the same metaphysical time/space; ours was a shared experience but individually perceived. I was living in the moment, as presented to me. I assume Adam was, too, but I didn’t ask him.

I lowered the binoculars, gave them to Adam so that he could embrace the heavenly joys above, and looked around the beach itself. There, I felt a curious sense of not being of that place and time; that I had transcended both and was actually the flattened horizon. I was the tepid embers of the now not-so recent sunset glowing in the west, the chalky black environs, the blue-black but still sun-warmed sand between my toes, the fresh-bordering-on-bloody-cold wind and the hushing, undulating waters slapping against the pummeled beaches. Looking straight upwards was an exercise in both self-induced terror and sheer irresistibility. I not only felt the pained and passionate tapestry of the universe before me – I was that tapestry. In the blissfully mind-numbing moments I was there, I could actually hear the quiet coos of the galaxy slowly turning before me. For those precious and totally unforgettable moments, it didn’t matter that I had multiple sclerosis; the universe is a big place and such matters as MS are meaningless.

So, does this make the universe a heartless place? Not at all. The sheer grandiosity of the universe is a marked contrast to its gentle, laughing quietude. It was a blessed break from the life choking worries of whether my body would work tomorrow or not or of why I had to develop MS. Those are about clinging to a past one cannot change and a future one cannot predict, let alone affect in the ways we and our persistent egos would want. At that point in time, I was just there and living in the moment.

This brings up the curious question as to why such moments are too infrequently perceived let alone truly lived within. I can speculate on answers ranging from the quietly but completely ingrained idea that humanity is supposed to suffer but for a greater “future” reward all the way to the artificial noise we have both created and reinforced as a way of convincing us that we are really alive because it's scary to imagine otherwise. The real irony, of course, is that we can only really know we're alive if we stop long enough and quiet our hearts and minds long enough. The clatter and noise we have created is just that – noise.

Language!!!

I did it again! I caught myself saying that I love something (it think it was chocolate I was referring to). It's a rather disconcerting habit I have, and like everyone else I know, am aware of it even as I do it.

I'm talking about our rather unsavoury habit of misattributing our feelings, but I'm also referring to the ways in which we do it.

We're taught from an early age that we should love people and use things – but we're forever getting it backwards. We tend to love things and use people...sometimes to get those very things we claim to love. How did we get into this mess anyway? Language.

I'm very fond of languages and I believe that I'm pretty good at both acquiring and using this amazing tool to get my message across. However, I am also very much aware that this tool is also a weapon. They say "sticks and stones may break my bones but names will never hurt me..." but they're totally wrong! Names do hurt and we (mis)use language to hurt others. We can call someone a poo poo head and feel nothing about it but our intent is to hurt and if the recipient of such unkindness reacts in a pained way then we know we've succeeded. How frightening, I think!

So, what is the purpose of language anyway? Well, we use language in order to convey information to others but we also use language to transmit cultural values to others – including this unsettling value that it's okay to use people and love things. This is a marked contrast to the culturally espoused value that we should love people and use things. It's a shame that we only pay lip service to such laudable ideals while we really enact the very opposite. Could we be then called hypocrites? Is that a nice thing to say? Are we all like this? I could twist my brain into knots over this issue but I won't.

Baby's second word...

So, where does language begin? Well, technically, it begins before a child is born but let's fast forward a bit.

Spoken language is a highly complex neurological, developmental process which requires lots of stimulation and interaction between (let's say) parent and child. That's all very well and we rightly praise baby's first word, whether that word is "dada", "platypus", "nose" or "doggiedie*". Such joy and smiles from hard working parents, however, are short lived. For, it is not baby's first word that we should be thinking about...it is baby's *second* word that we ought to concern ourselves with.

Baby's second word is some strange utterance understood only initially by other babies but it's a word which you, the caregiver, will soon encounter. I didn't have the benefit of anyone else warning me about this second word, so take this pearl o'wisdom as a forewarning...baby's second word will be *kweeve* a variation of which is *kweegit*.

If you don't believe me, and some of you may not, then I invite you personally to take a small child into a store. It doesn't matter if it's a grocery store, a department store or a rubber recycling plant. For, within about 2 minutes, you will be treated to an endless series of the word *kweeve* as in, "Mom, Dad, *kweeve* this?" or "Mom, Dad, *kweegit* this?" It doesn't matter where you are. The child will yank the fire extinguisher off the wall, drag it to you and present it for your consideration. "Mom, *kweeve* this?" Still don't buy it? Well, let me tell you what I encountered...

I made the horrible mistake of taking all three of my wee ones into a grocery store. Now, I like to read labels carefully. I want to know what I'm putting into the grocery cart so I can make sure we all eat the healthiest food affordable. Generally, my kids were pretty good in grocery stores. I didn't take them to the store (or anywhere else for that matter) if it was close to a meal or a nap. Doing that would have been sheer madness and I wouldn't have fallen prey to such traps! Ha! Ha!

It didn't matter.

Matt and Rachael were both walking while Nicholas was only crawling, but as Nick talked early he played right along. There I was, trying to read a label on a box of cereal when both my older two began waving nearby items under my nose. The exchange looked something like this:

Matt (showing me a bag of frosted something or other): "Mom, *kweeve* this?"

Me (sounding rational and a little saccharin): "Not today."

Rachael (waving a bag of mints under my nose): "MommMMM *kweegit* this?"

Me: "Sorry sweetie pie – not this time."

Matt: "MommMM, *kweeve* this?"

Me: "No, Matt. I'm not here to buy candy, okay love?"

Rachael: "MommMMMmmmmmm, *kweegit* some of 'dis?"

Me: (growing exasperated) "I'm trying to read the labels here, guys. Okay?"

Nicholas (the baby who now had a bag of jujubes that Matt has given to him): "Mamamama keeeev?"

This went on for some time but I didn't react as doing so only reinforces whiny behaviour.

Finally, though, I had had enough and so I quietly escorted my children to the produce section of the store. Armed with cauliflower in one hand and broccoli in the other, I began my own rendition of *Kweeve* and *Kweegit*. I didn't let up once – I whined and pleaded and went on and on and on about how lovely the spinach looked and could we pleeeeeeeeeeeeeeease get some, huh? Pleeeeeeeeeeeeeeeeeeease? I waved green peppers under their noses and promised to throw a fit if we couldn't get any organic ones...

It worked, or so I thought! Not a single one of my kids so much as blinked during my performance and we were able to complete the shopping trip without further incident. After getting everyone and everything into the car, I turned the ignition and, within a minute, we were away. About thirty seconds into the drive home, my daughter, Rachael, courageously chimed in with a gritted-through-her-teeth,

"Mom! Donchu EVER talk like dat 'gain!"

"Ah..." I said, feeling smug in my strategy "...so you don't like being bugged while you're trying to do something? Well, now you know how I feel."

Grocery shopping is now just fine whenever my kids are with me. The kids are pretty much grown up now but I remember that day with a smile and more than a few laughs. Perhaps one day they will have children of their own. I'll show them this story. By the way, baby's third word is *kweego*.

**The more astute readers will quickly mention that "doggiedie" is not, technically, one word. But then, neither is "wanna" or "gimme" but they're often written as if they were a single word and babies will certainly express these covalently bonded words as one single utterance/concept. The German language works along those lines too.*

Neologisms

A neologism is the creation of a new word which becomes an accepted word in the language. For instance, “internet” was not a word thirty years ago but it’s an accepted word now. Neologisms colour our conversations daily. For example, in 1971, a conversation would not have included anyone saying that their document was nearly 200kb in size and that they could more easily send it through a dialup connection at 56k if they use a zip file program than if they merely tried to send it as is. Conversation back then just didn’t look like that, but it looks like that now and it’s thanks to neologisms.

But, neologisms have their dark side, too. Some people pass off what are merely cleverly combined words into some sort of utterance as a neologism. This is wrong. Not that long ago, I read an article written by someone who claimed to be a “humourcillator”. I’m guessing that this person was a facilitator of some sort who uses humour to make a point. Personally, I’ve never understood the purpose of combining words into a new word ostensibly to come across as being more authoritative on any given subject. I would never, for instance, refer to myself as a “jocularist” (someone who uses humour {jocularity} in some clever little way) or a “survivorialist” (someone who advocates or who has experienced surviving something or other) or even a “jokinator” (someone who uses humour for some purpose). These are the sorts of so-called neologisms that we could do without. Besides, a neologism is a new word which is generally accepted by society at large, and, sorry, but “humourcillator” or “jocularist” are two examples which are not recognized, let alone accepted.

That’s not to say that these terms are false or misrepresentational in any way. I simply object to the presumed air of authority which is implicit in these fancy non-words. Neologisms have their place, but business forms are not those places. Please don’t hand me airy fairy titles which sound self-aggrandizing and expect me to take them seriously. That’s not how the evolution of language works!

Breakfast cereal labels translated

Breakfast cereals come and go but they're all just variations on a single theme: sugary glop thinly disguised as nutrition. These cereals all claim to be "low in fat" and "part of a nutritious breakfast" to give you the impression that choosing this awful garbage is actually a good idea. It's not enough to know what isn't in that box of frosted bits of solidified corn syrup; you want to know what *is* in the foods you're eating. The manufacturer is counting on you being easily fooled by fancy labels so I offer this handy pocket dictionary for your next shopping venture.

"Low in fat" certainly means that; but it also means "high in sugar".

"Part of a nutritious breakfast" means that supplementing that bowl of sludgy goo with half a grapefruit (like the picture on the back of the box) is better for you than supplementing that bowl of sludgy goo with another bowl of sludgy goo. Of course, you could simply just have half a grapefruit but then, where would the sludgy goo come into it? Remember, too, that something that is a part of something else does not mean it's a good part, does it? Carbon monoxide is a "part of our atmosphere" but we don't want to inhale the stuff. Same goes for that cereal!

"Fortified with (insert some vitamin or mineral)" sounds good and I don't doubt it is good; but "fortified"? That kinda sounds as if we're waging some sort of battle against some unseen foe and that we need to be "fortified" with something. I can't imagine being able to rely on breakfast cereal to "fortify" myself against the enemy of idiot drivers who never signal their turns, Canada Post delivery people who deliver you your bills immediately but who cannot deliver an important form or letter in any timely manner. I mean, aren't nations "fortified" with bombs?

"A good source of protein" is, well, good. However, our diets generally provide us with sufficient protein throughout the day. Kwashiorkor is very rare in the western world. Also, something that is a good source of protein is also going to be a good source of carbohydrates and fat. Do we need to be told the painfully obvious? We might as well be told that the cereal is a good source of molecules. Wow.

"High in fibre" is something to strive for, certainly. However, many people equate "high in fibre" with "inedible" or "wallpaper paste" and so may not be inclined to consider the value of fibre. Many cereals aren't as high in fibre as you would think. Nutritionists tell us that we should be eating anywhere from 25-30 grams of fibre every day but many cereals only provide small amounts of fibre per serving, and nobody is pretending that Count Chocula is a high fibre cereal. Unless you're prepared to eat 6 to 8 bowls of high fibre cereal every day (which nobody is), then you'd better take a good look at just how much fibre a serving actually is. Good cereals contain anywhere from 3-5 grams of fibre.

"Contains oats" is also good, but if that same cereal also contains refined sugar, food dyes and any kind of marshmallow atrocities, then this term is pretty meaningless from a health perspective. If crack cocaine also contained oats, would it be a good idea to indulge? However, you can counter this by eating a bowl of oatmeal, which also contains oats.

As an aside, it is always a good idea to avoid the following types of cereals:

1. anything that features a cartoon character
2. anything that has marshmallow bits that are supposed to look like something else (they never do, especially once the milk is poured on it after which it becomes a mass of brightly coloured toxic waste)
3. anything that includes a free CD or plastic toy thingy
4. any reference to the latest blockbuster movie

5. anything you find on television commercials which include kids

Special note for you Rice Krispy fans – marshmallows notwithstanding, I have a problem with this cereal only because it is sold under the premise that it makes neat sounds when milk is poured on it. This isn't a good thing at all – the last time I checked, food was for eating, not for listening to. If your toast laughed each time you put jam on it you wouldn't touch it, would you? If your food is sold under any premise other than nutrition, you may want to reconsider buying it.

Conversely, look for and get the following:

1. anything that is unsweetened, unsalted or otherwise unrefined
2. anything that needs to be cooked on the stovetop
3. anything that looks like birdseed
4. anything that looks like (and probably tastes like) tree bark or particle board. Don't worry, you'll develop a taste for it and will consequently discover that frosted sugar things taste wretched. No, seriously, I mean it!
5. anything that features a picture of people in any kind of sporting activity (except golf or curling which really aren't sports anyway)

I realize that the above lists are incomplete and that there may be others whose opinions differ from mine. That's perfectly reasonable; we all have the right to an opinion, so any complaints about this essay (or any others) can be sent to your Member of Parliament. They need a good laugh now and again too!

The Divisive Nature of Language

The purpose of language is to convey information from the speaker to the listener. That's as simple a definition as I can conjure up at this point, but I would like to speak more on this subject because I think it is a very VERY important one!

Language conveys a lot about the nature of information also. We use language to incite, to excite, to inspire, to categorize items in our lives and to transmit cultural values from one person to the next. As much as we like to sanitize the whole thing by emphasizing that language is a tool, we can't ever forget that language is also a weapon. Who has not been hurt by the pointed-ness of certain words?

Sadly, language has been used as a weapon more than as a tool. Take the word "straight" for instance. As pertains to hair, geometry or carpentry, straight is either a descriptor (sometimes a maligned one when one is seeking curls) or a desired outcome to a mathematical equation or the construction of a deck in the back yard. Take the word "straight" and insert it into questions about one's sexual orientation and the message is quite different. When we say "straight" we are referring to a heterosexual person. Fair enough, I guess, but what does the word "straight" imply? Straight tends to imply something predictable from the start to the finish. A "straight" person can be assumed to follow a prescribed and unwavering course in love and all matters associated with love. This also tends to imply its opposite: that someone who isn't "straight" (read: homosexual) is not predictable and will follow a more meandering course throughout love-living et cetera. The category "straight" carries with it a whole motherload of cultural values that we would presumably wish to aspire to while inhibiting and, thus, de-valuing "not straight". Such ideas only serve to divide and, in the case of "straight" vis a vis sexuality, they're simply wrong!

Our egos are a strange and, sometimes, scary thing.

Recently, I have taken up meditation as a way of reorganizing my thoughts into something, uh, "straight" (here used in a nice way). I find that sitting or lying quite still and simply letting thoughts, ideas, concepts and notions drift into my mind reside there (perhaps smoulder a bit) and then drift away to be both relaxing and rejuvenating also. Sages of all kinds have described the value of simply meditating as a way of relaxing the mind, of relieving stress and of clearing the cluttered thoughts that so often seize the mind and prevent us from simply living. The mainstream society we live in would pooh pooh meditation as some bizarre wacky "new age" fad that is simply a way of evading the reality of modern living, conveniently ignoring the fact that meditation has been practiced for thousands of years. "If you simply let go of everything, you will feel nothing, and that can't be a good thing." is the argument often postulated. This is ego at work as it desperately tries to talk the mind out of letting go and of rendering the ego less powerful, if not unnecessary.

In reality, the opposite takes place. When we let go of everything we think we want (directed and driven by our egos, of course) then we will find ourselves feeling everything. That may sound scary but it really isn't all that frightening. By feeling everything through meditation, we aren't overwhelmed by the quantity and magnitude of emotion; rather, we are given to us the gift of feeling. So, what does this have to do with the divisive nature of language?

Language, as I've said, is a powerful tool but it is also a powerful weapon and, sadly, it is used more often in the latter configuration than the former. Our language soothes the ego by creating dualities, such as "I" versus "they", the implication being that whatever unsavoury qualities present in "they" don't apply to "I" because "I" am a distinct and separate entity. This is also not true. It's a defensive mechanism designed to protect our ego-selves from the harsh truth of our own unsavoury characteristics. Meditation takes care of that duality created and maintained by our culture and language.

It is a fairly good understanding that, in meditation, the breather, breath and breathed cease being three separate entities and merge into one essence. I'm not that advanced in my own journey yet. In fact, I can't really adequately describe where I am but I can say that I reject the idea of duality. The problem is that our language has no real words for this idea. Our language makes sure that we remain separate and apart from the world, rather than being a part of and wholly within the world.

Digital Limbs on an Analogue Frame

Before I can explain the rather strange title of this essay, I need to first define the terms in the title itself.

By “digital”, I am referring to that mathematical understanding of binary systems, where there are only two operating positions, on and/or off, 0 and/or 1. In digital systems, items are either turned completely on (1) or they’re completely off (0). You can’t have a lightbulb sort of lit or not. It is either shining or it is not. Anything other than one of those two operating positions is inherently unstable and, thus, not sustainable. Experience a “brown out”, when the lights in the house dim from their maximum wattage (output) and the result will be either a “black out” or a complete recovery.

Hell, even atoms can be said to operate in a digital manner. Electrons, negatively charged particles in orbit around the nucleus, stay in a given orbit unless there is an introduction of energy into the system. At that point, electrons may find themselves flung into higher orbits until the extra energy is gone at which point the electron will “decay” back into its original orbit. (The excess energy is often expunged in the form of a photon, but that’s not really relevant to this essay). In other words, the electrons are either orbiting in one valence shell or another, but not both and not neither and not sort of one or the other.

Genes, the Watson-Crick discovery that revolutionized biological sciences back in the 1950s, are said to be either turned on or off with the attendant results of blue eyes, curly hair or bipolar disorder. In all of these cases, we are describing a digital system of sorts. Things don’t happen unless something is turned on or off and molecular biology attempts to understand this reality and also control our environment by manipulating genes – that is, by manually switching particular genes off and/or on to produce a desired result.

Conversely, analogue systems live within the infinite region between “0” and “1”. For analogue systems, there is such a thing as “sort of” or “partly” or even “a bit”. The human body works in this manner, in spite of it consisting of uncountable digital atoms and digital chromosomes. The human body understands that an arm can be partly retracted or partly extended – that it need not be clamped as tightly against the side as is physically possible or else fully extended so that the elbow is hyperextended. This allows for simple, human finesse to produce great works of art, for pilots to make perfect landings in less than perfect conditions or even for climbing up those annoying little “chicken steps” in front of such grand buildings as government buildings, universities or museums; where these “steps” are two feet long but only a half inch tall – enough to trip the unwary but not enough to be taken seriously!

I mention this only because multiple sclerosis is often manifest in “temporarily” (I would hope) having digital limbs glued to an analogue frame. Specifically, I found that my left leg had only two operating positions – fully extended or else fully retracted. This made walking not so much impossible but very indelicate looking. Walking, I resembled Frankenstein’s Igor more than my usual self with the lion’s share of the task of mobility relegated to my right leg which would invariably drag my clumsy left leg along. It looked strange indeed and it was quite frustrating at times because ours is not a digital world. We have to be able to act with finesse, to know when to slap our feet on the ground like toddlers taking their first few tentative steps or when to tread lightly and delicately like ballerinas.

Oh, we recognize the differences in digital and analogue systems but we favour the latter and find the former bothersome at worst and intellectually interesting at best. At its worst, we discover that the lightswitch we are flicking furiously appears to be “off” in either position. At its best, we manage to generate huge numbers in a binary (digital) system to represent simple, base 10

(analogue) numbers. Below is a table of numbers from “0” to “10” in both base-10 analogue and in binary (base-2) digital format.

512	256	128	64	32	16	8	4	2	1	0	
0	0	0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	1	0	1
0	0	0	0	0	0	0	0	1	0	0	2
0	0	0	0	0	0	0	0	1	1	0	3
0	0	0	0	0	0	0	1	0	0	0	4
0	0	0	0	0	0	0	1	0	1	0	5
0	0	0	0	0	0	0	1	1	0	0	6
0	0	0	0	0	0	0	1	1	1	0	7
0	0	0	0	0	0	1	0	0	0	0	8
0	0	0	0	0	0	1	0	0	1	0	9
0	0	0	0	0	0	1	0	1	0	0	10

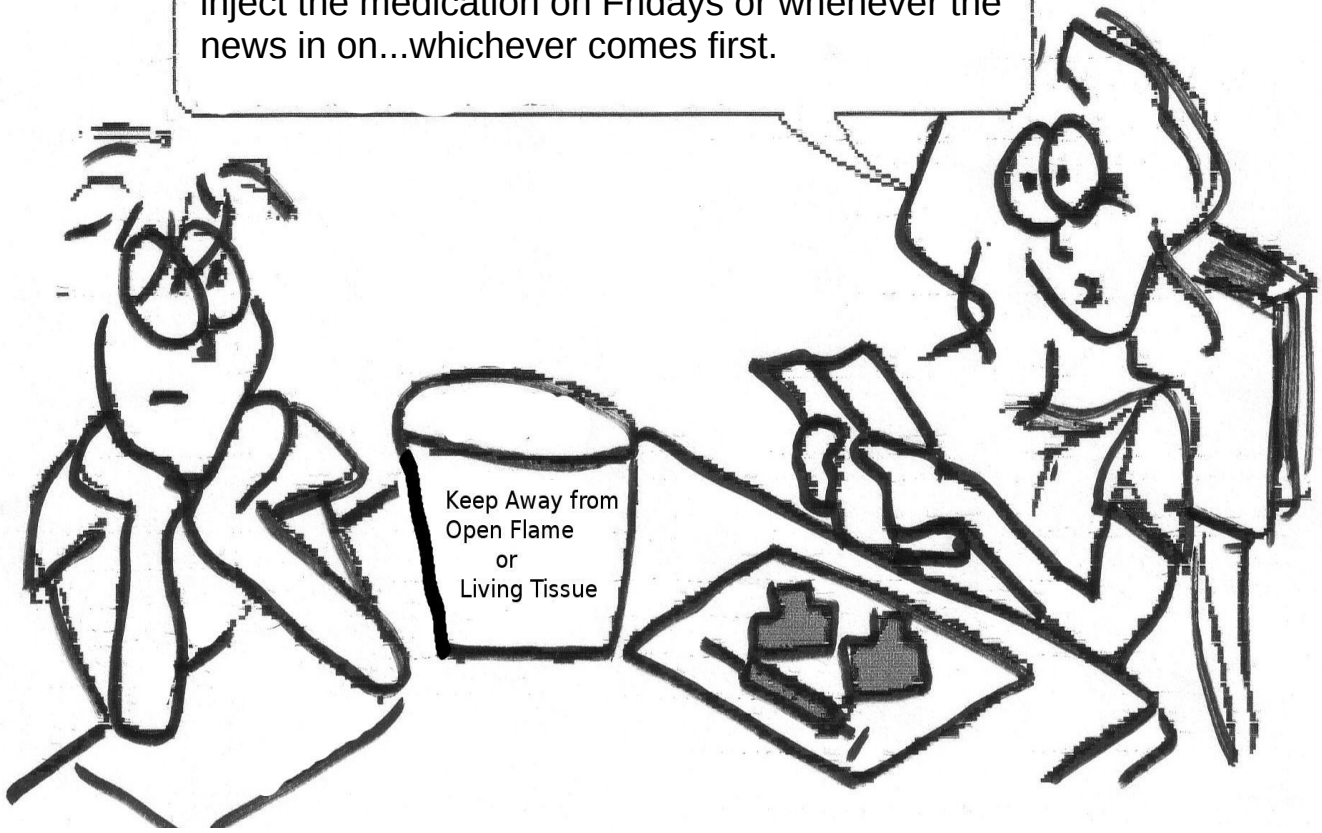
In the above table, the base 10 analogue number “6” would be written in base 2 digital math as “1100”. The digital number “10000” is analogue “8”. Can you see just how cumbersome writing “10000” is when a squiggly “8” would work just as well?

Metaphysics aside, my MS episode in the summer of 2003 and, indeed, like the one I had in 1999 involved my very limbs being cruelly reverted (if not perverted) from their usual analogue way into a more cumbersome digital way. My limb was either full out or full in with no compromise in between – the light switch was either off or on when “somewhere in between” was really what was called for.

The table above looks hopelessly complex, especially given the much simpler looking “base 2” mathematics involved. The reason the above table looks that complex is that ours is just not a base 2 binary world. This is what makes an MS episode especially frustrating – I have to try and work and live within a base 10, analogue world with my base 2 digital limbs.

Thankfully, I have pretty much healed from the unpleasantness of 2003, although I still experience some side-effects if I’ve walked for longer than 3 kilometres (that’s “110” digital for you and me) at my usual quick pace. Here is where I get the last laugh, however, as I now find myself walking at a more moderate pace, that is, not full out or full stop. This allows me to walk for a lot longer period of time without looking (too much) like Quasimodo or Igor. The irony is that by adopting an analogue perspective early on, I can avoid the digital features of this less-than-fun illness.

So, I have to keep this medication in the fridge or in the handy carrying case until sunset unless it's a full moon in which case I'll have to wear my glasses or yours if I don't have any and I have to inject the medication on Fridays or whenever the news is on...whichever comes first.



Okay, it wasn't really this complicated but it can be for some people who don't really understand why they have to keep this stuff in the fridge. You aren't supposed to inject this stuff cold because it'll hurt like hell if you do. No, really, it will!

Paradigm shift – no hemorrhages here!

By that, I mean that we need to redefine what is meant by “disability”. My own experiences with MS tend to reflect the unfortunate and quite incorrect conclusion that “disability” = “inability”. One of the more frustrating aspects of living with multiple sclerosis is that one isn’t always visibly disabled. As far as anyone can see of me, I look, act and move just like anyone else...but I still have MS and it periodically bubbles to the surface to play all sorts of cruel games with me. I have, as it were, a “non-visible” disability. One needs to watch me for a longer period of time to note my limits than were I in a wheelchair or using a cane or walker to get around.

At any other time, though, I’m just fine but at all times I prefer to be treated like anyone else would be. The problem there is that some others can’t quite seem to wrap their heads around the fact that having MS is not the same thing as *being* MS. Far too often, those of us with a disability are either treated like little children who are incapable of thinking independently or poor helpless victims who deserve tongue clicking sympathy, acres of pithy advice (since we’re too stupid to sort things out on our own) or else finger wagging “I told you so”s. This last bit perhaps a reflection of the too often made assumption that our own situation is a result of something we did wrong or didn’t do right .

The simple fact is that our society’s paradigm of “disabled” includes the implicit (and explicit) assumption that we are useless waifs, incapable of doing anything on our own. That may very well serve those “non-disabled” people who feel compelled to either assume a parental role or else launch into a dissertation on how we should move heaven and Earth to save us from our illness.

Save the dramatics for Hollywood – reality is a lot more mundane!

So, what’s the problem and what’s the solution? Well, the problem is simply that society works solely on the premise that citizens are full participants only...anything else and we become a burden. The solution is to change society so that we ourselves decide what we can and cannot do. Just because I have multiple sclerosis does not mean I am no longer a participant, nor does it mean that I am not a citizen with no rights. As I alluded to earlier in this essay, multiple sclerosis is something I have; it is not something I am. Please don’t treat me as a “sick” or “disabled” person. Yes, I have a disability but, right now, it isn’t too serious and I can do just fine at this point. If I trip, do not phone 911 and assume my brain is about to melt. If you do phone 911, then allow me the same privilege the next time you trip and I assume your brain is about to melt. Then, you can tell me how embarrassed and/or insulted you feel.

Please do not feel or feign any brand of pity or guilt. You didn’t cause me to develop MS nor do I particularly feel sorry for myself. True, MS provides many a challenge for me to adapt to, but I’m just as certain that everyone else will one day face illness, too. Also, pity is sometimes expressed by those people who only feign concern. What they really tend to feel is arrogant indifference; a variation of blaming the victim for his or her predicament. There is also a certain “thank God it isn’t *me* in that wheelchair” sentiment expressed in the, “How *do* you manage to get around like that? It must be so tough.”.

Finally, those of us with MS are many things but stupid isn’t one of them. Please do not treat me as though I were a total dolt. Telling me to, “stay out of the heat” presupposes that I don’t know this. But the simple truth is that, like almost everyone facing a major chronic illness, I make it a point to learn as much as I can about MS. So, the chances are very good that I already know to stay out of the heat. I’m surprised we aren’t then reminded to brush our teeth three times a day.

By learning as much as I can about MS, I also try to learn as much about the charlatanism that exists out there. Because MS often looks like anything (ie: extreme fatigue or periods of clumsiness – heavy gravity days as they are sometimes called), and because it follows a highly unpredictable course, there is a huge market for charlatans who will take advantage of some people's fears and uncertainties about their own lives. I'm thinking about those hucksters who insist that things like vitamin "D" deficiency is the cause of MS and that taking extra vitamin "D" is the cure.* We don't like the idea of illness because it scares us and reminds us of our own vulnerability and mortality. Even if we know that MS won't kill us, we don't like the idea of decline, of facing the possibility of a wheelchair for the rest of our lives. But it is here where the most important lesson of MS (or, indeed, of life in general) can be learned;

Live each and every single day to its absolute fullest. Reach out and grab life by the lapels; wear it, wrap yourself in it, live it and love it.

This is not to suggest that you could be stone dead in a moment; that's not the point at all nor does it mean that colliding with a tree on a slick cross-country ski trail should be the pinnacle of your day. The point is to see each day as a gift and to live it as well and as completely as you possibly can. Face it, I could very well wind up in a wheelchair next week, but not today.

But what about society in general? Well, human beings are social animals in much the same way that bees are. We collect under a single purpose, we build cities and communities and otherwise foster growth within. Perhaps what society needs to do is to shift its own paradigm from mindless buzzing to mindful growth. It would take a rather large amount of will but nothing too onerous I think.

So, what about some concrete examples of society's changing its paradigm. Well, there are some already such as making more and more places wheelchair accessible without making a huge fuss about it and many service organizations are created to help those whose lives are affected by major chronic illness. But, that alone is not sufficient; we need to staff service organizations with people who live with the very illnesses they purport to represent. I'm not just talking about a token "job" at the clinic or the local branch of the disease organization but a position of authority where insight and genuine understanding can help guide the policies and direction the association takes. Otherwise, employees of such organizations will only ever have an abstract understanding (at best) of the issues which people like me face each day.

This highlights a problem we humans tend to create when such ideals come to the surface – egomaniacs and other self-aggrandizing sorts sometimes wind up occupying positions of power. To the general public, these higher-ups often appear as sincere, dedicated individuals whose charitable inclinations know no bounds. But the façade is just that; a mask these un-knowing sorts wear when it's convenient for themselves but remove as soon as the coast is clear. These are the people who like a society in which only the able-bodied (such as they themselves) ever have a say or who have any power and who will suppress anyone who dares to question them or what they're doing. The reasons are many but they can generally be placed into one of two categories; either these self-promoting sorts are afraid of having their ignorance and general incompetencies discovered or else they are very frightened by the person with the illness because of the social description of disabled. This is what really needs to be changed and it is my intention to be a part of that social change!

**While there is some evidence to suggest that taking vitamin "D" can delay the onset of multiple sclerosis, it would be a fallacy to believe that this were the only factor to consider. MS is caused by many factors coming together in a certain way, from genetics to the timely exposure to childhood viral illnesses.*

More on Meditation

Much to my pleasure, my own daughter, Rachael decided to take up meditation. Coincidentally, her teacher and school counsellor have both informed me that her grades are going up and that she appears to be doing better overall. Wow!

So, what is meditation anyway? Well, I can't actually define it but I can say that it is becoming quite a lifesaving de-stressor for me, especially as I now must have liver enzyme checks done every three months due to the newly uncovered problems which may be present in those of us taking drugs to treat MS.

Ordinarily, I would have groaned and sighed in frustration, maybe cracked a few dark jokes about my lot in life and continue to feel helpless in my continuing journeys through the medical system. Instead, I actually find the whole thing rather amusing. This isn't me laughing indifferently at my own predicament; it is simply recognizing that no real predicament exists. Plus, the reality of having to have blood taken, ostensibly to monitor me, should my liver start to cause me problems, has not actually brought me any increased levels of disability or distress.

Actually, this is a perfect opportunity for me to put meditation into action. In meditation, I sit quietly and just allow thoughts to arise, linger and then drift away without clinging or overanalyzing them (this last bit is the hardest). So, I think (and feel) about things like liver enzyme tests, MS, my regular needles, the colour green, my totally moronic cat and then simply let them pass. The idea behind meditation is that we need not be held captive by our own thoughts, ideas, wishes and hopes; that we ourselves can (and do) create our reality, our universe. And, because we can create our universe, we can also change what it looks like. This introduces an extremely powerful force into our psyche; the power to choose what we feel and how we (re)act. It is said that life is an illusion but I like to think that life is quite real but that it is how we impose our own wishes and expectations that can (too) easily render life a journey of anguish and suffering. So, I am now finding that I can think about the issues pertaining to my life, like the MS, the meds, my liver, my brainless cat, or my daughter's having taken up meditation in a simple, almost detached way. That is not to say that I have no feelings; rather, my feelings do not have me!

The tooth, the whole tooth and nothing but the tooth

It couldn't have happened at a worse time. Well, I suppose it could have, but that's not what I thought at the time. It was very late 2002 and I was mid-way through my final year at university. I had a final exam for a half-credit course I was taking, a mid-term exam for another course, assignments due and was having a fairly busy life in general. I didn't have time for my adventures at breakfast.

I was sitting down to enjoy an english muffin and a cup of (lethal) java. Nothing too strange or weird. That's when it happened. I bit down into the slightly untoasted english muffin and, after a second or two, felt something like a little tiny pebble rolling around inside my mouth. Knowing that english muffins (untoasted or otherwise) didn't contain pebbles, I investigated and...ack... discovered a quarter of a molar. There was no pain, no bleeding, nothing untoward except this quarter molar.

A few phone calls later, I got myself an "emergency" appointment with a nearby dentist. He looked inside and, after some necessary probing and checking, declared that I would need a root canal procedure in order to be able to build up the tooth.

"But, I have exams, assignments..." I began to protest wanly "...we're supposed to go x-c skiing in January."

"Don't worry," the dentist reassured me "you'll be just fine."

What transpired over the next few weeks was a series of visits to the dentist and the endodontist. Going to a dentist never really bothered me that much. While I don't enjoy having needles dug into my mouth, the alternative is much worse and so did not mind having my jaw numbed five times (and several hundred dollars) over as many weeks.

Having root canal work done is nothing compared to all the hype and dire warnings (urban myths by now) about the procedure itself. I was seated in the endodontist's chair, appropriately numbed (the topical stuff was pina colada flavoured, so they told me) and then the dentist brought over a tray laden with a series of what looked like really nasty push pins. He began casually at first, and then more aggressively, to kill the tooth and prepare its hardened remains to accommodate what they called posts. At that point, they would be able to reconstruct a false tooth, wrap it in some shiny metal (mine is gold – I call it my gangster tooth) and send me on my merry way. Yet, mention the words "root canal" and people instantly have horror stories to tell about the near-death experience they had while the doctor accidentally injected anaesthetic into the wrong tooth or that they had to have their jaw broken first...in several places...and repaired with caulking... pina colada flavoured...or some such nonsense...and that their car won't start now or that they can no longer recognize their car...and had to take nine weeks off work to heal...all because of root canal.

Root canal work is inconvenient and I wished it hadn't happened during my last few months of school. I spent the better part of five weeks with one side of my face perpetually numb and only able to eat soft gooey things on the other side. Kissing Adam became an exercise in my constantly asking him if it felt nice for him because, I'm sorry, but I can't feel a thing. I wrote my final exam for my half-credit course with a numb jaw and I was sure I was drooling all over the exam booklet. But, it didn't stop me and Adam from enjoying a few days cross-country skiing in Val Morin, Quebec. As soon as I was proclaimed fit to eat crunchy things again, I bought an apple, but I haven't touched english muffins.

The Most Humbling Thing!

We're very good at feeling sorry for ourselves, aren't we? In these frantic and overly hectic times, we often find ourselves at the business end of one brand of frustration after another. Our inboxes on our desk are bulging with unfinished (and sometimes not even glanced at) projects, our ability to secure any kind of employment nets us nothing no matter how diligently we work at it, our cars won't work properly and can sometimes leave us stranded in the middle of nowhere where our cell phones won't work and where we quickly realize that we are going to be late... So, we either feel glum and sorry for our poor selves or we become frightfully indignant and overreact angrily. It's all someone else's fault but we have to solve the problems created by others...snort...

What we especially need at that point is a seriously good dose of humility; of that forced shift in our perspective that reminds us that while things may be tough, they're not nearly as tough as they could be. We recently re-discovered the perfect antidote to the "Woe is Me" off-Broadway production...doing our income taxes on paper.

It's a well understood fact that wading through any government form requires that you disconnect several lobes of your brain temporarily and assume nothing. Just pick up a pen and spend an entire afternoon just filling out the first page alone. However, the Canadian Income Tax package we got in the mail recently was the first warning that we are about to be made humbled. If we're going to feel sorry for ourselves because we missed the bus by a second and wound up eating bus exhaust just in time for the high flying seagull above us to jettison its load on our briefcase (the one we spent the better part of the previous evening scrubbing with the last of the expensive saddle soap that we'll never find again because it's been discontinued), then we'd best get it off our chests because the worst is yet to come!

I don't know who goes to bed at night and conjures up these arithmetic formulae that we continuously encounter on Canadian income tax forms but they're obviously sadistic little fiends who enjoy having the millions of Canadians who have to wade through all this paper twist their brains until they're wrung dry. Yet, there we were, Adam and I, sitting down at the table and armed with calculators, pencils, erasers and every possible piece of paper we could imagine needing. What should have been a simple half hour venture took over 5 hours. At one point, when the sweat was building up on our foreheads and smoke was emanating from our ears, Adam stood up to get something and exhaled, "I don't get all this, Ruth! You and I are very bright people but this is just SO hard!" All I could do was nod in quiet understanding, though I kept the smile to myself. I knew we would eventually sort everything out but it was having to be mentally up to the task that made it far too difficult for either of us.

Part of the problem is that in order to successfully complete one form, either of us needed a figure from the completed other form which could not be completed until the first one was. Joseph Heller wrote about this very dilemma in his famous novel *Catch-22* and we were mired in it. We kept our sense of humour but we also kept our wits about us, too. This is difficult to do when dealing with government forms because the only way to make it through to the part where it says, "sign here" is to disconnect your brain from the hand that writes in the various amounts. Neither of us is used to doing that. I still have it in my head that any serious writing involves as complete a mental connection to the task at hand as possible. Doing income taxes on paper is a complete contradiction to this truism.

We successfully waded through the whole pile of papers but, in the end, found ourselves to have been duly humbled.

...if negative, enter '0'...

...0...



Bladder infections as often as phone bills? I'm not kidding! Some of us will go to desperate lengths to secure a ready supply of antibiotics...until sense takes over and we then opt for the cheaper and less risky cranberry tablets!

Where are the Feelings?

I ask that question quite a bit with clients, especially those clients who have difficulty expressing their feelings verbally. “Where are your feelings? Point out to me where your feelings are?” I ask as a client describes a situation that is particularly painful and emotional and I invariably get responses ranging from the temples to the abdomen and sometimes both. From that point, we can extract other words to describe the previously indescribable. From the bodily sensation of tightness, we can re-label it as anxiety. From the bodily sensation of burning in the stomach, we can re-label it as terror. Regardless of words we use and in what manner, the point is that all feelings come from within ourselves.

We don't generally see it that way, however. For the most part, we are quick to place responsibility for our feelings squarely on persons or issues outside ourselves. This is incorrect, at best, and potentially quite dangerous at worst. We can hear someone mention that their partner is *the* “joy” in their lives. That all sounds beautiful, except that it places full and absolute responsibility for that person's feelings on their partners – and I'm betting that their partner is no more interested in “being” responsible for anyone else's feelings than they would be responsible for the phase of the moon. I know I wouldn't want that role thrust upon me!

In some other cases, we may ascribe our own despondence to the mundane realities of a dull job; but who's responsible for concluding that the job is dull in the first place? Who is responsible for making any given job uniquely their own? Who is responsible for one's feelings? To all of these questions, the answer lies squarely with ourselves.

We are each fully and completely responsible for our own feelings. That's not to say that others don't have any influence just that they don't have any power we haven't given to them, and that's where we flop as emotional guardians. We have carefully managed to rid ourselves of any responsibility for our own feelings. We either blame other people or circumstances for our entire emotional mindset or else we assume responsibility for other people's feelings...
...but the effect is the same; we have refused to take ownership of our feelings.

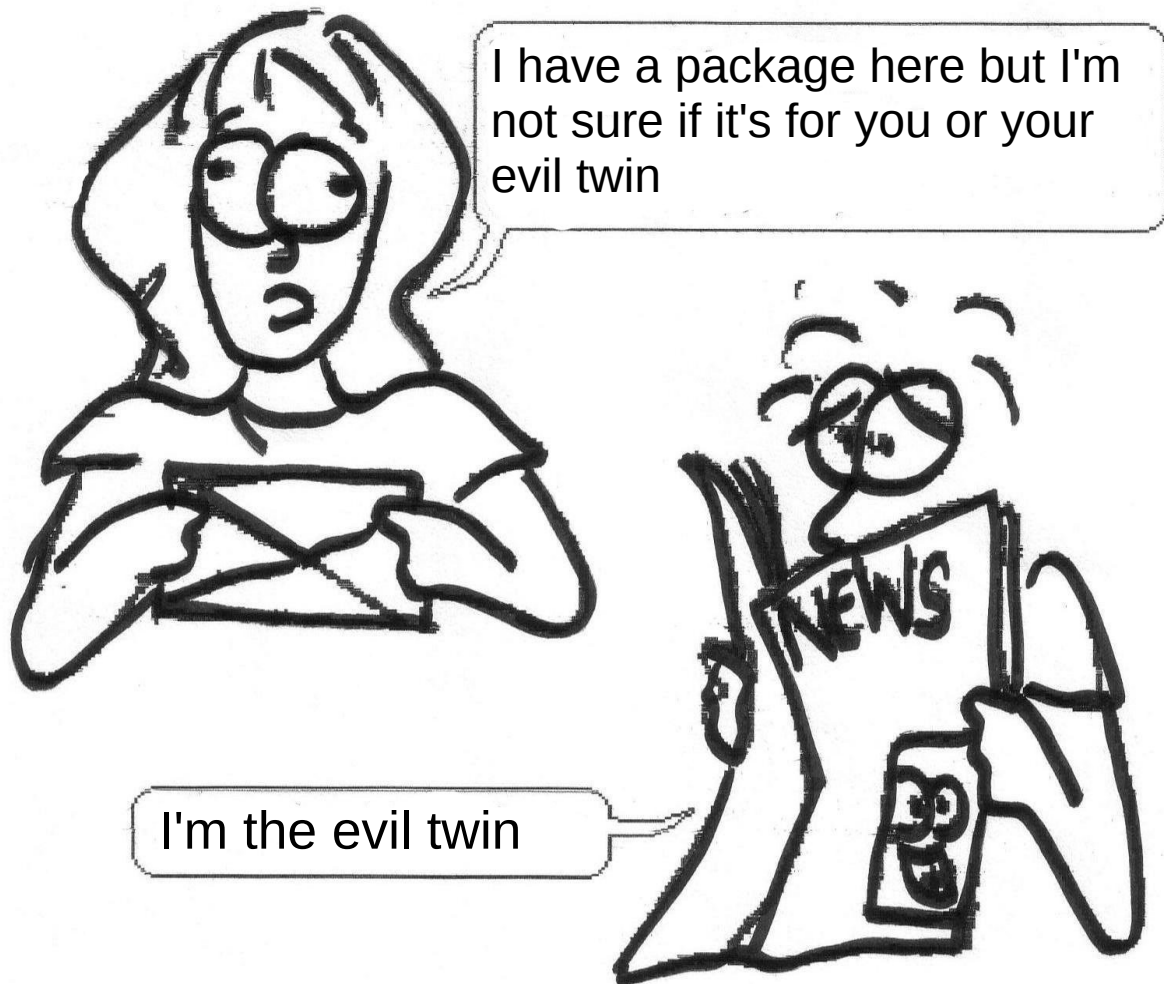
And by that, I'm referring to all feelings, positive or negative. Even joy, for instance, is a pretty heavy burden to place on the shoulders of someone else because that means that the “someone else” had better continue to bring you joy. Otherwise, upheaval and misery will be the outcome and the person will blame the disappointing partner/parent/child/friend. Would anyone want that kind of responsibility? Could I accept full responsibility for any joy I presumably am to my husband or to anyone else? How scary!!

When I took up meditation, one of the very first effects I noticed was an increasing sense of liberation from the self-made traps of taking far too much responsibility for other people's feelings. During the autumn of 2003, when my world unravelled due to a bad MS relapse, I was left naked, vulnerable and empty...and ready to receive some emotional nourishment. This time, however, the nourishment didn't come from an outside source – this time, it came from within myself. This wasn't as easy as it may sound. To completely divest myself from identifying my own sense of self-worth from the joy I could presumably bring to others, I had to actually turn my mind inward – to where the feelings lay.

What I found there was not pleasing to me initially. I found the feelings of fear, anger and, yes, victimization and guilt; the very feelings I had sworn never to even acknowledge. I had only ever seen these feelings used manipulatively or to hurt others that I never assumed that these could ever be positive feelings. Well, maybe not positive per se but at least spurring one on to think and act positively. I was so very wrong!

Recall that as an Adult Child of an Alcoholic (ACOA), any negative feelings and/or thoughts only ever lead to violence. I moved mountains to make sure that I never turned out that way; that I would never violently lash out and hurt another person. At times, I failed and I beat myself up pretty badly because of it. However, I made a serious and concerted effort not to allow negative thoughts and feelings overwhelm me. Of course, that presupposes that any negative thought or feeling would necessarily overwhelm me but the end result was a complete denial of any yukky feelings I had. Where are the feelings? Feelings? What feelings?

Meditation changes all that. It takes diligent practice and dedication to the process and while I consider myself a rank amateur really don't care about that too much. The important bit lies in the doing, not in the title or level of proficiency one has achieved. For anyone, I would highly recommend meditation as a way of unlocking one's feelings with the supportive reassurances that it will be all right and that no harm will come to you; but for someone like me who is living with MS, meditation becomes a vital and crucial tool (note: not weapon) for living well with MS. Where are the feelings? They're right inside me and they're okay to have!



Although it's a well known fact that the evil twin is always the one with the goatee, the newspaper could be cleverly hiding one!

Waddlers – is my sense of humour returning?

You've seen 'em; I know I have. They're waddlers and they're everywhere! You cannot go to a grocery or department store at any time without encountering them.

Waddlers are defined as barely ambulatory creatures who are always in your way and who always take up all the available space. Most of the time, they're large women but, increasingly, they're men, thin young women and anyone carrying several bags of items on either side of their bodies. Waddlers are the ones who will take their dear sweet time ambling and wandering aimlessly up and down grocery aisles as if nobody else in the world existed. They will make sure that nobody can get by without having to inflict some kind of injury (like a second degree burn or a compound fracture) and then they will act totally surprised that you are even in the same store as they are. As quickly as they elicit the startle reflex, however, they are back to mumbling incoherently about their socks itching and gawking at some hitherto unknown brand of pork rinds while blocking the entire aisle of the grocery store.

Waddlers come in all shapes and sizes, too, as I alluded to at the beginning of this rant...er... essay. There is the simple slowpoke; here is the waddler who occupies the very middle of the aisle and whose telltale shuffle clearly identifies them as such. They often have carts that are fully loaded with frozen french fries, godzilla sized boxes of Frosted Flakes, every conceivable flavour of rippled potato chip and several cases of pressurized explosives disguised as soft drinks. This kind of waddler isn't interested in what you need; they don't even know you exist. They could be living next to the Prime Minister or a mass murderer but wouldn't know it. Hell, they could even *be* the Prime Minister or a mass murderer and wouldn't know it.

Another kind of waddler is the one I call, "The Spider Plant" waddler. This is the waddler who is never alone. In much the same way that spider plants will sprout babies and then eject them over the side of the planter so that they can spread, the Spider Plant Waddler will eject his or her children from the clutches of their coattails and strategically plant each one in the middle of an aisle or else let them "wander a bit" somewhere in the cereal and cracker aisle while they themselves check out the baked goods section. These children (baby spider plants) invariably wind up dragging things off the shelf and/or knocking something over (usually twice) so that it splatters everywhere making the aisle impassable.

Yet another, newer kind of waddler is the older gentleman. Here we see the my-wife-is-sick-and-sent-me-to-the-store-to-pick-up-some-things kinda man who, though otherwise perfectly all right, seems completely lost in the labyrinth of the grocery store. He isn't sure at all what size or brand of household cleaner his sick-as-a-dog wife asked him to get, even though it's written down on a list that he himself wrote and which he clutches in his hand... So he compensates for his incompetence by parking his shopping cart in the middle of the aisle and then...he waits! Yes, he waits for someone else to turn the corner and, not knowing he is there until it's too late, nearly collides with the poor unfortunate shopper. At that point, he can apologize profusely (they really are sorry) and then feel compelled to excuse his inconsiderate action by saying that he is trying desperately to figure out just what his ill wife has asked him to get and so he really isn't paying too much attention to the happenings around him. He may then ask you if you know what the best kind of cleaner/margarine/tea biscuit/cat treats/dishwashing liquid is, where he may find it and would you be so kind as to reach up and get it off the shelf for him please. He will get that instead of what is on the list. He will then plunk it in his cart, right next to all the other things that aren't on the list but which he thinks ought to be. All this, while the shopping carts take up the width of the whole aisle, thus blocking anyone else! This is the same waddler who will then go right home, feeling smug about his brilliant ability to escape having to actually get the items on the list (it's embarrassing enough to be even caught in a grocery store, let alone having to resort to reading a list and, gasp, following instructions – it makes him look as though he doesn't know what to do) only to then discover that the case of automatic dishwashing powder he got on sale is useless because he doesn't even have an automatic dishwasher.

Then, there is the waddler disguised as a zoomer. This is the waddler who zooms up and down the aisles, rounding corners without even glancing to see if anyone else is there. Collisions are typical for these dolts as they race along the track grabbing anything they think they may need. You'd swear they were gearing up for some approaching natural disaster that only they themselves know about...until they come to their senses (?) and get in line, usually the express line with their a-lot-more-than-8-items. Suddenly, they're the slowest things on the planet and will think nothing of asking that some of the items be placed on a separate bill and could they pay for the soda water with Euros. I can't even imagine how these people drive their cars as I'm sure they run stop signs, change lanes without even looking, drive at nearly twice the speed limit...but completely fail to catch the advanced green light that more twitches nervously for a few seconds than actually blinks before one car can get through!

Finally, there is the chattering waddler. Proud of their ability to carry on three (or more) conversations with others (real or imagined) while shopping, these waddlers will openly and generally quite loudly discuss at length each product they're considering as if anyone else really cared. They won't let anyone get by without being treated to their opinion as to the suitability of one brand of orange juice over another ("I hear this brand can cause gangrene! I saw it on Oprah!!"). They may get into lengthy and boring discussions with the cashier about whether they should use this debit card or not and why and will ask whether they can get a cashback of \$8.00 when the minimum possible amount is \$20.00...then, when their cards are declined due to insufficient funds will then launch into a tirade about how the machine couldn't possibly be right and that the manager should fix it now...or else...

Yep, I'm feeling a lot better!

Tai Chi, Surrender and Health

I took up tai chi when I was 32. See, I'm a complete klutz and I always have been. I could fall down and miss the ground and I'd been like that since I was a kid.

I used to attribute my perennial lack of co-ordination as a kid to my weak left foot, which would turn in and conspire to trip me at a moment's notice. This made me an excellent candidate for taking up tai chi.

Tai chi is a series of gentle movements (there are 108 in a set) which are interconnected and which are designed, for one thing, to improve coordination. By gently working the various muscles and joints, a student learns to balance movement with posture and stillness with finesse...all of which are very useful for anyone but especially for anyone living with MS.

The set begins with a series of gentle warm ups, ranging from quietly flexing one's wrists, arms and legs to softly stretching one's back and shoulders. There's nothing dangerous or harmful about it and it's even a recommended practice for people with MS – hell, you can do the set from a wheelchair...sort of... It's often been said that doing tai chi in a group is a lot better than doing it on your own because there is a certain energy in the room which only works to inspire and guide any single person on. This is called "peer pressure". Okay.

But, for me, I prefer to do tai chi on my own for a few reasons:

- I get to choose the place and time to do tai chi, especially since ours is not a large sprawling house
- I can go at my own pace and not feel compelled to "keep pace" with others.
- I prefer to do a set completely naked which pretty much precludes having anyone else (except Adam) around

There is another reason why I like to do tai chi alone, and that's to do with the nasty egomania I've seen far too often in too many tai chi clubs. Invariably, many of these clubs are run by one or maybe two gang leaders whose sole purpose seems to be about showing off to others just how skilled/talented/masterful or clever they happen to be. Oh, they do a good job feigning humility most of the time but, deep down, they can't stand anyone who demonstrates any kind of ability that...dare I say it...exceeds their own. This is because anyone who demonstrates some genuine skill will equally demonstrate the Tai Chi leader's lack of same. The leader will then do everything in his or her power to suppress anyone else for fear of losing the throng of "faithful" followers. I have seen one other person whose skills exceeded those of the instructor, and he wound up being told that he would never be permitted to teach in *that* group. This sounds like a very bad made-for-TV movie, doesn't it?

The whole point to tai chi lies in directly but softly confronting our Western tendency of attacking life head on, as if we needed to take control and overpower it. In tai chi, we win not by throttling our foe (real or imagined) but by yielding and bending. A new and living tree branch will bend in the face of powerful winds but a dead and stiff branch will merely snap and splinter. The soft and delicate looking branch will rebound to its former shape and health while a snapped and brittle branch is still a snapped and brittle branch. The same could be said for us. I have found that the ones who can best cope with the innumerable setbacks, obstacles, challenges and disappointments are the ones who can flex the most. Flexing does not mean surrendering all that is our most basic being; the flexible tree branch doesn't give up its being a tree branch. Flexing, in the very human sense, means that we surrender our old and outmoded thinking. It means that we nourish our souls and restore what was once yielding but is now shattered and brittle. I see variations on this theme fairly frequently, as I'm sure everyone else does. Who among us is not

acquainted with that person who cannot understand that they can get a lot more out of life and living by flexing?

A more pedestrian example is seen in the person whose whole life seems to be falling apart at the seams. This is the person whose main relationships never seem to work out, who have extreme difficulty being with anybody and who will lash out randomly at anyone for little or no reason. Here is the person who looks at any words as potential weapons and who will jump on them and assume they have been insulted and horribly victimized by someone or something... again... Should these people take up tai chi? I don't see why not, but what I like is that anyone can counter such unwarranted attacks by using psychological tai chi...simply yield and flex and remain unharmed. To that end, tai chi is extremely powerful despite its seemingly gentle and highly relaxed structure.**

Related to this is the person who refuses to take any kind of responsibility for their actions/words and will immediately attribute any and all acts of hostility on their part as either deserving or else not their fault. Here is the person who will overreact to any perceived slight and who walks the Earth forever angry and defensive. That's no way to live and, on some level, these people must know this.

Conversely, the wizened tai chi practitioner is the one who always has a quiet air of confidence to them. They are not in any way pretentious or showy, preferring, instead to just simply be. These are the people who have adopted a worry-free style of thinking that is at the same time a self-invested one. The tai chi practitioner will help in any way but who does not strive to do so. The practitioner is also the quiet soft-spoken one who says only what is needed. There is no nervous sounding chatter or desperate need to be the one who does the talking (or shouting). The tai chi practitioner listens and is forever the student.

It would be great if we all periodically sat ourselves down and asked ourselves how our actions have affected our world, especially the others who live in our world. What I find is that those people who absolutely refuse to even consider that they themselves may be at least partly responsible for their situations are the ones most likely to be walking around utterly miserable and blaming others for everything that goes wrong in their lives. After awhile, these poor souls wind up living alone, thoroughly unable to have any kind of relationship with anyone at all ever. I can't imagine anything sadder than this!

A letter to Drug companies and some final Rantings

For some unknowable reason, some drug companies who make and distribute the medication some of us take for MS, feel compelled to mail out little tokens of appreciation for giving them huge amounts of money each year so we can take control of MS as best we can. Our grocery store doesn't send us letters or tokens of thanks each time we go there, but then, we don't spend nearly \$20,000.00 per year on cereal, vegetables and pasta.

In my case, these tokens came roughly every three months. The last time I got a gift, it came with a letter congratulating me on having successfully completed 9 months of therapy. The gift (read: consolation prize) was a CD of re-mixes of "soothing music" which was guaranteed to help me deal with the stress of living with MS by allowing me to listen to soothing calming music. (shrugs) Okay.

I brought the unsolicited, but not unappreciated, gift back to the house and plugged the CD into the player. What emanated was what had to be the worst slop I've heard since anything at all ever by Supertramp, Styx or Starship. Sarcasm aside (for now), the result was that the promised help was simply not there. I found myself visibly stressed until I could get over to the CD player and eject the horror, pausing long enough to apologize to the speakers for being forced to emit such garbage.

Now, I certainly appreciate the thought (believe me, I do) and even though I still retain the right to decide what constitutes calming soothing music, I am open to new ideas. I am not, however, open to bad ones. I wrote a letter to the company that supplies my medication and, though I never sent it, felt it best to include it here.

From: Ruth Merkis-Hunt

Subject: Your gift of the CD

Dear MS drug manufacturer/distributor People,

I wanted to thank you most kindly for your gift of a CD of the instrumental version of hits by Carole King. I have been taking my MS medication now for about nine months, an otherwise unimportant landmark. However, you thoughtful people felt it best to congratulate me, so I was very pleasantly surprised to find this CD in my mailbox yesterday.

I took the time to listen to it, as the accompanying note described it as "soothing". Unfortunately, I did not find it to be particularly soothing. There are many ways of combining music styles to form new and creative hybrids; however, there are also limits to this strategy.

Back in the late 1980s, I had the chance to listen to a cassette tape of the London Symphony Orchestra perform "The Best of Jethro Tull". As you can imagine, the results were not quite as charming as the tape cover intimated. Suffice it to say that I did not listen to it again, nor did I listen more than once to "Michael Oldfield's Tubular Bells" played in dancemix/disco style. I am forever on the lookout for such "fusion" music styles like "Hagood Hardy's keyboard renditions of Van Halen tunes from Beyond the Grave" or "Liona Boyd does Jimmy Page Guitar Solos in Her Own Way" specifically so that I can avoid them.

Please do not think me ungrateful because I am very grateful for all the help and care that you have provided for me. It's somewhat gratifying, though also somewhat disconcerting, too, to know that there are people out there I haven't even met who are keeping such close tabs on precisely how long I've been taking a particular medication. Living every day with multiple sclerosis is not

fun and just knowing that there are effective medications out there helps me a lot. I really appreciate the jar opener you sent to me (actually, you sent me two!) and the paper slicer, too. I make frequent use of the jar opener and gave the second one to a friend. However, I'm afraid the instrumental version of Carole King music is not soothing at all, so please accept my returning of this CD with the knowledge that I am grateful for your concerns and efforts but that I simply cannot listen to this without breaking out into hives.

Yours truly,

Ruth Merkis-Hunt

It becomes evident to the reader that I am being generous, though snide perhaps, and I am. I am honoured that a drug company that gets nearly \$20,000.00 of our dollars each year would send out free gifts like CDs, paper slicers and jar openers. I don't imagine that many other drug companies are so concerned about their patients/clients and so I am pleased to be a part of such a system.

I am soon reaching my first anniversary of my MS drug therapy (I reached that point in 2004), which means that another little "surprise" will probably come in the mail, if I have accurately divined their pattern. I can only imagine what it'll be – perhaps a tube of super duper EZ-to-use toothpaste in a bright Day-Glo yellow so that it is easier to see, a pair of self-dressing socks so that I won't have to do anything or maybe a Godzilla sized box of scratch 'n' sniff tropical fruity band aids. Can't wait.

Here's an alternative to dispensing gifts that drug companies are simply guessing that I'll want/need. How about if they send out forms to their myriad of clients and, gasp, ask what, if anything, they would want. The recent CD gift assumed that I had a CD player. Suppose I didn't have a CD player? I have received videos from drug manufacturers that are completely useless to me because we don't have a television or VCR. We could save these drug companies a whole bunch of (our) money if we actually let them know what we would want! Here's my list:

- a written promise, enforceable by law, that they will stop phoning me every three months and asking me if I have any questions about the medication. I have said before and will say again that if I have any questions, I will ask. Anyone else would do the exact same thing. We're living with MS, not mental retardation. I know how to use a telephone. This is too much like being woken up by a nurse so that you can take your sleeping pill. Stop fussing over me.
- do not assume that what you think constitutes "soothing" is the same as what I think constitutes "soothing". Personally, I have my own ways of finding peace every day and each way is marvellously soothing – having to endure sugary muzak that would make a goat retch takes away my power to choose. So, in the interest of preserving democracy, don't hesitate to ask me what I might need from you. Sending out survey forms is a tried and true method of making such determinations; surely this shouldn't be too difficult.

Please do not think me ungrateful or that I don't know how good I've got it (I'm VERY aware of how good I've got it!). Do, however, consider the deeper messages inside such magnanimous gestures. I don't doubt that drug manufacturers who make gobs of money from each patient of theirs feel compelled to offer at least some thoughtful gesture of appreciation to each one of us and that's as it should be. My only objection is that their ways completely strip me (not to mention others like me) of the power to choose what we would want for ourselves.

If I could choose, I would choose an instant cure for this neurological chaotic menace, not an endless parade of sympathy and certainly not the heaps of stupid advice handed out like candy. If I could choose, I would choose any music I like and commit that to a CD; not have some person(s) make that decision for me.

If I could choose, I would ask for a laser guided missile (complete with portable launcher) so that the waddler in front of me could be immediately removed from the planet.

Self-Absorption/Self-Investment

This is another term I've run across and, like many other terms I've encountered, I took the time to think about it while I was showering. What is the difference between someone who is self-absorbed and one who is self-invested, I asked myself as I dropped the soap (again) in the tub. I think I know, but I could be wrong there, too.

What I see as self-absorbed is the person whose entire existence is based entirely on getting their own way with the expectation that everyone else is just as concerned about that person getting their wishes granted. They want what they want and will not give a toss about anyone else. The self-absorbed person tends to enjoy playing the role of "victim" as a way of justifying their increasing demands for gratification and will spare no pains to let you know just how hard done by they have been. They will also try to blame everyone and everything else for their own lot in life and have a perpetually sour and glum look to their faces and bodies. The self-absorbed person feels entitled to getting whatever it is they want at that moment because they deserve a break after all the torment and abuse they've suffered. If they don't get what they want, then they will add that to their growing list of reasons why they're a victim and why that isn't fair. The self-absorbed person generally has no or very few friends.

In marked contrast, the self-invested person fully understands that theirs is not some end product that's been irreparably damaged from years of abuse and torture. The self-invested person sees him or herself as a work in progress and is willing and very interested in trying new and different ways of seeing things. The self-invested person will think nothing of eating a bit of "humble pie" now and again because they really don't see themselves as too different from anyone else who would perhaps get to enjoy a slice also. The self-absorbed person would only scream and wail and absolutely refuse to even think about the idea that their harsh and hostile reactions are simply wrong. The self-invested person is able (more or less) to see each day as a new opportunity for personal growth and is comfortable with the idea that they may not have as great a day as they hoped. The self-absorbed person would insist that their cruddy day is someone else's fault.

The self-invested takes calculated risks and knows that they may not win. The self-absorbed wouldn't even consider anything like that – preferring, instead, that everybody else take their risks for them, along with any of the responsibility for any losses!

I think most of us are a little of both, including (if not especially) me. There are days when it seems as though I truly am a victim (although of what I've never figured out) and those are the days when I'm no good around other people because I'm sure that they will merely hurt me or otherwise make my life a living hell! But, there are also days when I really feel that everything's okay and that I only need to step back from those negative feelings (not always easy but it gets easier with practice) and take a firm hold of my world. On those days, I tell myself that I can go for a good long walk or go that extra two kilometres on the cross-country ski trails up in Gatineau Park. As I have been told by some, "suffering is optional". So, I guess on those days that I do "suffer", it is a choice I have made. The self-absorbed person would never see it that way.

Now, those are the days I see returning to me in greater number. It's a little like the end scene in *The Wizard of Oz* when the good witch (the one with the sequined bristol board tube on her head) quips to Dorothy that she always had the power to go home. In that very same sense, I always have the power to have a good day – the trick lies in realizing it.

Subtle

I didn't really notice anything until I got onto the bus.

Adam and I live in the south end of the city of Ottawa and, from our back door, have a grade "A" view of the transit loop.

Ottawa's transit system is, in my view, second to none. Imagine having dedicated roadways just for buses where you could just hop on the bus, pay the fare and be right in the heart of downtown in roughly twenty minutes (are you paying attention, Toronto?). Yes, there are local buses that snake their way through the city streets but it's a far cry from having to (ugh) *drive* anywhere in the city.

But, back to the transit loop.

As I had said, we live in the south end of the city and, specifically, near that segment of the transitway where buses arrive and turn around to head back into the city. This has the enviable effect that we always get a seat as we're right at the end of the route itself but there is one not-so-great effect. As the bus must turn a fairly tight corner to reverse its route, it is not uncommon to have to either hang on for dear life or else dive into the nearest seat before you are plastered against the window wondering how test pilots and astronauts could do this with aplomb. Adam and I have trained my kids to get on the bus and sit down immediately before the driver decides to pull about 2 Gs going around the corner. I do it, too, but I sometimes don't even have time for that before the driver hits the gas and I am treated to the centrifuge I only ever imagined goes on in chemistry labs. Normally, the driver understands (although as he or she is the one in control, you'd think the driver would at least wait until I had sat down) and says nothing while I hang onto the pole for the entire four or five seconds it takes to swing the bus around the loop.

But, this time, the situation was a little different. After I dutifully took my bus transfer, which is a must, even if you have no intention of using it, the driver zoomed away and insisted that I could sit down now...

...except that I was too busy hanging on for dear life. The driver seemed puzzled and perhaps even slightly annoyed at my apparent failure to comply with his instructions. Once we had successfully rounded the corner, I quietly explained to the driver that I had multiple sclerosis and that my balance was not always so good. It was not an accusation or complaint, just a simple, even-toned explanation. He seemed mortified and apologized to me. I dismissed the event as nothing significant. After all, I don't look like I have MS so how could the driver know?

At any rate, I took my seat and started to think about it anyway. I asked myself what disability looks like. After all, according to popular media images of people with disabilities, I certainly didn't look the part.

I was diagnosed with MS back in 1999. Since that time, I have had a number of relapses but have recovered nearly completely after each one...thankfully! Yes, I certainly have limits – my neurologist had once referred to my MS as "subtle" – but I am not so obviously disabled. I can still walk, cross-country ski and even hobble around on ice skates. I take care of myself in as complete a way as possible and I do believe that those strategies, along with taking disease-modifying drugs, are having a positive effect on me and my life.

I am grateful to be alive and that I can still do a lot of what I was always able to do, although not everything. Having MS has opened more spiritual doors for me than has closed any practical ones (ie employment) and I feel much more enriched by it...but it doesn't change the fact that I face certain barriers on a day to day basis that only a few others may also face. However, just as

my disability is subtle (at least, for now) so is the type of discrimination I face, and it isn't by any particular segment in society.

It still bothers me that I can't work full time – by about 3:30 in the afternoon, I am totally exhausted so that rules out much work in retail. It also means that I often cannot accept any social engagements in the evening unless I have had the chance to take a little nap in the afternoon. Vision problems are de rigueur with MS and I have experienced problems with my eyesight which has meant that I no longer drive.

Yet, I am extremely fortunate in that I do not have to work so I can get the rest I need when I need it. Ottawa's marvellous transit system, the presence of bike paths and the thankful fact that I can still walk unassisted means that I do not have to drive. I can still choose at least that...
...but I often wonder what other people think when they see me outside and walking in the middle of what would be a workday. Do they know why I'm unemployed? Do they think I'm lazy? If I am having some problems with walking, does anyone think I'm drunk? In having lunch with other friends, all of whom work and all of whom know I have MS, I cannot help but feel acutely aware that I cannot share their frustrations and joys of their workaday world any more than they could understand my frustrations at not being able to see properly from time to time or my joys at being able to do yoga or a tai chi set without any significant unsteadiness.

For anyone who is in a wheelchair or who uses a walker, cane or who clearly has some kind of disability, there just seems to be a higher level of understanding from society. As for me, however, my disability is not immediately evident. I have what is termed a "non-visible disability" which simply means that you would have to watch me for quite some time before you noticed anything – that my formerly pristine penmanship is less than it was or that walking in the cold weather when I'm tired causes pain and subsequent limping. It's not always like this; MS is fickle but it must be considered every time I want to go somewhere.

Vacations are either fairly short, which is okay because I don't like long holidays anyway, so that I can be home in time to take my weekly shot or else I have to bring my expensive (roughly \$400.00 per weekly dose) temperature-sensitive medication and its associated ice packs and needles with me. I haven't heard of anyone being given a hard time with customs or any other official, but the possibility of being given grief is everpresent.

It also means that, when my balance is not always at its best, that I can't change direction very quickly, especially on a bus that's zooming around a corner.

It's not anybody's fault – really. Our society presumes that anyone who looks not-disabled is therefore not disabled. It's an easy assumption to make and I do it, too. But, it's just not true, is it? Disability is generally characterized by what people perceive. We're much more accustomed to reacting to visible disability than non-visible disability. We understand that the person in the wheelchair can't walk or that someone (usually wearing sunglasses) tapping the ground with a white cane or being walked with a seeing-eye dog is blind...or nearly blind.

But that doesn't really tell the whole story and I would argue that it doesn't even tell half the story. In my case, people perceive me as able-bodied. I can walk unassisted and my visual disturbance (washed out view in my left eye) has not truly interfered with my ability to get around or even to drive...

...but I still can't orient myself too well in three dimensional space while in a bus that's speeding around a corner. If I were using a cane or walker, the bus driver would surely wait until I was safely seated before hitting the gas pedal – but I now actually have to mention that I have MS and that my balance isn't all that great and could we wait until I'm sitting down before jamming full throttle? Admittedly, it isn't bad and it does actually force people like bus drivers (and store clerks – but that's a different gripe) to develop a sort of sensitivity to other people's immediate situations. It's subtle, but it's a good sign!

The Problem with “Educating the Public”

I do some volunteer work in my community. Hell, if I can't secure any gainful employment, the very least I can do is volunteer my time and skills (whatever those happen to be). I volunteer within the social services field and, in particular, within the community of the disabled.

We're a fiesty lot we are, and chock full of opinions, too. I am one of many volunteers and, like most volunteers in this area, most of us are comprised of counsellors, social service workers and the like. Because we go into this field to connect with people it's important for us to be seen as sympathetic with our charges as much as possible. Fair enough. We listen to the (way too many) complaints, fears, issues, challenges and (too few) successes of those in our care and we indicate our attentiveness through the usual gestures, nodding head, eye contact and the requisite, “uh huh”s. **BUT...**

...I draw the line whenever anyone says something like, “We need to educate the public”...on (insert an issue here – the one I'm thinking about concerns public transit). I hear those words and it's all I can do to prevent lunging at whoever said that and throttling the living ^%\$%& out of them. Instead, I usually just wince as quietly as possible because the statement, “We need to educate the public” tells me that the person saying that has no clue about how people behave and operate in a social setting.

“Educating the public” is a massive fallacy, I feel. It's a banal buzz-word that's tossed around like pedantic confetti. To me, at least, it seems to be something that is said to make the speaker look socially expansive and virtuous...except that it's just a fatuous, self-serving remark. What does “educating the public” imply anyway? To me, it strongly supports some sort of moral model of social systems whose main premise would be that *people will always act in the most prosocial manner if they only had all the available knowledge and resources*. This is, of course, utter nonsense. People, you and me and even your granny, act in a self-serving manner. We do what gives us the biggest reward, to maximize our gains and minimize our losses. We don't just suddenly slap ourselves on the forehead after being given a lecture (read: dressing down) on the plight of barnswallows, cheese makers, owners of 8-track players or left-handed paratroopers with bunions and change our behaviour. Why? Because it is not in our self-interest to do so. The only time we will change our behaviour is when we've concluded that it's in our best interests – even if the reward we earn is a quiet ‘thank you’ for giving up one's seat on the bus for a less able-bodied passenger. When I was diagnosed with MS, I had to (and still have to) make some behavioural changes in my life that I wouldn't ordinarily do otherwise. No more jogging, no more driving and no more biking. Worst of all, I now have to take breaks throughout the day – something that required a HUGE change in my thinking to accomplish.

Educating someone on an issue that has no relevance to his or her life is a waste of time. There is no point in conducting a seminar on how valuable the local airport is to someone who doesn't care about airports.

Educating the public is a self-defeating proposition, too, only because those people who are interested in the issue at stake are already very well educated and those people who are not interested in the issue cannot be educated. Nor will they be.

Nor should they be. Nobody in Ulan Bataar really cares whether there is enough funding for the annual tulip festival here is Ottawa. But, there is something even more sinister at work here.

Implicit in the concept of “needing to educate the public” is the unspoken feeling that those of us who have a vested interest in a given issue have more rights than those of us who do not have a vested interest. By that, specifically I am referring to a city transportation working group meeting I attended last year. The subject was accessibility for those people who have disabilities and the

overall impression I got was that those who are affected by increasing costs, funding cutbacks and limits to service should somehow be exempt from having to face those realities. It was seen by some as yet another barrier to movement which would, or at least should, somehow, be removed through the magic of public education.

Nonsense! Educating a weary public already feeling quite resentful towards what they see as subsidizing those with disabilities won't make things better – and they won't make things different either.

The public doesn't want to be educated on your silly little issue!

...For the Children...

I only caught the last few seconds of it on the radio but the message came in loud and clear anyway...we need to (insert some noble positive action here) to preserve the (planet... playground...library...park...) for our children and their children and their children's children...et cetera...ad nauseum.

As I am not in a particularly charitable mood, I'll cut to the chase: who writes that kind of idiotic barf anyway and how can we stop them? Don't get me wrong, I'm all for doing whatever it is that the writer of that message said we should all be doing, assuming it's something really worthwhile, but to use the preservation of our children and subsequent generations as a reason is just plain stupid. In my mind, it makes no sense whatsoever to put effort into, for instance, preserving our parks if only our children will ever benefit from it. I want to benefit from having clean, safe drinking water, smog-free air and garbage-free streets as well. This idea that working hard now to preserve something for the future is doomed to defeat because success is always put off until some as yet determined time. It's social procrastination at its worst, thinly disguised as martyrdom and it's just plain wrong!

For me to say anything like that, however, places me at risk for being labelled a careless, child-hating polluter with not even the slightest ecological slant. Nothing could be further from the truth. We recycle, diligently, refrain from buying products which harm the environment, walk or bike wherever and whenever we can. We regularly use public transit and only drive to places where there is no other way. But, make no mistake, we do it for our own benefit; the fact that my children (and, yes, I have three beautiful children) stand to benefit – somehow – is purely coincidental. It's a nice coincidence but a coincidence nonetheless.

Face it; we all do this to some extent. Who among us consciously thinks that their act of separating paper and plastic items for recycling is "for the children"? Answer: nearly nobody. That doesn't mean we don't care about our planet. It doesn't mean we just do what we're supposed to do – glassy-eyed and as anaesthetized as a Wal-Mart greeter. It just means we want to make sure our recycling items get picked up. Kids don't enter into it...not deliberately at least.

There is another problem with making such magnanimous gestures solely "for the children"; it tends to generate a sense of martyrdom from some of this generation. These same sorts will ensure their children know about the huge sacrifices they made every single day forever and ever. This would surely breed irritation and resentment from both generations. I know it would annoy me to get a steady diet of, "We worked hard to make sure you kids have this, ya know. If it hadn't been for all the times we walked 10 kilometres to work every day uphill both ways and not used our gas guzzling SUV every day, you little brats wouldn't have clean air/water/socks..." or "Your mother and I spent 48 hours in a row sorting out every molecule of number 2 plastic every week for twenty-five years so you kids wouldn't have to smell the dump..." My answer would have been something like, "Thanks dad, but didn't you get anything out of it?"

Et cetera...

So, who writes this kind of bilge? Generally, I find that the sort of person most likely to do this is someone who is, perhaps, not the greatest at being able to examine issues a little more critically than they ought to. Unable to form an informed opinion, they resort to trite, so-called, "motherhood" kinds of statements. In a way, it's kinda crafty – who wouldn't want to have clean air/water/streets/playgrounds? Indignantly (arrogantly?) proclaiming that we ought to "do something" so that our children – and no one else – can benefit is a no-lose position to take. To me, that smacks of a certain dishonesty. Why not take an informed if perhaps somewhat

controversial position? Are you afraid of having to defend your position? Unable to defend it? So, here is my position...

Never mind preserving the planet for our children – how about we take care of things for our own benefit? The children will learn proper stewardship instead of banal martyrdom and we of this generation will also stand to benefit from having a clean environment. Doing good just for the children leaves a heavy burden on their shoulders. If they themselves cannot continue the good work that their predecessors did, what will *their* children think of them?

A Final Word...

For those of you who have finally made it to the back of this tome, I must thank you profusely for allowing me both the space and some of your time to rant, blather, whine a bit, fuss and otherwise make fun of multiple sclerosis. There is, however, a need to address some of the more serious issues surrounding this disease.

First of all, multiple sclerosis is a very serious disease. It strikes young adults in their most productive years and often turns an otherwise ordinary life into a series of roller coaster rides where we feel okay one day, bloody awful the next and, sometimes, just plain stupid. Multiple sclerosis is not something that can be cured, no matter what anyone has to say. Believe me, I've heard a few of these so-called "cures". This often leaves many patients feeling utterly terrified, just knowing that the only thing doctors can do is help slow down the progression of this illness. Every time we see someone in a wheelchair or who is walking with some sort of assistance (i.e. cane or walker), we wonder if that person has MS too. We generally don't spend entire weekends wondering about it, but we're sometimes troubled by what we see and feel. When we see someone with a cane, we wonder if we are looking at ourselves at some point in the future. It is fear of the unknown...and fear of the known, too...that leads us to periodically obsess and fuss. I have tried my level best not to fall into that gaping and bottomless pit but I do know that I have sometimes visited that place...its name is Hell.

Secondly, we did not "cause" our MS to develop and/or emerge. We have undoubtedly been told that if we hadn't done something or visited a place or had eaten more or less of something else then we would not be in the predicament that we are in at the moment. The universal laws of cause and effect are certainly at play here, but we ourselves have nothing whatsoever to do with that in the matter of MS – at least, not knowingly. There is a certain brand of randomness at work here; at least, until we can sort out all of the factors. In my case, and to the best of my knowledge, nobody in my family's past on either my mother's or father's side ever had multiple sclerosis. Playing the blame game is both futile and stupid. Even if we could find someone or something to blame, that doesn't change anything. Perhaps the closest thing to a mistake we ever made was being born. However, I am not sad or sorry that I was born, so I guess I don't feel the need for self reproach. Neither does anyone else who is living with multiple sclerosis.

Thirdly, we have multiple sclerosis, not mental retardation. Whether we are confined to a wheelchair, have permanent vision problems or slurred speech we are not stupid morons who need your pity. When someone is diagnosed with MS (or indeed with anything), I can guarantee you that the doctor will dispense all the information anyone would ever need to know. Please don't assume that we don't know to stay out of the heat and please don't presume to know what help we would want or need. The last time I checked, I still had all rights to self-determination and the power to choose whatever path I take. That means that no one, not a drug company, a parent, spouse, employer, social group or physician, can make any decisions for me.

Fourth, for those of us who are living with multiple sclerosis, our lives are different from most other people's, but our lives are still very similar to anyone else's also. Please don't concentrate solely on the "sick" aspect of MS – we know we have an incurable illness but we would just like to have as average a life as you do. People with cystic fibrosis or diabetes have lives that are different from yours or mine and your life is different from anyone else's. I still shovel the driveway, collect the mail, clean the bathroom and still remain physically active. I still brush my (dumb) cat and I still enjoy playing Scrabble with Adam most weekend evenings and I sometimes even win! Even though I still have to take a fair amount of medication, I refuse to let that fact alone define my reality.

My life is how I define it, so is yours.

Fifth, the fact that I have multiple sclerosis has not yet stopped me from participating in life. Of course, I have to change what I do and how I do it when I'm "enjoying" a relapse, but I try to take it all in stride. Besides, don't you have to sometimes take a different route to work when the road you normally take is closed due to construction? While it is quite true that MS removes many choices from its victims, it cannot remove all of them. I also realize that my current ability will likely change over time, but I can't worry about a future I cannot predict. I try to live in the present, not some distant future or some nostalgic past.

Finally, I don't want to leave you with the impression in the last paragraph that I have adopted a combative posture regarding this terrible disease. What I have undergone, and continue to undergo, is a series of personal and spiritual changes which have all helped me to adapt as well as I can to living with the uncertainty of multiple sclerosis. It's a never ending balancing act between medication, side effects, fatigue, sleep, depression...the whole bit! They include the fact that each day is the eternity they all sing about and it's mine to savour as it is yours! I have become a lot less anxious and over-concerned about pleasing other people since I took up meditation and things are settling into place as they should. I gain strength by yielding (that's a very Taoist/Zen kind of thing – if you don't know then I can't explain) and I yield to the chaotic intrigues knowing I do so in strength. Let the changes continue! I'm ready for them...I think!

The Tao of MS

This is a selection of passages from the Tao Te Ching as told within the context of multiple sclerosis. What follows that is a commentary by me.

The Tao Te Ching, an ancient Chinese text written by Lao Tzu can be found in the homes of many intellectuals, spiritualists and other eclectic types who shun many modern cultural artifacts except Bugs Bunny. For those of us who are living with MS, there is a lot to be learned by reading the Tao Te Ching...

...but that's not to say the original text is particularly easy to understand because it isn't. Partly this is due to the limits of translation but also because the ideas expressed in the TTC are themselves alien to more typical – uh – Western thinking. Even those who swear by the doctrine of the original text admit that it takes a lot of brain twisting just to grasp some of the more elusive concepts, which is most of the 81 chapters. This makes it a near perfect gift for people affected by MS as living with the caprice of this disease also requires a lot of brain twisting. So, what I've tried to do is take a few more germane passages from the original text and to translate it contextually. This is as much for my benefit as for anyone else's so don't accuse me of altruism...

If you don't already have the TTC at your disposal, I would urge you to get one. You can compare what I've written to the original. I've also tried to take a humourous approach to this project. Multiple sclerosis is not fun (I know this personally)...but sometimes it's funny...

Enjoy!

RMH

Chapter One –

The disease that can be told is not the eternal disease.

The diagnosis that can be diagnosed is not the eternal diagnosis.

The nameless is the beginning of ordered tests and procedures.

The named is the mother of ten thousand trips to see specialists.

Ever desireless of sitting in waiting rooms for hours at a time, one can read outdated magazines debating the merits of the Apollo program

Ever desiring, one can see that you can get out of the office and catch the bus to go home before your transfer expires.

This is about two thirds of the original chapter with the rest devoted to how mysteries are manifest. For those of us with MS we already know why we're so tired, can't see or walk properly so it's no mystery to us.

Chapter Two

*In hospital corridors all can notice people with canes only because most people don't use one.
All can know help as help only because there are VERY unhelpful dimwits who insist on sending
you 12 ice packs with your medication each month.*

...

*Therefore, the technician goes about, doing nothing and asking you to be quiet while she adjusts
something on your forehead*

*The ten thousand electrodes record all manner of information you didn't know you had without
fail.*

Displaying funny squiggly lines that it didn't, personally, create.

Churning away selflessly like a good little piece of equipment

Test complete, then information purged...

Unfortunately, many of us wind up spending way too much time going for tests in hospitals. While we wander up and down labyrinthine corridors we notice other people who are in wheelchairs or who use walkers or who are prone on stretchers. We take special notice of them partly because, barring our current situation, it's unusual to see people like that. Technicians are experts par excellence when it comes to plying their trade and so busily go about gluing things to your body, so that you no longer resemble a human being. Then they run their tests happily and leave you to head home and spend all night washing that horrid glop out of your hair, thus washing away any trace of where you spent your afternoon. You're welcome.

Chapter Five –

*Government health officials are ruthless;
They see the ten thousand regulations as only a starting point.
Drug manufacturers are ruthless;
They see their patients as cash cows*

*The space between the ears of government officials is like a huge helium filled balloon;
The shape changes and makes their voices squeak when they talk
The more it moves, the more complex your tax return becomes.
More words are more fun
Hold onto your medical expenses deduction...*

Here is the very first paradox we encounter. While everyone's experiences with MS are truly unique, coping with both government and drug manufacturer types isn't. The medications used to treat MS are expensive and some people rely on help from the government to stave off some of the costs of these drugs. Speaking with government or drug manufacturers will surely result in you reconsidering your feelings on euthanasia, especially when drug manufacturers insist that they are required by law to cram a dozen soggy ice packs into your monthly shipment. I don't want to talk about tax returns; besides, I don't have to, now, do I?

Chapter Seven-

New specialists and rebooked appointments last forever.

Why do new specialists and rebooked appointments last forever?

Damned if I know!

The TTC mentions something about “unborn” and “ever living”. But, anyone who has ever had their appointment changed from the middle of three months from now to the end of another month half a year hence will know what I mean, especially when it's for a new doctor they've never met.

Chapter Eleven-

*Hundreds of patients share the neurologist's time;
It is the physician's brain that makes it useful.*

*Consider your drug expenses form;
It is the empty spaces where it asks you to fill in the name of every single drug you have ever
taken in your entire life that makes it too funny for words.*

*Open the damp box of dripping ice packs;
It is the hermetically sealed box of medicine inside that makes it useful.*

*Therefore, don't worry too much about the inanity of MS, the drug manufacturers or employees
who cannot spell your name;
Be grateful that you even have a doctor!*

We will spend much time hanging about in waiting rooms with other patients, filling in forms that ask you for your complete medical history in under two lines. It's nothing compared to the mental gymnastics doctors have to perform juggling patients, their schedules, their patients' schedules not to mention family and other facts of life. We will spend much time air drying the gelatinous ice packs while trying to remember if styrofoam is recyclable or not. Receptionists, who are at least as busy as the doctors for whom they work but who do not earn as much as doctors, will have a tough time remembering that it is you who lives too far from the MRI clinic to make it to the 4:00 am appointment and not the one who will be out of town for the next six weeks. That's nothing compared to the countless others who don't even have access to the medical system, let alone one, that's so goddamned funny!

Chapter Twelve-

The five drops eye doctors put in your eyes makes everything blurry for hours.

The five music “choices” you have to listen to in between each MRI scan will have you humming “Lady in Red” by Chris DeBurgh, something awful by ABBA or anything at all by Phil Collins until you become homicidal.

The five course meal you have later that day will make you sleepy.

Racing to get that parking spot closest to the clinic door because you are too tired to walk far won't madden the mind...it'll just make you mad.

Therefore, the wise MS patient is guided by the mantra, “This, too, shall pass.”

Visual problems are common with MS; so is having them thoroughly examined by yet another specialist. This involves having those really neat drops put in your eyes that make your pupils as big as dimes and as black as coal. This will also result in you not being able to focus on anything for several hours, so make sure to have someone with you to count your change after you buy a java at Starbuck's. Having your upper body prone on a chilled ironing board and inserted partway into some heaving, asthmatic piece of machinery can be rather daunting. Technicians will put earphones on you and give you a choice of either hours of aging, Geritol™ chugging old guys named Rod Stewart or the local amateur junior Gregorian chanting festival to listen to in between taking another scan of your already picked-on brain – when they're not reminding you that you have to be perfectly still during the scan. “I cut that old lady off in the parking lot to get here early for this?” you may ask yourself while you glance at the mirror they put in front of your eyes so that you can see your feet and not require sedation.

Chapter Sixteen-

Empty your head of expectations

You're too tired to get excited about it anyway.

The ten thousand relapses come and go while you sit and read the latest opinion on who really killed Diana and Dodi.

The numbness, stabbing eye pain and gait ataxia make you look like Quasimodo after one too many chocolate liqueurs

And then...poof...they're gone (the symptoms, that is).

The way of MS is cruel, random and evil caprice

As it is a constant companion, hence the irony.

If you can remember that, everything will be just fine because fighting that fact will lead to you falling down, unable to get up.

With an empty head, you can just get on with living

Getting on with living, you will act safely

Being safe, you will live long enough to make drug manufacturers mind numbingly wealthy

Even if you die, there will be someone else to replace you.

No, really, it's true!

There aren't a few months that pass without some kind of "new", "revolutionary" treatment for MS. Some of those so-called treatments actually claim to cure the disease. Of course, there is no cure but there are some new treatments; just don't expect any miracles because there aren't any.

Yeah, some of us look drunk when we shuffle around trying not to fall over. It won't last; it'll sink into remission for the next while. If you delude yourself into thinking remission equals cure then you will not bother to live your life; opting, instead, to deny the situation at all. Hell, you might even take up something like snowboarding off the Matterhorn...blindfolded...naked... If you do that, you will surely regret it... Symptoms can resurface as quickly as they disappear.

So, while you neither expect any miracle cures nor fuss and worry too much about having MS you do need to actually live your life.

Twenty-Three-

*To do little is natural.
Numbness does not last all night.
Not being able to walk well does not last all season.
Why is this? That is the nature of MS.
If MS cannot always exert its influence on us all the time
How is it possible for us to exert our influence on it all the time?*

*He who rides the relapse out in simple, quiet dignity
Will do well with this disease
He who fights it to the ends of all time
Will be lost in uncertainty, fear, loathing and sadness.*

"When you are at one with loss, the loss is experienced willingly."

The last line is a direct quote from the Tao Te Ching and I felt it important to include it here. In regards to MS, it's commonly interpreted as enduring loss after loss but that's not entirely true. The only thing MS patients lose is that delusional attachment to the idea of constancy and independent, personal control over all aspects of one's life. This is a weird disease that progresses at a highly variable rate. Symptoms arise and go into remission seemingly randomly. The point of this chapter is that trying to wrest control over multiple sclerosis is a waste of time and it's true! It is not to suggest giving up living; on the contrary, it demands that we live the life we have as we have it.

Twenty-Four-

*He who stands on tiptoe is one lucky sot
until he falls over, of course. Then we can all laugh at him.*

*He who walks a zillion miles an hour will have the same fate as the hare
and have no one else around him because he's zoomed past everyone.*

*So, you can walk without a cane – today –
that doesn't make you better than anyone else*

*Your self-care is not the only one, ya know so stop pushing your point of view on
Everyone else*

Nobody cares!

That isn't really as unpleasant as it may sound. Yeah, it's nice to be able to reach high places but it won't last – and neither will your relapse. If you regain your abilities, even a little, that's great! Don't get too excited about it and, please, please, PLEASE, don't go around proclaiming any kind of victory over MS. Not only isn't it true, but your self-righteous ego will annoy everyone else. Then, we will really laugh at you when you fall over...perhaps with some help. No, really, we will!

Twenty-Nine-

Do you think you can take over the offices of the pharmacy that delivers you your meds but who include unsigned and outdated receipts for reimbursement...and then take a three week vacation thus ensuring that you can't resolve the matter?

I do not believe it should be attempted without my help.

Give me a shout when you're ready.

Who hasn't ever felt this way about some organization at least once in their lives? Who hasn't ever concocted a detailed plan that includes some sort of shoulder mounted nuclear device?

Thirty-three-

Knowing other patients is wisdom;

Knowing the self is necessary.

Mastering government officials who have created yet more rules for your pleasure requires a great deal of force;

Self-restraint is called for here.

...

Hanging in there is sheer will;

But know your own limits – or else.

Isolation is probably the worst psychological effect of chronic illness, and multiple sclerosis is certainly no different. Consequently, meeting with and learning about how others cope with MS is both useful and contributes widely to self-knowledge. After all, we're all in this together.

The exception lies within having to contend with the baffling and utterly Byzantine rules and policies of various governments, almost none of whom have ever come into direct contact with MS – except for the occasional reference by some city councillor whose neighbour's mother's best friend's sister-in-law had MS. Of course, as the Tao Te Ching speaks much of yielding, you will have no choice but to do just that. This will demand a great deal of self-knowledge, as such things like free bus passes may no longer be feasible. So, take such inanities as opportunities to ask yourself whether you really needed a bus pass at all, especially if you don't really have any place to go each day as employment rates of those with MS is rather low. If, after you've spent time in bald, sober thought, you feel wronged; then by all means fight...but know when to stop!

Thirty-four-

The great reams of paperwork flow everywhere.

All rules and programs for which you just might qualify are born from it, yet it doesn't create them, so don't blame the poor clerk.

It pours itself into a cup of coffee, yet it makes no progress. It raises many hopes, yet it doesn't actually answer any questions you may have. Since it is separate from all things, including your medical records and hidden in their overtaxed hard drives, it can be called inaccessible. Since all your medical, personal and medication records vanish into it and it alone endures, it can be called a bastard.

It is keenly aware of its greatness; thus you are truly screwed.

At one point, you may find yourself in front of a clerk of some kind whose stated purpose is to help you with something. Noble as his or her intentions may be, you will find yourself mired in much bureaucratic nonsense. This is especially likely if you think you may actually qualify for some assistance in some small way. Ask a question, and you can be assured of getting no useful answer. After a few attempts, you will develop an entirely new vocabulary all of which demonstrates your newfound lack of knowledge about all matters anatomical...but it's sure funny to envision!

Thirty-Five

*She who is first inside the waiting room
can sit where she wishes, without risk of having to sit next to someone who wants to tell her all
about his foot fungus.*

*She perceives the soonness of her appointment, even amid great and annoying garbage,
because she has learned to keep her distance or to turn up the volume on her discman.*

It's a good idea to be the doctor's first patient of the day. That way, you likely won't face a crowded waiting room full of other people who may try to bring you down. Yet, even that becomes a non-issue, too, because being the doctor's first appointment is a solitary prospect so that when you emerge and see the filling waiting room, you can just leave. Failing that, just crank up the volume of your discman, or your MP3 player.

Thirty-Six

Tests and procedures must follow the doctor's orders.

Relapses must follow remission.

Being plugged into strange machines never before seen outside a museum must follow having multicoloured wires glued to various body parts.

Getting your drugs delivered to your house only happens after you have given the correct address to the clerk from the drug company who is phoning you for the second time this week to confirm your address even though you have already told him or her.

This is called reality.

Patience, oh, so much patience overcomes the perfectly reasonable urge to stomp to death some dink who proclaims that he has cured his MS by taking up yodeling and that you can learn his amazing secrets if you buy now.

You can't exchange your brain for another, nicer, one.

Patients in hospital gowns should not have their rear ends displayed in public.

Chapter 36 simply talks about the eternal flux that is life and nowhere is this underscored but in living with MS. As we strive to increase our knowledge of this disease, we will be made to undergo various tests, ostensibly for our own good. Of course, the equipment used does look, well, antiquated but, as with everything else in MS, being forced to sit and stare at a television screen displaying alternating black and white squares won't last. Try as you will to emphasize to delivery clerks that your address hasn't changed since the last time they phoned and so there is no need to phone again, you will likely be phoned again by another clerk who missed that part of the conversation.

Thirty-Eight

A truly good patient is not aware of the troll sitting next to him in the waiting room.

And is therefore truly good.

The troll in question tries to help the good patient by talking endlessly about potato chips, hockey, politics, golf, non-conducting metals or socket sets.

And is therefore looking to be killed.

...

Ignore the troll.

I would really like to thank the following people and this is why...

For me to list every person who has blessed my life with their smile, wit, wisdom and loving kindness would take more disk space than I have. So, I will do my very best...

My husband, Adam Hunt, who has been there for me every time I needed him to hold me. For the many times he simply smiled at me, stroked my hair, wiped the tears from my eyes, cleaned me up when I couldn't move, put me through most of my university, held a bucket under my chin so I could barf during labyrinthitis, laughed at my silly cartoons (even the ones he didn't get) and assured me that we would be fine, I can't begin to thank him enough. It was through Adam that I got my first taste of my inner spirit; he was my tai chi instructor, who first told me of Lao Tsu, the *Tao Te Ching* and who is my unending support in all my endeavours. Adam is the one whose arms are around me when we fall asleep at night and again in the early morning when we rise. We don't start our days without a morning kiss and hug. How therapeutic! He is the one who quit his job to stay at home and take care of me. He is as affected by my diagnosis as I am and has had to muster up the courage to stick with me through all this. What a beautiful man!

Matt, Rachael and Nicholas Dye; my three beautiful children. They have had to undergo many changes in their lives before and (especially) after I was diagnosed. They were just as scared and, like me, they were hungry for knowledge. I made sure they were with me when I gave a talk in 2001 about Adapting to a Diagnosis of MS. I think they applauded the loudest. I wonder if they heard my heart twinge in simple joy.

Dr. Randy Knipping; aviation medicine in Toronto. Here is the doctor who (very patiently) tried many times to convince me to take up meditation and to convince me that it is okay for me to jettison unhealthy relationships. I finally actually paid attention and I am feeling and doing much better these days. I don't know how long that will last, but who does? Dr. Knipping has tolerated my little e-notes (complete with signature files consisting of bad jokes translated into different languages) with grace and good humour and for that, I am eminently grateful! Thank you so much Randy!

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Dr. Hyman Rabinovitch, at the MS Clinic here in Ottawa. I've already skied over 270 kilometres this season, doc, and I'm still going strong!

Dr. Peter Davison; my GP and both mine and Adam's Civil Aviation Medical Examiner (CAME). He has always been able to accommodate my needs, even if that meant he had to stay a little late because that was the only time he could see me. He has a love of flying that shows through his medical practice – even his waiting room magazines are current!*

Sogyal Rinpoche's book *The Tibetan Book of Living and Dying*; which was a gift from Adam! Each time I read it, I get something new from it. It isn't always a brand new epiphany, but, quiet or not, the book itself has brought me more reassurances than I thought possible.

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Okay, even Zuby the Dumbest Cat Ever (no really, she is! She used to eat silicone caulking!)

- *It's true! Dr. Davison's office does **not** have TIME magazines which ask whether man is really ready to fly to the moon..*

About the author:

Ruth Merkis-Hunt received a diagnosis of multiple sclerosis in August of 1999.

Since that time, she has both spoken and written about the psychological effects of this disease in public and with clients she saw while she was running her counselling practice. She has three children, one husband, novelist Adam Hunt, and a crabby and irritable cat named Zuby. Their home website is <http://web.ncf.ca/adamandruth/> . Ruth can be reached at rmerkishunt@yahoo.ca