COPING WITH VISION LOSS – Reflections on the journey

I have advanced glaucoma. The result is a gradual loss of vision. The passage from the sighted world to the unsightred is full of challenges. I would like to share my journey as a kind of ongoing blog. In addition to personal experiences, I would like to provide general information, and in particular the lessons that I and others I have met, need to learn in order to make the journey less harsh and more hopeful.

As I have got to know people with both partial and total blindness, I have come to understand that there are simiular patterns of adaptation. However, there are two main divergences, no matter what the cause. First, how quickly does the loss of vision occur? Aand secondly, what is the resulting degree of vision loss?

Like any other disability, it helps to not feel alone and vulnerable as the condition worsens. Information, guidance and support are essential, especially at the onset of irreversible losses that chip away at life-long habits and along with that, conditioned assumptions and expectations.

Before sharing my journey, I need to first give a list and brief explanation of the major kinds of visual loss.

(1) Macular degeneration: a disease that destroys sharp, central vision
(2) Glaucoma: an optic nerve disorder that starts with loss of peripheral vision
(3) Diabetic retinopathy: a disorder of blood vessels in the retina of someone with diabetes
(4) Cataracts: a cataract is a cloudy area in the lens of the eye that can cause blurry vision
(5) Retinitis pigmentosa: a genetic disorder
(6) Retinoblastoma: cancer of the eye – occurs in children and is relatively rare.

In addition, vision loss can occur due to infections and accidents. Less serious vision loss that is usually temporary can be due to migraine, keratitis, conjunctivitis and corneal abrasion.

A picture is worth a thousand words:

What you see with normal vision:

With macular degeneration;

With glaucoma:

To conclude this Introduction, I want to say that I am fortunate in that in my case vision loss has been very gradual over many years. In addition, although I have now lost peripheral vision in both eyes, I still have functional central vision in my right eye which is focussed enough that I can use an iPhone and navigate without use of a cane.

Ray Charles made a big impression on me when I first heard him around the age of 10. At that age, I had no clue that my father would be completely blind within fifteen years. I was learning the cello classically and exploring the piano on my own by ear. At first it amazed me that Ray could play the blues so soulfully without vision. In order to play cello classically, I took it for granted that vision was essential. Ray couldn't play piano from scores so he had learned notes, chords, melodic patterns through the senses of touch and hearing. The more I thought about it, the more I realized that even on the cello, it was touch and hearing that enabled me to shift positions on the strings. The visual sense was almost completely for 'reading'. And on piano, as long as I stuck to the key of C (at first), it didn't take long to develop muscle memory as far as basic chord positions and variations on the pentatonic scale. And it didn't take long to figure out that the dominant seventh chord and the flattened third note were the gateway to the blues.

From an early age I loved blues and felt an affinity for them. And later, when I watched Ray on TV, it was somehow comforting to know that if I was ever to lose my sight, I would still be able to play.

In my twenties, I was the keyboardist with the original Stephen Barry Blues Band in Montreal. At that time the lead singer was the incomparable Chaim Tannenbaum. Chaim also sang with Montral luminaries like the McGarrigle sisters and Loudon Wainwright. With support from the music community, the band became well known. However I knew that this was not the path I wished to follow. In 1976 I left the band in order to pursue my career in Education. Kenny Pearson, keyboardist with Janis Joplin, took my place.

It was in that same year that I visited my parents in Edinburgh. I knew my father had glaucoma and vision loss but I did not know that he had become completely blind in the years that I had been in Canada. During my visit, he had a stroke and died.

I did not think much more about vision loss until my forties when I too was diagnosed with glaucoma. There followed a couple of decades of prescribed eye drops to lower intraocular pressure. The ophthalmologist told me that glaucoma was genetic and that it was sometimes referred to as the cancer of the eye. It was progressive. There was no cure and the only treatment was to keep the pressures down.

Although I was aware of how vision loss was beginning to change my perceptions, it was only in my sixties that it had a significant effect on my day-to-day functioning. For example, gradually I realized that I could no longer take my usual driving habits for granted. My ability to see clearly in different light and dark conditions decreased, as did my peripheral awareness of cars merging into the lanes or approaching from the right or left. After some close calls, I decided I should give up driving. Around this same time the ophthalmologist became increasingly concerned about elevated eye pressure and decided that surgery was necessary. In successive years he carried out trabeculectomies, first on the left eye and then on the right. A trabeculectomy is basically an operation in which the outflow of fluid from the eye is increased by creating an 'ostium' to help filter out aqueous fluid – in simple terms, drilling a hole in the eye to release pressure. The goal is to slow the deterioration in vision for as long as possible.

I am fortunate in that, since that time until the last year or two, I have been able to function more or less normally. But at the same time, I had to start adapting to both the present situation and future consequences.

Now, in my seventies (77), as my vision has continued to gradually deteriorate, I have become more aware of how it has affected daily functioning. With loss of peripheral vision, anything that is up, down or to the side may not be seen and therefore potentially a danger. Curbs, steps, tree branches, furniture when you bend down, people when you turn around, are some examples of tripping, falling, bumping, hitting and colliding that I have experienced in the last few years. My brain is still conditioned by a lifetime of seeing things quickly and accurately and so being used to responding with appropriate movements. I have to keep reminding myself to slow down, check things out before acting, substituting caution for spontaneity and fast reflexes.

Psychologically, I have become more vulnerable and more in need of information and guidance. Three years ago in 2021, I joined CNIB (The Canadian National Institute for the Blind). A year later I joined VLRC (Vision Loss Rehabilitation Canada). Both associations offer services to the visually impaired. For simplicity's sake, from here on, I mean 'visually impaired' to include the whole spectrum from partially 'blind' to completely without sight.

I started learning whatever I could about the different kinds of eye diseases. I read biographical accounts of famous musicians such as Stevie Wonder, Art Tatum, Jose Feliciano, Ronnie Milsap and Andrea Bocelli, writers such as Milton, James Joyce and Jean-Louis Borges. There was so much I didn't know. I discovered there were even artists and sculptors who were blind such as Edward Degas and a contemporary Scotsman named Keith Salmon who paints landscapes including in the fascinating medium of what he calls 'painting with sound'. I also read memoirs and autobiographies – moving personal accounts by 'ordinary' people of going blind and being blind – the shock, grief, enormous challenges and necessary adaptations that they had experienced. Then there the extraordinary individuals like Helen Keller, Harriet Tubman, Erik Weihenmayer who climbed Everest and Paraolympians like Henry Wanyoike, the marathon runner. Such accounts would usually either depress me if I was feeling sorry for myself and grieving what I had lost, or inspire me if I was grateful what I still had and how much greater challenges others had faced and overcome.

I read about the 'stigma' of blindness and came across the term 'imposter syndrome'.

I had already experienced a kind of 'imposter syndrome'. I wasn't sure that I 'belonged' with CNIB. After all, I wasn't "blind'. It wasn't just that I thought others might think I was an imposter if I didn't have a white cane or seeing eye dog. I had conceptualized that perception myself in the past when, for example, I had seen a supposedly 'authentic' (white cane and sunglasses) blind person on a bus pull out an iPhone and immediately questioned whether they were in fact 'blind'. But now I was experiencing things the other way around. I had indeed lost peripheral vision and my left eye in general was hardly functioning. However, I still had central vision in my right eye that allowed me to use my cell phone and read signs and labels, given that the print wasn't tiny. My family knew I had irreversible 'advanced glaucoma' but I knew they had trouble understanding what I could and could not see. It was only then that I realized that an image would provide a much better explanation that words.

That said, once again, here are two image to show the difference between normal vision and what you see (and don't see) with glaucoma:

*Degree of side (peripheral) vision loss varies based upon severity of disease

It is quite common for people to resist accepting the reality of vision loss let alone the deterioration to actual blindness. In my case, I had initial resistance to joining CNIB. Then I had resistance to signing up for their Zoom sessions. In the past year that resistance has lessened. I had been told that my loss of sight could be slow and gradual, or it could happen quickly. Apparently there was no way of predicting. I realized I needed to set serious about preparing for any eventuality.

I started learning Braille and Voice Over (more about the extraordinary advances in assistive technology in a future post. But I definitely did not feel ready to use the collapsible white cane which CNIB had given me free of charge. Then one day I had a conversation with a guy who was almost completely without vision. He told me about an incident that had been a wake-up call to his inner voice of resistance. Years before, when his vision was similar to mine, he had been in a busy store one day and had just paid for a purchase. "I turned around to leave", he said, "and knocked over a young girl." He went on to describe how he was immediately confronted by a very angry mother and other onlookers. "There was no way I could tell them at that moment that I had vision problems. They wouldn't have believed me. They probably thought I was drunk or on drugs." He then explained that the white cane has two uses. One is 'sweeping' for obstacles. The other is to simply hold the cane in its collapsed state (about 16" long) to let others know that you are visually impaired so that *they* can be aware and cautious. He told me that following the incident in the store, he adopted that strategy.

Fortunately I have not knocked over a young child but I have collided with people on a couple of occasions and I nearly got hit the other day by a car crossing an alley. I was on the sidewalk but the driver didn't see me because he was talking to his passenger and I didn't see him because of lack of peripheral vision and because I had assumed I was safe on the sidewalk.

So … bringing things up to the present, I am in the process of trying to overcome my hangup about being seen as an imposter. I know it's about time to give some unambiguous visual signals to others.