



## **Living with Blindness and Chemical Sensitivity: Two disabilities with different challenges**

*Sometimes things happen in a person's life which are totally unexpected and life changing. For Manon Lavoie, this happened twice. At the age of 40, she became legally blind and now has only 5% of her vision. At the age of 48, she became severely chemically sensitive. Now 61 years old, Manon speaks with Barb Harris from UPdate about how these two disabilities affected her life.*

*What was your life like when you realized you were losing your vision?*

At the age of 39 I was a hard working woman. I worked 10 years for the Bank of Montreal. I was responsible for the current and savings department in a major branch. After that I was sales manager for the National Film Board for Quebec for 5 years. Then I worked 10 years in real estate. I was a very happy go lucky person. I had a lot of energy and I was happy with my life.

The most difficult part was not to know what was happening to me. Once I got diagnosed [with Retinal Pigmentosis], I was referred to the RPI Research Foundation. For the first time in my life I was in touch with people who had lost their vision. Some of them were completely blind, and some were partially blind. I realized that life was not stopping after that. I joined them and I did volunteer work for them for 13 years. I learned how to cope with the loss of vision. I learned that there were tools and appliances that I could use. Now I realize that the only thing that I can't do without vision is driving.

I had to stop working in real estate because I couldn't drive any more. So I followed an intensive computer course for 8 months. Then I started working from home. I was working for a major newspaper in Montreal, *Le Devoir*, and at the same time I was helping companies organize their telemarketing departments. Both of these together were bringing me a very good income.

*Did becoming blind change your social life and your friendships?*

I did make new friends because I joined the RPI Research Foundation. But I didn't lose the friends I had. They were very sympathetic. I think at one point

it was almost harder for them than for me. They were scared for me.

If I was going shopping with a friend, I used to say, well you need to go slower, or I have to take your arm in order to be able to follow you, but that was about the only thing that was a problem. It didn't stop me from cooking or entertaining or having people home.

There was another problem. I was having a relationship at the time. My partner was a very hard working man also, and it was difficult for him that I was not the Manon that I used to be for him. I was not as active and he thought that I might become, I guess, more vulnerable or more dependent, and the relationship started to deteriorate. I was saying, 'I think I am doing quite a good job. If you are having a hard time accepting my vision loss, I don't think I can help you in trying to cope with my disability.' I was trying to cope with it the best I could and it took my energy. So finally we did break up, but I don't think that the vision loss was the only problem.

*What was the most difficult part about losing your vision?*

For me, having a car was a very big thing in my life. I really thought that life was going to end without a car. I thought I was losing a lot of my independence.

But then I started walking, and I started enjoying walking. But still, after so long, I miss having a car. Especially with my sickness now, I'd really like to have a car so that when I'm not feeling good I could drive somewhere where the air is good and try to recuperate somewhere. Maybe I wouldn't have enough money to have a car anyway, but ...

*At the time you became chemically sensitive, what was your life like then?*

That was 13 years ago now. I had adjusted to my vision loss. I had a beautiful apartment where I had my office. I had a lot of friends. I had moved back to Montreal because of the transportation difficulty. I had lived many years in Montreal so I got my old friends back. We were always meeting and going to a restaurant -- you know how Quebecers are, talking, eating, drinking. I was working during the day and in the night either we were dining at some one's house or going out to dinner, or going to see a movie or a play. It was a very social life.

*How did you become chemically sensitive?*

I rented a new apartment in January. In summer, I got the apartment painted. Maybe a month after, I started feeling a little bit sick, more like a flu or a cold.

One morning the fish in my aquarium were all dead. I didn't ask myself many questions then. A couple of weeks later my cat started coughing. I thought he was having a fur ball. I gave him some medication, but he was still coughing and coughing so I took him to the vet. By that time, I was also feeling sick.

The vet examined him and she said, 'There is nothing wrong with your cat. He is in perfectly good health. I think his coughing is due to your environment.'

I was getting sicker and sicker, and I was getting some skin irritations. One night I was watching TV and I had my cat on my lap and he was coughing and it just clicked. I thought, 'I'm sick, the fish died, the cat is sick -- something is wrong in my environment!' I couldn't believe it was the paint. I started making all sorts of phone calls, I called the Public Health Department, I called the Department of Health Services, but nobody could tell me anything.

I was seeing the same doctor for 13 years. I would see him once or twice a year, if I had a cold or something. Then I started getting all those symptoms. I kept going to see him and he kept referring me to one doctor after another. Finally, somebody referred me to Universite de Quebec. A lady there asked me all sorts of questions for over an hour. At the end she said "Mrs. Lavoie, you have environmental sickness." Eventually, I called the company which made the paint. An assistant there said, 'Yes, we had a problem with a batch. Call where you bought the paint and they will replace it for you.' So that's what they did. I got the whole apartment sanded and repainted. I tried to return to the apartment, but I could never go back. My cat died. My cat couldn't make it.

My GP referred me to a dermatologist. She said, 'I'm not used to working with chemicals, but I know a doctor in St. Claire who has worked a lot with pesticides, and she might be able to help you.' So she referred me to Dr. June Irwin. The next day, I was in Dr. Irwin's office for four hours. She told me that I was chemically sensitive, and that I had probably been exposed to toxic products. In the meantime, I had seen a toxicologist who diagnosed me with chemophobia. He referred me to a psychiatrist, and he diagnosed me with delirious problems.

Finally I called the CMHC and I was in contact with Jim White. He explained to me that when a paint is defective..... after the water or oil dries out it goes back to its original state which is a powder which is left in the air. That is what I ate and breathed. I was working from home so I was there most of the time. It entered my skin, it entered my food, it was everywhere. I had stayed there for almost 8 months before I was aware of what had happened.

I was not working at all throughout this time. I was too sick. I couldn't stay in my house, and had spent my savings cleaning my apartment -- sanding, repainting, cleaning the ventilation. So I ended up in shelters, which are for a maximum of three weeks. I went from one to another. I lost everything. I had to get rid of all my furniture, my clothes.

*When you got a diagnosis that you were chemically sensitive, did you understand what that was going to mean for your life?*

No. June referred me to an environmentalist doctor in Ottawa, Dr. John Molot. When I saw John Molot I had testing and found I was reacting to formaldehyde, phenol, chlorine, oat, corn, milk, vinegar, tomatoes, all sorts of things. I had never had any allergies before. Everybody was very happy for me that I had been diagnosed finally. I remember I was with a girlfriend and we were going through the documentation that Dr. Molot had given me. She was quite desperate reading all that I was reacting to. Finally I said, 'I guess I have only two problems in life', and she looked at me as if to say what... only two, and I said 'yes, its only that I eat and that I breathe. If I stop these two things I'll be ok.'

I fought for so many years against this sickness, trying to push myself, saying I'm going to make it anyway, but it never happened. I just got sicker and sicker.

I was not working any more, and I was not on disability yet. Then I realized I could ask for disability because of my vision. They would not give me disability because of my sensitivity, but they would give me disability because of my vision. My income was \$600 a month. I found an apartment for about \$400 a month and then I got sicker and left that apartment. I think I moved about 40 times in 10 years. I would find a place, and after maybe a month I was finding that there was something in the apartment that was making me sick.

*If you had had a stable place to live, could you have worked?*

No, I was feeling too sick. I had a hard time breathing. I had a hard time concentrating. The vision that I have left becomes all blurred most of the time because I am reacting to things. I feel dizzy most of the time. I cannot take on any commitments. I even have a hard time making it to my doctors appointments - sometimes I can do it and sometimes I can't.

*How did being chemically sensitive affect your friendships and your social life?*

Oh that, well it was finished. Nobody believed me. Nobody wanted to believe me. I was telling them I was reacting to them if they were wearing perfumes and things like that. Well, people just stopped coming, even my nieces, my family. Still today I don't think that they believe me. They will say, are you still into that thing, as if it was a philosophy. It was very hurtful.

At the same time it was hard for me to fight to explain to them. I didn't even have the energy to do that.

Finally, I met Joel Kreps who is a psychiatrist who is environmentally sick. Joel was a great help. He was always very helpful, especially when I started questioning myself, wondering whether it was psychiatric or physical.

That's the difference between my vision and being chemically sensitive. With my vision, nobody ever questioned whether it was psychiatric or physical, so I didn't have to debate that. Rehabilitation for my vision was concentrated on helping me in finding a job, helping me in being functional in a job, finding tools and all that. I didn't have to debate whether it was real. With chemical sensitivity, you always have to debate that I find.

*When you became chemically sensitive, did it change your self image, your sense of where you fit in the world?*

I don't think it has changed the inner part of me. I'm still the Manon who I was in my mind, and I am still the same Manon that I was when I lost my vision. I fought that. I managed to make it with my disability, but now I can't make it. I can't because I'm physically ill. My vision loss didn't bring me any pain, and I didn't have a hard time breathing, and I didn't feel tired all the time, and I didn't have any muscle pain, and my skin was not itchy from head to toe, 24 hours a day. And I didn't have to justify to people, because I had my white cane. People saw my white cane and they said, oh well, she's blind. If I wear a mask, they ask themselves who I am, or what I am. If I say that I am chemically sensitive, well, you see question marks in their minds.

*Is there a tool that could put you back to work with chemical sensitivity, or at least make your life better?*

Treatment.

*How do you compare the medical help and support that you get for your vision loss and your chemical sensitivity?*

It doesn't feel the same to me at all. I find I am more handicapped with my sensitivities than with my vision loss. The most difficult thing for me to live

with is that I know there are cures, or treatments that are done, that I cannot get. That is quite frustrating.

When I lost my vision, they were saying, whatever tools I needed to counter the disability I could get it. They would give me a \$15,000 computer and equipment so that I could do the work I needed to do on my computer, and they would give me the white cane, and they would give me magnifying glasses, and they would give me tape recorders, because the sickness is recognized and the government is willing to pay for these things for us, because we are blind.

But when we are chemically sensitive, the government does not want to pay for the blood tests that we need, they don't want to pay for the treatments that we need, the chelation, the IVs, the acupuncture. I did try acupuncture at one point, and I found it was helping me a lot. I could not continue it because I didn't have money. These services are not paid on the medical card, but everything I need for my vision is paid by the [Quebec] health card.

The most important thing that I would like to add is that I wish that they would stop linking environmental sicknesses with psychiatric sicknesses. I just wish that that debate would be written off once and for all, that we wouldn't have to fight that.

I wish that they would provide us with the proper cure and treatment that we need in order to make us functional, independent people.