

MY HUSBAND'S JOURNEY WITH NORMAL PRESSURE HYDROCEPHALUS

My husband Frank's journey began in the Spring of 2011. We had been retired by then for nearly 19 years. We try to stay active and enjoy walking, especially along the Seawalls in West Vancouver or North Vancouver. We also went to the local Recreation Center for Senior's exercises on a weekly basis. So life was rolling along very well and we were both enjoying travel and good health.

I started to notice a difference in my husband's walking, but just thought maybe he had bumped his leg, or slept the wrong way on it the night before, and so I didn't mention anything to him. But it didn't improve any at all. He was not walking his normal long stride, but taking smaller steps and dragging his feet, especially the right one, and leaning to that side. I would ask him why he was walking that way he would say "I don't know". I asked if his legs were hurting, and he said "No, I just can't move them". That was the only way he could describe it. And that was always the answer when I would mention it

Then a few weeks later when we were out walking, he said that his balance was "off" and he felt a bit dizzy. So we had to sit down on a bench for a while. Those were the only symptoms he had---his walking gait, shuffling of his feet, leaning to one side and the problem with his balance. The condition seemed to be staying at the same level then and didn't seem to be getting any worse, so we let it go for a while. I was looking up things on the internet, and everything seemed to point to it being Parkinson's disease. We carried on with our life and even went on a cruise to Hawaii. One 24 hour period on the ship, was the roughest time we had ever had on a cruise ship. He would remark that it was a bit hard walking on the ship that day, but nothing too unusual. We were hitting 25 foot waves! That night at dinner the dining room was almost empty!! But my husband & I were there eating with gusto. So we figured his problem couldn't be anything too serious, since this movement wasn't affecting his balance too much.

After we returned from the cruise in September, my husband went for his annual checkup with our family doctor.



Frank and Lorraine Newlove

and of course we told her about his problem. She checked him over and said she didn't think it was Parkinson's, but said he definitely had a problem of some kind. She sent him for a CT scan. Of course, there are always long waits for procedures, and then waits for the next Dr. appointment.

When we went for the results of the CT scan, the Dr. said yes, we have found something. But don't worry it isn't a tumour or cancer. She said it was something called "Normal Pressure Hydrocephalus". Right away I said "I know what that is. My Great-nephew was born with Hydrocephalus and had a shunt put in 28 years ago. She said this was a bit different than the type that babies are born with, and explained what it was. She made an appointment for us to see a Neurosurgeon about 6 weeks later. My husband was the only patient our family Dr. had ever seen with NPH!

Our children were very anxious of course, to hear the results from the CT scan, so I phoned them that night. Our daughter right away said "I can't believe I didn't think of that". She has her PhD in clinical psychology and said that it didn't cross her mind. She said that of all the things this could have been, this was the best outcome. Our other daughter was SO relieved; as she was afraid he had ALS! I'm certainly relieved she didn't mention that to me at the time!!!

By now we were also beginning to notice a slight change in his mental ability, mainly trouble remembering people's names, but he was 79 at the time, and we thought it was just normal aging. I also have trouble remembering names of people too, especially if you don't see them on a daily basis. The one symptom of NPH that he didn't have at any time was incontinence, which was a relief.

On our visit to the Neurosurgeon, he checked him over, but wasn't quite sure it was NPH and wanted to send him to a neurologist, to see if there was something else causing his symptoms. Weeks later Frank saw the neurologist and he said he wasn't too anxious to put a piece of plastic in his brain. We were told to come back in 6 months.

In the meantime, I had been on the Internet and found the Spina Bifida & Hydrocephalus Association of Ontario. I contacted them right away and asked if they could send me some information on NPH. I had an answer immediately asking me if the information I wanted was for a child or an adult, as there were two different packages. In no time I had a large package of information. This was so helpful for us. We read every article and learned more about Normal Pressure Hydrocephalus. But with NPH being so unusual, there was never a person that you met who had heard of it, or knew anyone with it. I kept saying it would have been so nice to meet someone who had gone through this and talk to them about it.

Frank didn't tell me, but he had started falling when he was working in the garden! So, we decided it was time to sell the house we had lived in for 42 years and move into a condo where we had no steps and no garden to look after.

The biggest blow for my husband was in the Fall of 2012. His birthday was in Sept. and he was going to be 80---a very young and active 80!! In British Columbia, when you reach this age, the Government sends you a legal sized document which you have to take to your family doctor. It has all sorts of questions pertaining to your health and ability to drive a car. My husband has driven since he was 16, and always said he would drive until he was 100. The doctor had to report on this form, that Frank had a neurological condition, and had to give him a Cognitive test. Unfortunately, Frank kind of froze when the doctor started asking him all the questions. Three months later my husband was asked to turn in his license!! That was a bad day. Lucky he has a Chauffeur.

As time went on, his balance started to get worse. This was the hardest thing for me. I was always afraid he would trip or fall, and there was no way I could pick him up. I couldn't let him go out walking by himself. He was always more comfortable in the condo, with no balance problems. Maybe it was the walls around him. So, for a long time we would walk in the malls as he was better there too. One day we were out walking on the street and his balance got really bad, the worst I had seen. I had so much trouble trying to get him back to the car. He was leaning way over toward his right side away from me. I'm sure people driving by were saying "look at that poor woman trying to get her drunk husband back to the car"! Once he sat down, he was fine, but I sure wasn't fine. It was very scary.

A few weeks later Frank had another appointment with the neurologist. I told him about the balance incident and how bad it was, and right away he said to meet him in emergency the following week and he would do a Spinal Tap to release some of the pressure and see if it made a difference. He took off quite a bit of the cerebrospinal fluid, and for the next 14 days my husband was perfect!! At last!! However, on the 14th day his balance went off again. As soon as the neurologist heard the results, he said it was time to go back to the neurosurgeon and get the shunt put in. He looked at my husband, pointed his finger at him, and said "If you were my Dad, I would tell you to have the operation". He also told us that the dementia he had, was the only kind that was 100% curable.

Frank had his surgery on March 6 of this year and has never looked back. It is amazing what that little shunt & valve can do!!! Within 2 days he was walking through the halls in the hospital and lifting his feet right up off the floor. His balance was great and he didn't lean to one side anymore. The big surprise is how other people are seeing him now. I see him every day so I guess it isn't as obvious to me, but everyone says he looks so much better! He has more expression in his face, his color is better, he moves his hands around when talking, instead of them just hanging by his side. The only problem is that he wants to be out walking all the time----he's wearing me out!!!.....And I'm loving it!!!

We went back to Ontario in June, and the last time all our family had seen Frank was in January for a wedding. They were all so surprised to see him looking so well and looking so happy. They couldn't believe the difference this surgery made to him.

We will continue to support SB&H, in the hopes that someday a complete cure for NPH will be found. Or at least find a way to diagnose it faster. The sooner the shunt is put in, the better. You shouldn't have to wait 3 years or sometimes longer, to have the surgery once the diagnosis has been made.

Thank you for all the information the Association has given to us.

Frank & Lorraine Newlove

Hydrocephalus Canada

We are the voice of
Canadians living with hydrocephalus.

Every day we strive to empower those impacted by the condition to experience the best life possible.

We do this by establishing environments that protect, support and enhance the lives of those living with, or at risk of developing, hydrocephalus.



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