BRAINWAVES
HYDROCEPHALUS
CANADA

Meet Gilda

Personal Story

Five Years After My Shunt

I hope this article will offer some encouragement and guidance to adults with late onset hydrocephalus and their families. As I start writing this, five years almost to the date after my shunt surgery, I am almost back to my normal self. I feel as if I have been given a second chance at life, so great is my improvement.

I am now 73 years old. In April, 2007 at age 67, I had a ventricular peritoneal programmable shunt inserted in my brain at St. Michael's Hospital, Toronto because I had adult onset idiopathic Normal Pressure Hydrocephalus, also known as iNPH. The diagnosis took over two years to make and even more years to confirm. I saw many specialists, from an allergist to a cardiologist, a respirologist, a rheumatologist, and a urologist, but I always tested "within the normal range". My first awareness that something was wrong had been a difficult to describe but distinct feeling of tremulousness inside me, in the fall of 2001. I then started to feel I was walking on gum, that I could not lift and place my feet down in a normal manner and almost was shuffling along. I progressed over time to requiring a walker and then a wheelchair, to uncontrolled urination, to having difficulty concentrating and understanding complex ideas, and to having trouble remembering things.

My husband is fond of saying: "During the Jewish High Holy days in September, 2006, before Gilda was shunted, I had to take her to our synagogue, which was half a kilometre from our house, in a wheelchair. During the same events in 2007, she walked there and back each day for the two days of Jewish New Year, and three times on the Day of Atonement." However, my memory, concentration and ability to figure out things were still weak and I was still urinating frequently, sometimes without much control, despite taking a medication prescribed by a urologist.

My Life Pre-shunting

I would like to share what my life was before my final decision to get shunted. I saw several neurological specialists along the way some of whom encouraged shunting and others who felt I should wait. Well into my search for a diagnosis I was told by one highly respected specialist that it was "all in your head", meaning it was only psychosomatic!

Gilda in Venice, Italy.

Doctor A (movement disorders): "You've persuaded a doctor to order an MRI and are now pinning everything on it.“

"Not true", I said - I hadn't even known what an MRI was. Having an MRI had been the decision of my GP who had already arranged an appointment with a neurologist as nothing else had explained my symptoms. When the results of my MRI came back the neurologist said, "I find it difficult to believe, but you seem to have hydrocephalus. I'll send you to a neurosurgeon, because they know much more about it.“

Doctor B (neurosurgeon 1): "Come back when you are in a wheelchair and diapers and not taking notes.“

Doctor C (consulting neurosurgeon): "I see some signs, but you are not ready for surgery yet.“

In view of these and cautions from my neurosurgeons regarding the risks of shunt surgery, I decided to go to the US Hydrocephalus Association's annual conference, held that year in Baltimore, Maryland to learn more about my condition. I went with my younger daughter and a fellow member of the SBHAO adult support group (described below). I was going from one session to another, when I lost control of my walker and walked into a wall. This attracted the attention of one of the speakers, Dr. Michael Williams, a neurologist who then was co-director of the Adult Hydrocephalus Clinic at Johns Hopkins University Hospital and a member of the Association's Medical Advisory Board.

Dr Williams: "If you like, I'll see you for a consultation in a month regarding your diagnosis and potential for benefiting from a shunt. I can see you in three months for a continual lumbar drainage test, under special conditions which require you to be in a neurosurgical bed for three nights.“

The test was known in Ontario, but rarely done because there aren't enough neurosurgical beds to reserve one 'merely' for four days of testing. I have since learned that now it is being done in London, Ontario. I wish that had been true six years ago, because having done it at Hopkins cost us over eighteen thousand dollars. The results also are not "gold standard", as so much related to iNPH seems not to be. If your results are negative, it does not necessarily mean that you won't benefit from being shunted. Think about it.

In addition, lumbar drainage must be carried out very carefully, as it involves continual drainage of cerebral spinal fluid via a lumbar catheter, which stays in place for three days. There is a significant potential for infection. It requires careful monitoring to avoid over-drainage, frequent testing of one's walking ability, and repeated cognitive testing. After the first full day of drainage, Dr. Williams took me out in the hall. Pointing to my husband at the end of the corridor, and with a twinkle in his eye and a proud look on his face (or so I interpreted), Dr. Williams said to me, "Walk over to your husband and give him a kiss."

"Walk without a walker?", I thought, "I can't!“

But I could and I did. I felt like a patient in the movie Awakenings, in which people who had been "frozen" in time and space due to their infection during the 1918 influenza pandemic became functional (for a time) after being given 'el dopa'. I wondered whether a similar time-limited result might be my fate. So far it hasn't been.

The testing at Hopkins indicated that I had an 85 to 90% chance of significant improvement with a shunt. This was an enormously important result. I had been told in Toronto, "About twenty percent of patients suffer inter-cranial bleeding and possible strokes while on the operating table during the shunting procedure, and something like five percent actually die; while statistically only about half of those shunted experience significant improvement in their symptoms." This was the dilemma I faced. "How can I find out which half I'd be in", I thought? Dr. Williams offered me an answer.

In the United States, if one isn't on welfare receiving Medicaid, or doesn't have an employment-related or other paid health plan (HMO) that covers the specific medical situation, on entering the hospital one first pays and only then enters the treatment area. In our case, we had to present our credit card (whose limit we had already raised substantially). The total of some $18,500 CND covered the original consultation, testing, doctors' fees and the hospital stay of four days and three nights. Thankfully we had a GIC we could use - due to a technicality OHIP refused to reimburse us for the medical expenses. We should have applied before we went, which until the last minute we did not know we had to do and which did not make sense. Further, my condition was steadily deteriorating - if I didn't seize the moment offered by Dr. Williams because he'd had a cancellation, I likely would have had to wait another six to eight months! Surely, we thought, it was one's medical condition and circumstances that ought to prevail, not a regulation cooked up by the Health Ministry. Our appeal failed, but the high fee made me more cognizant of and still grateful for our OHIP system despite its limitations. I believe that test saved my life. It gave me confidence to have the surgery in Toronto (which was fully covered by OHIP), despite its risks.

Spina Bifida and Hydrocephalus Association of Ontario (SBHAO)

Long before I was properly diagnosed, let alone shunted, I had investigated pre- and post-operative services and found there were no support groups for adults with hydrocephalus, and my husband and I wanted to join a support group. I called the Spina Bifida and Hydrocephalus Association of Ontario (SB&H) and asked if I could set up an Adult Support Group under their auspices.

"I'm a social worker and have worked with groups much of my professional life, and I'm confident I could take this on with help", I told the director. She replied, "Lets set up a meeting.“

After we met, the director offered me the library at the Association's headquarters, a staff member to attend and share the group meetings, and their use of e-mail and newsletters to contact potential attendees and advertise the service. We have been meeting once a month for over eight years, and include a conference call component so people can call in without charge and participate from anywhere in Ontario.

We've had approximately 31 people over the years. Some stay on, while others drop out once they feel they no longer need our support, and still others come back from time to time as their condition changes. Here are some examples of issues we've dealt with: a woman born with hydrocephalus was shunted soon after birth and then had 17 revisions, but though she's been OK medically for over 20 years, she has issues that she finds the group able to help her cope with; sisters who needed to learn more about the iNPH of their newly diagnosed father got first hand suggestions and information; a just diagnosed but not yet shunted young mother, whose own mother was trying "natural" methods to help her that were not working, found the group's shared experiences very helpful; a young man who had three shunts in his head and was working through a hard period with the intensive help of his family, who came with him until the situation was resolved, received the strong support of the group; a middle-aged professional woman (together with her husband), whose working ability had been severely compromised by adult onset hydrocephalus, received sympathetic advice towards her decision about shunting; two women who were each struggling with their decisions regarding ETV (endoscopic third ventriculostomy), an alternative to shunt surgery were able to talk to a group member who had recently been through the operation; and many others, each with their own unique stories and problems.

Course of My Post-Op Rehabilitation

Now that I am at the five year post-op mark, I feel I've been given a second chance at life. In addition to getting the shunt, my improvement has taken a lot of hard work. Following surgery I was told I needed to strengthen myself physically. I had never participated much in sports or exercise apart from swimming, which I loved. After trying the help of a personal trainer without much success, I decided to take aquafit exercise. For about a year I did exercises in a large group at the Bathurst Jewish Community Centre run by a woman who had been through a serious accident and used her skills to lead the exercise group as part of her own healing. Her example was an inspiration to me. Unfortunately, this facility was shut down. I took an eight week day program at the Baycrest day centre which got me out of the house and helped me with memory and some physical activity. They also had games such as scrabble which I enjoyed. I tried Feldenkrais, a movement therapy that teaches ways of moving to help relieve pain and improve mobility. It did not suit my temperament although I picked up some good pointers such as how to get out of bed more easily, which I was finding hard.

I took aquafit classes at the Douglas Snow Aquatic Centre at Mel Lastman Square, and attended until my application to Toronto Rehabilitation Centre's Neuro-Rehab facility came up in late 2009 for an eight week intensive asessment service.

The assessment team (nurse, physiotherapist, speech pathologist, occupational therapist, and a geriatrician) met with my husband and me, took a history of my hydrocephalus, and developed a specific plan for the eight week period, during which I attended their facility twice a week. At the end, they recommended I go to the 12 week geriatric program given in "H Wing" at Sunnybrook Hospital. Although at first I rejected the referral because it was called "geriatric", I changed my mind and decided the name was not important.

What was important was the service they offered; it was right for me. It consisted of physiotherapy, speech therapy, occupational therapy, and art therapy. Pictured with this article is a painting I did after many years of never drawing anything, although in public school I had been very good. The staff were always accommodating, encouraging and kind. At the end, in the early spring of 2010, they asked me, "What would you like to do to continue your rehabilitation?“

"Aquafit in a warm pool with a good instructor", I answered right away. They suggested Suomi Koti, the Finnish Canadian retirement residence, which is not very far from where I live. The salt water pool is warm, I go two mornings a week, and the instructor is truly marvelous. He stands on the side of the pool and for 50 minutes demonstrates exercises, which we follow. Due to my still present, though significantly lessened, memory deficits, this is the kind of instruction that works for me. My walking and balance have improved a great deal. In the early spring this year my husband and I went on our first cruise - to eastern Mediterranean ports and Venice. I was able to walk everywhere, up and down the Venetian bridges over the rest stops. I even made it most of the way to the Accropolis in Athens! I owe a lot of my improvement to this instructor for his kind ways, repetitions and his overall effective program.

Before I was shunted I had felt it necessary to resign from my elected position on the Board of Directors of the College of Social Workers and Social Service Workers. I found I couldn't concentrate during the meetings and I had problems understanding complex ideas. I have regained some of this ability, probably due to my efforts, but I still often do not feel comfortable with complex ideas and I tire easily. After my operation and until I tested myself by taking that Mediterranean cruise I did not want to do cooking or housework and was often apathetic. In retrospect, I think I was depressed because I had taken early retirement and my job was an important part of my self-concept and self-esteem. I also loved working. But I was afraid of making mistakes and did not want to face the consequences. I gradually recovered using volunteer work as a means. I also started to help my husband and now share making meals and cleaning up, and I willingly take the garbage down the hall to the chute.

I still use a cane, and am always careful when walking in both strange and familiar places, especially where the ground surface is uneven. My husband always alerts me to this condition so I am not taken by surprise by a sudden rise or drop. While on the cruise I fell twice, once missing a step leading from the bathroom into our bedroom, and once as the ship lurched when I was not expecting it. I had no symptoms, no headache, nausea or dizziness, nor any pain. In preparation for my annual neurosurgical check-up last April, I had a CT scan which showed that for the first time in five years my moderately enlarged ventricals had shrunk somewhat. This may be why I feel better. I also learned that I'd had a small brain bleed most likely due to the falls on the ship. Though it did not seemingly affect me, it indicated some problems related to the shunt that my neurosurgeon felt called for additional tests and scans. He saw a larger than acceptable space between the inside of my skull and the surface of my brain – called the sub-arachnoid space.

Community Services I have Used

I use Wheel Trans to get to various places and programs which help me improve. I also am privileged to have been accepted as a client by the Community Care Access Centre, which we arranged from the hospital after surgery. The services they provide help me with showering, laundry, some food preparation and a few other personal things. My hydrocephalus has rendered my fingers less flexible. These services also help my 72 year old husband who has taken a lot of care of me and understands more about my condition than I do. He accompanies me to my many medical appointments, does the food shopping, keeps track of my meds and appointments, and is often exhausted. It is important to consider your caregiver or partner's health in your plans.

I took a 12 week memory program at Baycrest and try hard to use the hints they gave to improve memory. One of their suggestions was to use a daily diary or planner. On the whole it is very helpful; however I don't always remember to look at it! I do large-print word-seek puzzles (crosswords or sudoku are also very good) and we purchased a Nintendo DS machine with two "Brain Age" software chips which have a large variety of mentally stimulating exercises and it keeps track of my performance. I try to use it daily to increase my mental ability and speed, and thus form new connections in my brain. I joined a choir, because singing is good for your brain and strengthening synaptic connections. My first choice in a choir was above my capabilities, but I stuck to it for a year. I then joined a less demanding community choir and have been working at it for almost one year. It is a challenge for me because I cannot read music. Challenges such as learning piano or a new language are supposed to help return some of one's mental and cognitive abilities. Lately, I joined a creative writing group, which encourages me to write a story or poem each week. In fact, this article began as one of my assignments for the group. Writing is stimulus for the brain. I joined the American Hydrocephalus Association, which has a helpful newsletter sent to me by e-mail that compliments SB&H's excellent Current magazine. For many years I also have subscribed to the Hydroceph-L listserver. Although many of the postings come from parents with children who have hydrocephalus, there are enough comments from adults with the condition and their families to keep me interested. I am also able to share my own experiences and give advice to others on the list. One cautionary note is that it's usually people who are experiencing difficulties who post messages and questions.

I am lucky that my condition did not become severe until I took early retirement from work. By the time my final working day came I literally could hardly walk out the door. I also voluntarily gave up driving because I realized my perception, reflexes and judgment were not good enough to drive. Although I wish I could give up a leg or an arm (LOL) and not give up driving, I know it was the proper decision to make and my husband supported me in making it. I could not face being the cause of an accident with injury to myself or others.

Giving Back

I have always tried to help others and indeed chose to work in a helping profession, social work. But when I could no longer practice as a professional, due to my cognitive limitations, I searched for ways I could help through volunteer positions. I also realized this would help me too as it would stimulate my mind and help to rebuild my self-concept which takes a real battering with iNPH. Once a week, I work with a developmentally challenged man in a literacy program run by the public library. The choir I joined goes to seniors' residences and gives concerts, which the residents really appreciate. Sometimes they sing along with us. One evening a week I meet with immigrant women at a conversational English program run by the Salvation Army.

However, volunteering is not all rosy or ego enhancing. I once was asked to leave a program which taught children math and I was asked to leave another volunteer position when I revealed my illness. Both of these were blows which I handled by searching for less challenging positions. I also volunteered at an after school homework program for new-Canadian children but left it voluntarily after a year because I often did not have a child to work with when I arrived and it was clear to me that the children preferred the teenage volunteers to a grey haired lady like me. There, my grandmotherly image did not work.

Then There Are The Draggy Things

Because Adult Onset Hydrocephalus usually occurs in one's '60's or even later, one is also experiencing co-existing conditions of aging. I dislike the large number of follow-up medical appointments I have to attend. I know they are important but there are so many!

I have annual appointments with a urologist, a heart specialist , and a gastro-enterologist (I developed colon cancer and was operated on eleven months after my shunt surgery). My cancer operation was highly successful; I did not require either radiation or chemotherapy. This year I thought I had to have another follow-up colonoscopy, but found out that there is an effective alternative that does not involve any unpleasantness. I have Type 2 diabetes and see my GP every four months. It was discovered during the course of exploring my symptoms pre-shunting. My condition is controlled with medication and diet. I am not a happy camper, however, because I love sweets but I check my glucose levels every morning and have cut down considerably on sweets.

I've had two MRI's over the past year to keep an eye on a benign multicystic lesion on my pancreas. Since preparing for my annual neurosurgical checkup last April, I've had four CT scans, three invidvidual x-rays (head, chest and abdomen), a nuclear shunt patency test, and a special brain scan - all because of the small brain bleed I had following my fall on the cruise. I had an ultrasound in May to investigate a lump that was developing under my skin where the distal end of my shunt goes through my abdominal wall and into my peritoneum. The lump turned out to be a small hernia which they don't treat. And then there are visits to the dentist every four months for cleaning, and a podiatrist appointments every six weeks. Breast screening examinations come every two years. I know I should be grateful rather than 'gripeful' that we live in such a wonderful country with good medical care, and deep down I am.

I encourage everyone reading this to fill out all evaluation forms for any service received, as this will help with grants. Some of the current research in hydrocephalus involves looking at families to see if there is a familial history. My family seems positive for hydrocephalus on my mother's side. Years ago a maternal uncle of mine was wrongly diagnosed with Parkinson's disease. We visited him in the hospital where he was in a wheelchair - basically nonverbal and looking terrible. A bright young resident saw him at one point and thought he should be taken off Parkinson's medication and checked for hydrocephalus. He was diagnosed with iNPH, shunted and the next time we saw him he was dancing with his wife at a wedding, and enjoyed several years of quality life before he died. In addition, a cousin of mine 6 years my junior was diagnosed with hydrocephalus and responded to a shunt. I also had another cousin on my mother's side, a male who was diagnosed with hydrocephalus but not shunted because of his advanced age and a number of other co-existing conditions.

Post Script

Just as I was putting the finishing touches to this paper I saw my neurosurgeon in late August for the results of the third CT scan of my head done in mid-July, and the other earlier tests he had ordered following my mid-April appointment with him. The results showed that I had been over-draining since the second CT scan at the end of April. On checking my shunt, he found that the shunt setting had moved from its usual mid-range 1.5 to the lowest setting of 0.5! We had to conclude that the neurosurgical resident who had checked my shunt setting right after my June abdominal MRI likely had not reset my shunt correctly. However, I had experienced no dangerous clinical signs since then, and the mid-July CT scan did not show evidence of any bleeding. Indeed I was not only feeling better but for the first time in several years I have been able to swim.

At the August appointment, my neurosurgeon reset my shunt to it's 1.5 mid-range setting, the setting which it has always been set since it was placed in my head on April 24, 2007. I am assured that the setting is now correct. A fourth CT scan in mid-September, demonstrated that the old equilibrium had been re-established. My advice to everyone with a programmable shunt such as mine, is that after an MRI, which subjects your shunt to an extremely powerful magnetic field, make sure that the setting is checked by someone who really knows how to use the detection and re-adjustment devices. They are tricky to use correctly.

At my 73rd birthday celebration in late July, for the first time in my life I experienced a few moments of slurred speech. I had no other symptoms and it completely cleared up after ten minutes and has not repeated. It seems likely that I had a TIA (transient ischemic attack, or mini-stroke) possibly due to the overdrainage of CSF as a result of the incorrect shunt setting. My neurosurgeon is very doubtful about this as a cause. My GP has ordered a test which may result in my having to take some type of blood thinner. And so it goes - never a dull moment and always seeking new challenges.