

Would You Like A Cup Of Tea With Your Syrinx?

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By Esther Aitken, Somerset England

"Have you heard about your scan?" My mother asked. She rang me one Thursday morning in January 2004.

"No" I replied "But I expect its okay. I'm sure they would have let me know by now if there was anything wrong." I said reassuringly.

The scan had been a week ago, last Friday evening. I had waited seven months, my case was not considered urgent. The ear nose and throat consultant I had seen thought my loss of balance was due to small growths in the inner ear and it was hoped this would show up on the scan.

I had progressively deteriorated, experiencing vomiting, usually triggered off by strong tastes and smells like morning sickness, violent headaches, tiredness, unable to do anything, even read a book. In the last few days I had noticed my left hand feeling numb. For nine months I had been unable to work. I was a nurse at the small hospital in the town where I lived.

I had been back and forward to my General Practitioner. I was treated for sinusitis taking several courses of antibiotics but felt no better.

"Could it be a brain tumour?" I once asked him. But he said I would have no symptoms if I had a tumour. Another doctor suggested I was depressed and prescribed Prozac. Of course I was depressed, I didn't know what was wrong with me! I never took the Prozac. I was existing not living.

Two hours later, at about one o'clock, the telephone rang again. This time it was the ENT surgeon's secretary asking me to come immediately to see him at Weston Hospital about nine miles away. I couldn't find my husband, Tom, to take me to the hospital. As usual his mobile telephone was switched off and he wasn't answering his office telephone. I began to panic. How would I get to the hospital? I couldn't drive myself and certainly could not walk to the bus stop. I would probably 'throw up' before I got there. In desperation I rang my sister and her partner, Peter, immediately came to take me to the hospital.

I didn't wait long to see the ENT surgeon. When I went into his consulting room he looked grave and was rather embarrassed and apologetic. He told me I had hydrocephalus due to a large cyst in my brain. This was hard to believe. Up to now my condition had been considered non urgent and my symptoms almost trivial. Now it was serious.

He said he would ring Frenchay Hospital in Bristol, where the regional neurosurgery unit for the South West of England is located, for their advice and asked me to wait. He suggested I went to have a cup of tea, a good British tradition, when you have been given bad news!

It was arranged for me to go immediately to Frenchay Hospital and I was told to go home, pack a bag ready to go into hospital. Peter took me home and helped me. I remember packing my new teddy bear I had been given for Christmas as a lucky mascot.

By now it was 6 o'clock. I still couldn't find Tom. Peter offered to take me, a drive of about 20 miles. He lived about 40 miles from Bristol, so he would have a round trip of about 80 miles if he took me. At last Tom arrived home. I briefly told him what had happened and we left for the hospital.

I was told to report to the Accident and Emergency Department. We had a long wait to be seen by the duty neurosurgeon. I felt tired and sick. Other patients came and went. Finally I was called to see a doctor. I saw a registrar. A registrar, in the British system, is a qualified, experienced surgeon training to be a specialist. This surgeon was training to be a neurosurgeon, taking about seven years.

The registrar gave me a thorough neurological examination testing my sense of touch, range of movements and reflexes. Whilst he examined me he talked to me asking me what my job was. I told him I was a nurse. His relaxed approach put me at my ease and made the whole situation less scary.

"Have you seen your scan pictures yet?" he asked me.

"No" I replied.

He took me over to the screen where they were displayed. Immediately I could see how abnormal they were. The cyst appeared to be about the size of a golf ball and I could see my brain was distorted and full of fluid.

"How long has it been there?" I asked "years" he replied "You were probably born with it."

The registrar pointed at a shadow at the top of my spine. "There is something suspicious here as well." He said. That was the syrinx.

At 11pm I was finally taken to a ward and went to bed. When I left the Accident and Emergency Department I wondered if I would ever come out of this alive. My bed was by the nurse's station in a large, old, open ward. This part of the hospital was built by the American forces in WW2 and is still in use 60 years later. I was tired but could not sleep. It had been such a traumatic day and yet in a strange way I was relieved, at last something was going to be done to help me.

In the daylight I looked around. Everything seemed very familiar the same beds and equipment as the hospital where I worked. Even the nurses' uniforms were the same as mine - blue and white striped tunics and dark blue trousers. The ward looked rather shabby as if it could do with a good coat of paint. Some of the window frames had been replaced others were old and rusty. The other patients appeared to be older than me. There were men as well as women. An old woman in the bed opposite mine chatted to me. She had a shunt and explained she was unable to fly to visit her son in America because of it. I hoped I would not need one to relieve the hydrocephalus.

The rest of the day was taken up with endless tests. In the evening I had another MRI scan of my brain and spine. The scanner had broken down so I had to wait for it to be repaired.

My daughter, Maggie, came home from the Island of Jersey, where she works, and took leave to be with me. She came to visit me that afternoon.

My operation was scheduled for Monday or Tuesday so I had to wait over the weekend. I still couldn't sleep. The nurses could tell I was anxious and at night would talk to me and bring me a cup of tea. I remember one nurse said "You know too much." She was right.

It was arranged for the consultant, I had been allocated, to come and talk to me about my operation. He came on Saturday evening. Tom was with me, but he agreed to come back later when I was on my own. I didn't want Tom there. He is not very good at handling sensitive situations and is apt to make embarrassing or inappropriate remarks.

My consultant, returned about one hour later, after Tom had gone home. He sat on the bed, not making eye contact. He just explained in a matter of fact way what he was going to do and the risks involved in the surgery. I had to put my complete trust in this man. He said he needed to cancel his routine surgery to operate on me. Then I really knew this was serious. He stood up, turned towards me, looked at me and gently touched my hand, "I'll see you on Monday" he said kindly. I felt everything would be all right.

On Monday morning I was taken to the operating theatre for the surgery. The cardiac monitor electrodes were placed on my back as I would be laying face downwards during the surgery. A needle was inserted into my arm and the anaesthetic drugs administered.

It seemed like a moment later I opened my eyes. The same people appeared to be standing around my bed. For one awful moment I thought everything had gone terribly wrong and the anaesthetic had not worked. I could feel all my limbs, I had no pain, I still had my hair and there were no bandages around my head. A figure standing near the foot of the bed spoke,

"It all went very well, you didn't need a shunt". It was my consultant speaking to me. I smiled with relief. "Thank you" I replied weakly.

I stayed in the recovery room for about two hours. I appeared to be the only patient there and it was late afternoon. I had probably been in surgery for about 5 to 6 hours. I was taken back to the High Dependency area in the ward. Tom and Maggie were there after a long wait. I was high on morphine and very thirsty. I tried to talk but they could not understand me because the oxygen mask covered my mouth.

It was another long night and I did not sleep. Every half hour or so my blood pressure was measured and I was asked the same questions to see if I was still conscious, the date, where I was, who was the Prime Minister. By the following morning the effects of the morphine had worn off and I had a lot of pain in my neck. I could not move, everything had to be done for me. The nurses washed me and were very attentive. I had a urinary catheter, which was a great relief. Maggie visited and all I could do was complain about the pain.

Over the next few days I improved. The Physiotherapist helped me to walk using a walking stick. I still could not sleep, my neck and head were painful and I was disappointed because I was still vomiting. On Saturday afternoon after my visitors had left I buried my head under the bedclothes and tried to sleep. I became aware of two shadows hovering at the foot of my bed.

"I think she's moving" a voice said. I angrily looked up.

"Can't I have a few minutes peace to get some sleep?" I snapped

It was my consultant and his registrar. He looked a rather taken aback and I felt embarrassed being rude to them after all they had done for me.

For my last two nights in hospital I was moved to a single room and managed to get some sleep.

I went home on Monday after the wound clips were removed and the Physiotherapist made sure I could get up and down stairs. Maggie drove me home. It was quite frightening traveling along the busy motorways. I felt my head being jolted when she braked suddenly as a large truck pulled out in front of the car.

After a few days I started vomiting again and running a temperature. Maggie took me to the General Practitioner who diagnosed a urinary infection. Maggie was not convinced and took me back to Frenchay. My consultant saw me and confirmed it was a urinary infection.

"He's a bit scruffy" Maggie remarked when we left his consulting room "But he's a good consultant" I added.

He had trained to be a doctor in London and worked as a consultant in the North of England. He went to the Barrow Neurological Institute, Phoenix, Arizona where he continued his training as a neurosurgeon. working with two eminent neurosurgeons. I felt very lucky to have such an experienced neurosurgeon.

Over the next few months I slowly improved. My wound healed well. I washed my hair regularly with tee tea shampoo. The vomiting remained a problem. I asked my General Practitioner if I could have acupuncture. One of his colleagues was an acupuncturist. He gave me a 10 minute course of treatment. I vomited violently in the car on the way home and that was the last time.

After 10 weeks I had another MRI scan and in April returned to Frenchay for an out- patients appointment. I was examined by the registrar I

met the night I went into hospital.

"Oh you're the nurse with the archnoid cyst." He remembered. He showed me the new scan pictures. The syrinx had vanished. I didn't need another operation.

I was starting to enjoy life again and desperate to make up for lost time. I took the short flight to Jersey to visit Maggie and was none the worse for it. I was able to shop and bought myself new clothes and a pink pair of shoes.

Most of all I wanted to go back to Scotland. It was where I had met Tom, where my children were born, where I belonged. When I was in hospital I wondered would I ever return there again. Tom and I went back for a visit in May. I will never forget my feelings as we approached the border and my first sight of the Scottish hills. The joy I experienced being able to walk beside a rushing mountain stream in the Galloway Forest, the carpets of bluebells in flower in the woods, enjoying a dram and the company in the hotel bar. I began to paint and draw again and was happy to be alive.

I was contacted by the Occupational Health doctor to be assessed for my fitness to return to work. Family and friends advised me it was too soon to return to work but I was desperate to get back to normal. I asked the Occupational Health doctor if he needed to contact my consultant for advice before he made any decision but he said that was not necessary. I was still a little unsteady but I could pick his pen up off the floor so he pronounced me fit to work.

I returned to work in June. At first I was happy to be back with my friends and colleagues. After a few weeks it became a struggle. My back and neck were sore from handling heavy patients and pushing wheel chairs. My headaches returned and I was depressed because I felt I was failing. My work colleagues could see things were not right. The Matron or head nurse asked to see me. I just broke down in tears. She rang Frenchay Hospital and I spoke to my consultant's secretary, and was sent an appointment to see him again.

I saw him in October. He was very reassuring and examined me thoroughly. "You have looked after your scar well" he kindly remarked. He agreed I should not have returned to work saying it was too stressful. He did not think the cyst had returned but thought the pain was due to arthritic changes in my spine. He requested another MRI scan which I had to wait several months for.

I saw the Occupational Health Doctor again and he finally requested a report from the consultant.

I never returned to my nursing job. I was given a temporary office based job, which I am still doing. I had the MRI scan a month ago and thankfully it was normal. My consultant wrote to me giving me this good news saying he did not need to see me again but 'would be happy to do so should the need arise'.

I want to leave this episode in my life behind me now but it has changed me forever. There are things I took for granted I don't now reading, traveling, driving and the support of my family.

I had never heard of a posterior fossa cyst or syrinx before this happened to me. When I researched this subject I discovered it mainly occurs in early life as it is usually a congenital condition and can go undetected causing no symptoms. I felt very lucky to have lived so long on 'borrowed time' having had a husband and two wonderful children.

Due to the skill and techniques of modern surgery and diagnostic tools available today I have come through this relatively unscathed but I am expected to be just as I was before - but I am not. I have had to find out my limitations. My balance is not perfect, my left hand is slightly weak and I still have pain in my neck and back but it is bearable. I do not want to be treated as an invalid, just to have a little understanding. One day at work, for instance, I had to ask some one to lift a heavy box off a high self for me. She looked at me as if to say 'What's your problem?' If I had been able to say I had a syrinx and she knew what I meant it would have been simple. The Occupational Health doctor is convinced my back pain is due to arthritis from the wear and tear of work. He will not consider there could be some connection with the syrinx because he knows little about it. Outside the specialist neurosurgery units very little is known.

You go through the same emotions of anyone suffering from a serious illness but I felt unprepared for this because of the general lack of understanding and support. I did eventually go to see a counsellor. This helped a great deal working through my emotions and putting things into perspective.

It is difficult when there are so many diseases and conditions competing for our attention and money. I can only hope my story will go some way towards highlighting the lack of knowledge and understanding of this condition and that in the future there will be more awareness.

The author (below) with her husband and daughter.



Would you like to share your perspective? Submit to: director@conquerchiari.org Type "Perspectives" in the subject line.

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