

Nigel David Kelly.

## Acoustic Neuroma.

How it affects me.

1. The worst symptom is a very severe form of vertigo attack. I have mini seizures throughout each day. These are feelings of dizziness and unbalance. They can come on for no reason, or because I have stood up too quickly or turned around too quickly, or just looked up, bent over, reached up to get something out of a kitchen cupboard etc. I have learnt that if I remain calm they will pass in a few minutes. I would have anywhere from half a dozen to a dozen plus of these every day and sometimes at night if I have had to get out of bed. Sometimes they can be brought on if I turn over in bed too quickly.
  - These often starts with prolonged bouts of violent, continuous vomiting, which can last for hours. My wife tells me my record is four and a half hours.
  - During these bouts I will often also soil myself. I have had to purchase incontinence pants.
  - I am totally physically incapacitated during these. I cannot walk or stand or move in any way.
  - During this time I am often unaware of my surroundings and have no idea of the passage of time. When the vomiting stops I can only move by crawling very, very slowly, on hands and knees with my forehead pressed against the floor and my eyes closed as any attempt to open my eyes will start the vomiting again. Using this method of moving I try to make it into bed where I stay for the rest of the day and sometimes for several days.
  - Each severe attack is followed by many more over the course of the coming weeks, with each getting a little less severe until they eventually stop. I can be awoken during the night to find I am having one in my sleep. During this time I cannot do anything. I cannot do work of any kind, using a computer, reading, etc. During this period I have to use a walking stick to move around indoors.
  - When I am feeling well enough to return to work I do so. However after a few days or at most a couple of weeks of working I have another attack and the cycle continues.
  - These attacks start in two ways
    1. In the first I experience my surroundings moving around me, followed by a sensation of intense heat which results in me perspiring to the point where the perspiration is literally dripping off me. I then feel violently sick and try to make it to the nearest bathroom where I start vomiting.

2. In the second it starts with a sensation which I can only describe as someone rubbing a cloth over the surface of my brain, inside my skull. With this form I feel as if I am moving instead of my surrounding. I do not get the heat sensation and the vomiting can sometimes be controlled if I can make it to bed and take a tablet in time.

2. I have tinnitus which can vary dramatically in intensity. This got so bad towards the end of 2016 that my doctor diagnosed me with Clinical Depression. My wife had to take two months off work as I could not be left alone. I was on anti-depressants for two years, only getting off them finally in March 2018.

3. I have a constant fuzzy headed feeling, a feeling of pressure in my head. I often have headaches.

4. I feel tired all the time and it has now become a question of degrees of tiredness.

5. I always feel unsteady walking.

- When trying to walk outside my house I use a walking stick and walk slowly. I also only walk out of doors if my wife is with me as hold hands gives me another point of contact as well as my walking stick to help stabilize me.
- Even while walking outside in a straight line, I often stumble and have to concentrate to walk straight ahead or I will veer off to one side.
- When walking indoors, I am continuously aware of trying to keep my balance, being careful while turning around or changing direction as I can very easily become unstable or stumble. Also my feet can get tangled if I turn too quickly.

6. I cannot walk if the sun is shining in my face as I cannot see and this greatly impacts my ability to remain balanced. This is also true in the dark. Also wind affects my balance much more than with other people and if it is windy day I cannot walk. The walking stick has saved me from falling over more times than I can count.

7. While walking I try to avoid looking sideways, or looking up, as these makes me feel unbalance and it takes a few seconds for it to settle down again so I can continue my journey.

8. Any sudden change in my surroundings often brings on vertigo like symptoms, an increased fuzzy headed feeling together with poorer balance. This can be something as simple as walking along a pavement and then going into a shop.

9. Emotional upset or stress or simply being tired, can also bring on symptoms.

10. Encountering a lot of visual stimuli such as people moving around me, moving colours and shapes or even cars passing can also bring on symptoms.
11. I must greatly restrict any form of activity. i.e. I must keep my use of a computer down to an hour at most, usually half an hour, as if I extend this time I will start to feel dizzy and unsteady and must sit or lie down for a while to become steady again. Sometimes I can start using a computer and within minutes have to stop.
12. I cannot do any form of physical activity which involves fast or sudden movements.
13. Travelling is a big problem. I can do the occasional trip, maybe once a week. But if, for example, I have to travel on consecutive days, this usually brings on vertigo symptoms again. Also the shorter the trip the better.
14. If I find myself in a situation which is busy and loud, such as in a shopping centre, this can also bring on vertigo symptoms. I therefore try to avoid places where there is loud music playing and a lot of activity. This includes places like restaurants which play loud music, fun fairs and cinemas.
15. I find everyday activities such as doing house work, gardening and shopping difficult due to my balance and the effort involved often makes me feel worse and can bring on an attack.
16. I cannot use public transport as the degree of activity, the constant stopping and starting, the constant movement of people getting on and off make me feel unsteady. Also the risk of having an attack during the journey. If I do the bus driver cannot turn round to take me home. So if I have to travel my wife drives me or if absolutely necessary I take a taxi.
17. When renewing my driver's licence two years ago, I lost it for a year when I had to tick the box which asks if you have a brain tumour. I got it back with the help of my doctor but it is medically restricted.
18. However I cannot drive and would not even attempt to as it would be too dangerous. If I turned a corner and the sun shone in my face!
19. I am registered disabled with the local Social Services office in Downpatrick. My social worker/care manager is Nora McMahon. 028 4461 6915
20. I have a monitoring system installed in my home and when alone I wear a pendant which detects if I have fallen. This is monitored so when the monitoring station receives a message they firstly contact my wife. If she is not available they contact one of my neighbours who has a key. My social care manager got this installed because my wife would sometimes come home to find me lying on the floor in a pool of vomit, not knowing how long I had been there.

## Medication –

- I was on anti-depression medication for a period of two years from March 2016 until March 2018. This was Citralopram Hydrobromide.
- I have a vertigo medication Prochloroperazine Maleate which I take in two ways. I have 5mg tablet which I take under my tongue if I feel a bad attack coming on and I have a 3mg tablet which I take three times a day during periods of repeated attacks.
- I have an anti-vomiting table Zofram Melt which I try to take if I feel that I am going to vomit. Unfortunately the vomiting comes on so quickly that I am seldom able to take it.

On Wednesday 25th April 2018 I underwent Gamma Knife Surgery at the Bexley Wing in Saint James Hospital, Leeds. Mr Flannery performed this surgery. So I am currently in the recuperation period for this which is four to six months.

Due to the surgery I have had to extend my unpaid career break for another years, starting July 2018. So at the time of writing this I have not had a pay check for fifteen months.

However my employer is currently processing me for possible ill-health retirement.