

All I Want is to Breathe the Air That I Need.

I have provided this story in the hope that it will assist others who have unusual respiratory problems. My research and need for diagnosis has spanned some 25 years and it is only with the help of my family, some close friends, a good GP and a wonderful Physiotherapist (Specialised in Respiratory Issues) that I have been able to withstand the emotional trauma of this 25-year period. My heartfelt thanks also to Hilary who has been the recipient of many questions over the years and has often referred me (amongst other places and people) to the Lincolnshire website for the information we have so gratefully downloaded.

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My apologies to the author of one of my most favourite songs which is the "The Air That I Breathe" sung by The Hollies and very popular in the 1970's. Of course that does somewhat date me I know.

Apart from being a catchy melody this song with its chorus including the line "All that I need is the air that I breathe and to love you" encapsulates my feelings about my addiction to air. The love I have is for my husband and my three sons who have stood shoulder to shoulder with me during this battle I have fought to find answers about my respiratory problems and to be able to breathe easily.

As the years have passed since the initial Polio diagnosis (1954) and the later recognition of the impact of the late effects of Polio (1983) I have been searching for answers for my frustrating breathlessness. This breathlessness has always been with me but, spicing up my life considerably, have been intermittent episodes of acute breathlessness and respiratory distress.

Ask many of my doctors and they would say "Oh no, Margaret, not respiratory distress but an anxiety/panic attack". How silly of me to think that I have respiratory distress when I can't breathe. It is so infuriating to be told that you are having an anxiety attack when you are fighting for composure as breathlessness escalates. Do the Doctors not understand that if one allows oneself to panic at that stage the breathlessness just keeps on getting worse?

I would not like to bore my readers with a long and detailed description of my search for answers so I have prepared a brief synopsis of the many avenues I have tried to get assistance.

I must add that I fully recognise the difficulties I have experienced have been exacerbated by the fact that we, as a family, have had a number of moves within Australia which has meant that I have had to start all over again with new GP's and Specialist Medical personnel each time we have moved. (This sort of reminds me of another song... "pick myself up, dust myself off and start all over again").

In 1954 I was hospitalized with Poliomyelitis and while in hospital I developed Polio encephalitis. On one night some 5-6 days after being hospitalised I was deemed to be 12 hours off being placed in an Iron Lung and my parents were told that I might not live through that night as I was an extremely sick child. I was just nine years old.

Being the stubborn and determined individual that I am, I did survive, albeit somewhat disabled, having lost the use of both arms, neck muscles, some left leg muscles and respiratory muscles, which were also damaged. The degree of damage was not made available to my family after my discharge as some nurse "lost" my muscle chart when my aunt, a Physiotherapist, rang to find out the extent of the damage. All I know is that I was fed thickened fluids and kept under direct observation from the Nurse's station even in the non-acute ward.

I was taken home for rehabilitation. I spent 6 months on a double Thomas splint day and night,

(enforced quadriplegia as I could only move my right hand during the day). I then spent another 12 months on the splint at night and was slowly taught to walk again.

When I returned to school some 21 months later I had to wear an arm splint and have a nap every lunchtime and I spent every Sunday in bed for total rest.

Eventually after some 4 years of intensive physiotherapy I was put back into the community as so many of us were, to function as best I could. I got on with life but noticed that strenuous exercise (dancing, bushwalking, rock-climbing etc) caused me to be very breathless even though I exercised as much and as regularly as my peers. It was often thought I was unfit but I felt there was another explanation. I had already learnt to wake myself up when I became breathless during sleep and not to panic when I was breathless, whatever the cause, as panic just made it all so much worse.

While working as a dialysis technician in the mid 60's I was diagnosed as having a benign familial tremor, which causes me to be very shaky in the hands and voice and legs especially when anxious. This is a genetically inherited condition and my family has a number of members who have this disorder. I am in exalted company here, Katherine Hepburn (I am told) has the same condition.

In the late 70's I developed respiratory problems, which were diagnosed and treated as asthma. At this stage I was told that I was acutely anxious and my GP tried to alleviate my acute respiratory problems associated with the asthma attacks by injecting me with Valium. I hasten to add that nearly rendered me unconscious but did not stop the acute breathlessness.

In the 1980's having moved yet again I met another woman who had Polio and who was using ventilatory support. I talked to her and as a result went to St Louis USA to a Polio Conference to see if I could get any answers to my questions. Following this trip I was provided with a volume cycle positive pressure ventilator and told to use it only as a daytime support mechanism. This helped but not significantly and I eventually drifted away from this treatment. I was still having regular Emergency Department visits with respiratory distress but usually leaving after some treatment with the words "Panic Attack" ringing in my ears.

I was still using a number of "tricks" to be able to sleep including pushing my chin up with one hand to assist in opening my airway, sleeping with the head of the bed up on bricks and waking up and sitting up whenever I became breathless and then breathing deeply and regularly until I felt that I could lie down and sleep again.

In 1993 I became very breathless following an infection and I did not pick up afterwards. I went to a variety of Doctors who eventually determined that I had weak diaphragm and inspiratory muscles and asthma and following a sleep study told me I had hypopneas during sleep. Importantly there was no Carbon Dioxide (CO₂) monitoring during this sleep study.

My Oxygen (O₂) level would drop to about 91% during sleep but this was considered not serious. However I was prescribed CPAP with low pressures between 4 and 7 cms of H₂O. In the first few weeks I found it very hard to use this treatment and I became progressively more tired. After about 12 months treatment I became so tired that I would fall asleep at work at 2 pm each day and I headed off to yet another Doctor.

This doctor prescribed BiPAP S as a "cure-all". I mentioned my volume cycle ventilator and was told that it was a dinosaur and that no one used volume ventilation any more. Pressure was the treatment of choice.

I found that BiPAP was a much better form of ventilation for me than CPAP and for some months after the change I was feeling a lot better but still having episodes of acute respiratory distress requiring hospitalization although the number of hospital visits was decreasing. I might add that no Doctor to date had been willing to provide me with a diagnosis.

After yet another period of respiratory distress and hospitalization, I found yet another Doctor, a sleep specialist, who having done, you guessed it, another sleep study again with no CO₂ monitoring during sleep, decided that I was well enough to fly to the UK mid-1998 with my husband on a business trip. In order to fly I had to use my BiPAP during flight and thanks to the airways not accepting BiPAP machines in flight I had to rent a different machine (VPAP), which had spontaneous/timed mode to regulate breaths per minute.

I moved onto that machine for 48 hrs pre-flight and found to my delight and amazement that I felt better. My husband was also amazed having had no energy for 3 months I suddenly had to be told it was midnight and time for bed. The trip went well although I did get into trouble when the crew depressurized the plane rapidly at 10,000 feet but after a short period we landed and I was able to catch my breath. Much better than other flights without the VPAP when I would turn blue and be acutely breathless for some hours after a flight. Life went on this way but over the last few years I had been feeling progressively older and more tired. I was still working full time and was in very stressful job, which placed 8, 10 and sometimes 12 hour days on me which was extremely stressful and tiring even though the job was quite sedentary.

I had started using an electric scooter for mobility back in 1992 and even with that it became an effort to get out much. My life became a never ending round of work, sleep and housework at the weekends. I sought assistance at work and eventually with no assistance provided, I went on sick leave.

Following this period of stress and worry I developed a pinched nerve in my neck, which led me to consume large quantities of pain medication just to manage a day's work and although I returned to work part-time I was unable to sustain this level of work and I landed in hospital with acute breathlessness. Unfortunately this time I did not recover and was unable to undertake most activities of daily living from that time for a period of some six months.

During this time my husband and I found that while using the VPAP machine my tidal volume (the amount of air one takes in one breath) was not consistent. It would vary from around 180 mls per breath to 480 mls on another breath. There appeared to be no reason for this variation that we could see.

My physiotherapist looked at a few of the many papers I had on Post-polio respiratory issues (mostly obtained from the Lincolnshire website) and then suggested that we look further at the secondary references and after a long search through many University libraries we tracked down those relevant articles.

It was a paper by Plum and Swanson from 1958 that for us, made such interesting reading. This paper discusses the damage to the brain from polio and the effect this damage has on the ability to breath while sleeping. [Ed note, we have a copy of this 27 page article]

Shortly after reading this paper I passed it to my specialist who, for whatever reason, chose to prescribe more VPAP ventilation while advising me that I was suffering "anxiety that required psychiatric treatment".

In desperation I dug out my old volume cycle ventilator and started using that for my afternoon naps and eventually full nights.

"Is there anything sweeter than the first rush of cool air into the lungs after a period of breathlessness?"

Source Unknown

Within a couple of days I was feeling very much improved and then I started looking around for some way of getting to a specialist physician who would be able to assist me with the use of volume ventilation as I was very well aware of the dangers of "do it yourself" home ventilation.

Eventually through the Internet I found the Australian Ventilator User's Network who were kind enough to inform me of a Clinic in Melbourne some 2000 kilometers away. My husband and I drove down to this clinic earlier this year to find that indeed I required volume ventilation and that amazingly we had nearly the correct settings on the "old dinosaur".

The issues for me were that I did build up CO₂ during sleep but as I trained myself to wake up my CO₂ levels did not rise to the same levels as they do for many other people. The breathing pattern I had varied in both rate and depth giving rise to nocturnal hypoventilation and the "panic attacks" were in fact respiratory failure.

We purchased a new ventilator, a PLV 100, and after a couple of sleep studies and some other respiratory tests we were allowed to come back to Brisbane, with the added assistance of phone and email contact with the clinic.

Since that time I have improved so much it has amazed all who see me. I am able to swim a kilometer now having been able to swim just 8 meters in February this year, my pain levels have dropped, my brain fog is much less and I can tolerate cold better than previously.

I have just this week driven the 2000 kms (and return) by myself to the clinic for a follow up sleep study which determined that I am well ventilated but still having disturbed sleep probably from pain so now I am on pain medication at night and I am feeling even better than previously. I have also tracked down an appropriate doctor, newly arrived in Brisbane, who specialises in sleep disorders in people with neuromuscular diseases and he has agreed to provide on the spot care for me with annual check ups from the Melbourne clinic.

I am now looking forward to some years of reasonably stable respiratory capability and in the short term to continuous improvement in my muscles of the shoulder back and chest so that my breathing capacity is the best that I can make it. My heartfelt thanks to all who have assisted me in this period.

Margaret has sent us a copy of the 27 page Plum and Swanson 1958 article.

Next newsletter long article on respiratory problems. Please ring/write/email us with any questions that you would like answering on this subject.

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