

Sleep Apnea Awareness Day – My CPAP and Sleep Apnoea Journey *by Karen Hocking*

About four and a half years ago I went to my GP because I was feeling tired all the time and had no energy - this is where my saga began. He ran the usual barrage of tests and everything came up clear so he suggested I go around to the local chemist (I am in a rural area in central NSW) and get wired up for a sleep test. By this time I was so desperate to figure out what was going on that I agreed. I had the test, the microchip got sent to Melbourne for a specialist to analyse and two weeks later the results were in - severe obstructive sleep apnoea. Now keep in mind, I have never fallen asleep behind the wheel of a car (I had been brought up that if you are tired you just don't drive - simple), I have a clear driving record and I don't sleep through the day.

So off to the chemist to sort out a CPAP to trial for 2 weeks (you could try before you spent the \$2000 on the machine). It did not go well - it would take me ages to go to sleep, then I would sleep for about 2 hours and then wake up gasping for air. I had never woken up gasping for air without the machine, but with CPAP it was a regular occurrence. After the 2 weeks I gave up and returned the machine to the chemist. It was at this time that I decided to change GPs. The one I was seeing would not give me a referral to an Ear, Nose, Throat (ENT) specialist. I wanted to find out why I was suffering with sleep apnoea and if there were alternatives to CPAP. My GP believed CPAP was the only answer.

So off to my new, wonderful GP who was only too happy to write me a referral to an ENT. The next available appointment was in 5 months. In the mean time, I had been advised by my GP that severe obstructive sleep apnoea was a notifiable medical condition for my licence (which was coming up for renewal) and that I would need to list it on my licence. I did some research and discovered that if I didn't notify and I was in an accident and it was discovered I didn't notify, there could be serious consequences including gaol time and I could not take the risk. So I went into Roads and Maritime Services and completed the paperwork to notify of my newly diagnosed medical condition. And there began my fight to keep my licence.

A form came for my GP to fill out which she did. The problem however was that she had to put on the form that I was 'non compliant' with CPAP use as I could not tolerate it. She added that I had an appointment with the ENT to find out what was going on. Apparently, the licensing rules state CPAP is the ONLY recognised treatment. They agreed they would give me an extension on my license until I saw the specialist. If the specialist would not sign off on the letter then my license would be suspended.

I saw the ENT who said that I needed to see the sleep specialist to complete the form (I had a referral for him as well - 7 month wait, but 2 months after the ENT). So, more waiting. I saw the sleep specialist who would not sign off on the form as CPAP is the ONLY recognised treatment and if I couldn't tolerate it, then that was my problem and I would have to give my licence up (I was 45 at the time). He advised me that I should stop driving immediately. I decided to hire a CPAP and try it again so I could keep my licence. I live about 15km from town in the centre of NSW and there is no public transport. I have ageing parents that need assistance, my husband is self employed and travels away for work and I travel to see friends and for horse events. This was going to turn my life on its head. The sleep specialist gave me a referral to have a 'maintenance wakefulness' test at Royal North Shore hospital in Sydney. If I passed this, he would be happy to sign the letter for me to drive. Basically, for this test they wire you up, put you in a dimly lit room, and you need to watch the wall for 20 minutes at a time 4 times through the day to prove you don't

have micro-sleeps. When I tell people about this test, they often say 'OMG I couldn't do that'. Well guess what, I could – easily. I passed with flying colours. It was another 4 months wait before I could get this test so in the meantime, the licensing authority suspended my licence until I had medical sign off. The result of this meant that I needed someone to drive me to and from work, someone to take me shopping and to medical appointments and I had to give up going to horse events with my horses. It was devastating and completely changed my life (there is no public transport where I live - I was completely reliant on others).

Once the results of the test came in and the sleep specialist wrote a letter for the licensing authority, they reinstated my licence with restrictions. I could not drive at night and not more than 50km from my home. This meant that I could get myself to work, shopping and medical appointments but I no longer had any social life. To be honest, I became depressed and required treatment for that.

Whilst this was happening, I was trying to use the CPAP. I could manage a couple of hours sleep and then would wake up gasping for air and couldn't get back to sleep. I persisted for 6 months and was in tears every night. I had been told by doctors and so many others that CPAP would change my life in a positive way and if I could manage it with 6 hours sleep a night, I could have my licence back in full and get my life back. I needed to see the sleep specialist again. I took the chip to the chemist to get a print for my usage as my licence was up for review again and I needed specialist sign off. When I said I couldn't manage more than a few hours a night he wouldn't even look at it and told me there were no other options and I would just have to accept I couldn't drive any more. He pretty much accused me of not trying and that it was all my fault. I left there in tears again for about the third time. I vowed I would not go back to that specialist.

I went and saw my GP again who felt really badly for me and felt that the licensing authority were being too harsh given that I was doing everything correctly. She wrote a letter for me including that the loss/restriction on my licence was having a detrimental affect on my health and being able to care for my family. By this time, my father needed to see specialists hundreds of kilometres away and my mother had been diagnosed with breast cancer. She required surgery and possibly treatment hundreds of kilometres away. So I wrote to the licensing authority outlining my exceptional driving record, no accidents in my driving career, copies of the medical reports/letters, that I take my responsibility as a driver seriously, that I understand the focus on falling asleep behind the wheel etc and that I don't drive distances often however due to my location, there are times I do need to drive further. I asked them to review the kilometre restriction and compromised by saying that I would be happy to retain the no driving at night restriction. This still seriously limits what I can do however they removed the kilometre restriction which made a big difference to my life.

I decided after the last horrible experience with the sleep specialist that I would go back to the ENT. Thank goodness I did. On further investigation, I required nose surgery (I had always had trouble breathing through my nose). I had to have septoplasty to straighten a deviated septum which was partially blocking my airway and a turbinate reduction. I had a 12 month wait for the surgery due to waiting lists here, so that was April 2017. To be honest, I didn't realise how restricted my nose breathing was until after the surgery and healing. Wow!

Before the nose surgery I had another sleep study organised by the sleep specialist using the CPAP. That entailed a 300km round trip and was a total waste of time. I slept 2 hours the whole night. I also had another sleep study done (another 300km round trip) after the

surgery. My sleep apnoea was still severe but there was a reduction in episodes. It was now considered borderline moderate/severe. One thing remained the same, I still couldn't tolerate the CPAP.

So back to the ENT again around April 2018. We talked some more about options (this ENT has an interest and speciality in sleep apnoea as well). He was telling me he had gone to Germany for a seminar on the latest CPAP technology and they had made each of the attendees wear the CPAP overnight to see what it was like. He told me it was a real eye opener and he could see why some people really struggled with it. We discussed the option of the mandibular device (the device that goes in your mouth) but as it was \$2000 to have made up and fitted, he felt that it would be best to conduct a sleep endoscopy to see if it might work. So, another 4 months wait to get the test done. This was day surgery with valium induced sleep. My jaw was manipulated to see if the device could open my airways more. When I woke up, I was told "sorry, we moved your jaw that much that if we went any further, we would have broken it and it made no difference. You snore on your back and sides, there is multi-level severe collapse. The only option now is multi-level throat surgery". So back to the ENT office a month later to get paperwork for the hospital and to go on the wait list. So basically, I can't tolerate the CPAP as due to the severity of the collapse, the increased air flow suffocates me. I know it sounds silly, but I feel vindicated. I wasn't being difficult, I wasn't being a sook, there is a legitimate medical reason I cannot tolerate CPAP. Needless to say, I will never set foot in that sleep specialists practice again. I felt belittled and in no way helped. My ENT has been brilliant.

The paperwork was lodged and the ENT wanted the surgery done as a priority, within 6 months. I had a surgery date of 20 March (6 months to the day) but on the 18 March, the hospital rang to say they had to cancel my surgery due to emergencies and they would reschedule. Our ICU only has 12 beds and covers not only our area, but a huge amount of western NSW. As I require an ICU bed after surgery, this is going to cause issues. So, I am now rescheduled for the 1st May. We will see if it goes through.

In the meantime, I battle to keep my licence and my sanity. Thankfully, it hasn't affected any of my other systems so far. No heart, blood pressure or other issues. I still have to plan everything I do carefully (or rely on others) or I have to miss out on things because I can't drive at night. If I'm tired, I don't drive - everyone should be like that anyway!

I am not naive enough to think the surgery will 'cure' my sleep apnoea - as long as it reduces it, or makes CPAP or the mandibular device viable, then I will consider it a success.

For me CPAP has been the bane of my existence and as I've been told it is the ONLY recognised treatment for severe sleep apnoea, it has restricted my life in so many ways. It has also been depressing seeing all the advertising etc on how it is the be all and end all that will improve your life so for people like me that can't tolerate it, it is another kick in the guts when dealing with a condition that has far reaching impacts on your life.