Personal statement from Rob Holt to the NICE appraisals committee for Continuous positive airways pressure (CPAP) for the treatment of obstructive sleep apnoea/hypopnoea syndrome (OSAHS) August 2007

I was diagnosed with severe obstructive sleep apnoea 8 years ago following the birth of my second son when I was aged 32. At this point in time I had been married for 7 years and had 2 young children one aged 3 and one 6 months.

I have no past medical history to speak of apart from suffering from familial hypertension which was diagnosed some 4 years earlier. I was fit and well-a little overweight but in reasonable good shape and fitness for my age.

I had always been the kind of chap to have a little ‘nap’. Even in my teens it was known for me to nod off in the chair for half an hour. My wife thought it normal that I needed half an hour to come to on returning from work and not unusual for me to nod off or even go to bed early. I had always snored too. Worse after a drink or 2 and certainly worse if I rolled onto my back but I soon got a ‘prod’ and then I’d return to sleep once again. My wife and mother used to compare notes on me and Dad’s snoring often commentating ‘it must be in the genes’.

Over the years my snoring became much worse. It became very loud and much more constant. Again it was something my wife and I just adjusted to and didn’t seem to cause us any problems. It did however cause problems for others. The snoring got so loud in the end that we stopped having overnight stays with friends or relatives because of the noise I made. As I say at first it was a bit of a joke. When staying at my in-laws one weekend with my wife’s whole family staying also I kept the whole house awake with my snoring. My wife’s mother commented that I sounded like a freight train, my sister in law said she hardly slept a wink because of the noise and my brother in law said I must have blocked nasal passages causing me to make such noises.

Everything started to get much worse after the birth of our second son (now aged 8).

I had noticed I was feeling more tired lately and wasn’t able to shake the fatigue of at any point as I had usually been able to do. This we put down to waking 2-3 times per night to feed and sort out the baby. We thought that when the baby settled down into a routine then my tiredness would too.

At this point I was starting to regularly have a nap on the way home from work. I had worked out 2-3 stopping places where I could safely park up and get 30 minutes sleep and then carry on with the rest of my journey. Initially this would happen twice a week but in the end it was nearly every day. On getting home though I would need a nap at some point before I went to bed -again another 15-30 minutes. I would normally retire at 10pm and fall asleep instantly as my head hit the pillow.

My job started to suffer .I am currently employed by a IT Services company. At this point in time I had worked for the company was over 10 years. I was irritable, moody, lacking concentration, fatigued, dozy, craving sleep. Having to do a full days work when I was so tired was a constant battle especially as it involves driving over 35,000 business miles a year. My managers and peers started to comment on my performance and lack thereof. The quality of my work was sliding due to constant fatigue and previously good working relationships were frazzled and tested. I must point out here that I have never had a day off work due to my tiredness.

But it was my family life that suffered the most. It got to the point that I just didn’t want to do anything at the weekends or when I got home from work because I was so tired. My wife’s patience was wearing thin as I wasn’t supporting her or the children in any aspect of their day to day lives. I would fall asleep as soon as I got home only waking for a meal. I fell asleep during lunch once. I would fall asleep feeding the baby. I was unable to be a dad to my two young children. We didn’t go out as a family anywhere because I was too tired. Going on holiday was a nightmare because I would need regular sleep stops which meant the family having to wait for me to sleep before carrying on with our journey. My relationship with my wife suffered as I was not able to communicate properly with her. She & I could not understand this constant need for sleep and she became resentful tearful & angry about my constant lack of support towards her and the children. She commented that she felt like a one parent family because I did little or nothing in the house or with her and the children. Whether this contributed towards her post natal depression I am not sure but it certainly didn’t help. It got to a point once when my wife felt it better that she live with her parents for a while until I could get my fatigue under control. This was an action I believe she would have followed through with had things got any worse.

I felt helpless and confused. Why was I so tired? Why was I always asleep? Why couldn’t things be back to the way they were before, after all we could all manage then?

This all carried on for 3 months.

My wife returned to work when youngest was 4 months old and was working evenings initially until we had secured childcare.
When she came home from work I would already be in bed asleep. Some nights I had been asleep for a good couple of hours when she got in. Some nights I managed to stay awake fearful of the retributions that I would receive if she found me in bed asleep again with the dishes not done or the clothes not away. It was a bit of a juggling act let me tell you.

One night she retuned home and on that particular night I had been asleep for a couple of hours so was in a deep sleep.
She woke me up very distressed saying that I wasn’t breathing properly at all. I was taking a big snorty breath and then just not breathing at all until I took another big snorty breath some 20-30 seconds later. She had watched me for a while to make sure what she was seeing and hearing was true and then woke me. She was genuinely worried and scared about my breathing patterns. Next morning she wanted me to visit the GP and explain all this to him. She knew that some children suffered ‘apnoeic attacks’ and had special monitors in their beds. Could this be what was happening to me?

So I went to see my GP. Explained all the breathing symptoms my wife had observed along with all the other ‘stuff’ that had been happening to me since the baby’s arrival.

The sleepiness, fatigue, relationship issues and how rubbish my life seemed to be. He mentioned he had seen a similar gentleman a couple of weeks ago who presented with all the symptoms I had presented with and he was diagnosed to be suffering from Sleep Apnoea. He would need to refer me to the hospital for tests to confirm a diagnosis.

I was referred to the local sleep unit. I have since found out that we are very lucky to have such a specialised service in our area.
Initially I did not see a Dr but had an overnight Sleep Study performed, This involved all manner of electrodes and machines being hooked up to me to observe a nights sleep. I was very nervous and worried about not falling asleep but as usual I was so tired I had no control over falling asleep.

One month later I had an appointment to see the hospital consultant. I was the first patient to be seen that day and my wife came with me for moral support. He explained that I did indeed have Sleep Apnoea. In fact I had a severe case causing my airway to completely collapse every 5 minutes with my oxygen saturation levels falling to 55% (I later found this out to be dangerously low). The treatment available was in the guise of a machine called a CPAP (Continuous Positive Airway Pressure). I would have to wear a mask over my nose attached to a long tube attached to a compressor that blows air into the back of my throat to keep it open and allow me to breathe normally. This machine would be with me for the rest of my life. Shock relief I'm not sure what I felt first.

I was told the secretary would make me another appointment to have the machine fitted and tested out with another sleep study. When we saw the secretary she had a cancellation for the following week and did we want it. Did we??? The consultant told me that now I was diagnosed I was not insured to drive until I was being treated by this CPAP. So a weeks not driving was do-able- my wife even took my car keys away until I was treated. I was told the chap after me had to wait 3 months for his machine. Imagine not being able to drive for 3 months? Imagine being dependant upon driving for your career. How do truckers and bus drivers get on?

At the next appointment I was fitted out with a mask and a machine. I have to say the machine looked massive. My wife asked if the machine was quiet or noisy. The nurse said this one was noisy as it was an old machine but that the newer ones were better, New machines were for patients living out of catchments and we had to have this one. My wife promptly burst into tears saying this had an impact on her life too, that she was only 31 and wanted a quiet machine. The nurse took pity on our plight as apparently at that point I was one of the youngest patients to be diagnosed. We got a quiet machine. A Sullivan 5 with nasal mask.

Would this machine really change my life as the medical profession was so confident it would?
Yes is the answer.
Even after the first time of using the machine I knew that I had slept properly. Over the coming days and weeks I continued to feel refreshed when I awoke in the mornings. I was catching up for all the times I had not slept properly.
Looking back the transformation was really quite amazing. My energy levels returned my fatigue disappeared and I became myself again. No more stopping on the way to

and from work, no more falling asleep in the chair, no more weekends of sleep, no more falling asleep on my wife. My life literally had got back to the way it used to be.

I'll admit the machine did hamper the intimacy levels at night time but my wife and I slowly adjusted. She found the machine reassuring knowing I was getting a proper sleep and finally after all these years I wasn't snoring. I was just so relived that I didn't have anything worse wrong with me that I took to the machine and using it very quickly. I am what they call a compliant patient. I can imagine that some people don't get on or want to get on with the machine as it is quite invasive.
I did have my machine checked a couple of times by the hospital. They worked it out that I average 7 hours sleep per night-glorious restorative hours. The hospital had to stop checking my machine as funding was withdrawn by the PCT but I know I can call the clinic any time if I have a problem.

CPAP really is amazing. I cannot for one minute imagine my life without it. It comes with us everywhere. Holidays to America, New Zealand, Australia, Prague, Spain, Germany. There are no limits as long as we have power and a long extension lead! The children have grown up with daddy's machine and don't know any different. Both my wife and I are observant to their breathing as genetically they may well be at risk.

CPAP is a cheap option; it is not surgery, not long term medication but a one off prescription for life.
Had I not had access to a CPAP I would not have a wife & children at home, would not have a job, would have no quality of life or worse than any of those I may well have fallen asleep behind the wheel of my car and not been here to tell you my story.

Rob Holt
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