NICE Appraisals Committee Meeting Thursday 9 August 2007 Sleep Apnoea – Continuous Positive Airways Pressure

Personal Statement by Frank Govan

Background & Experience I have been treated successfully with nasal CPAP for the past 16 years, although I now believe that I had been suffering from sleep apnoea for a much longer period. This statement is based on my own experiences, although I have come to realise that they are quite typical of the average sleep apnoea sufferer.

I believe that the first symptoms of sleep apnoea became apparent in my early 40's when my wife started to complain about my snoring. We led a busy life with two young children, while I had a demanding job in the City of London as a tax consultant, which involved a daily commute to the city together with a good deal of other travel. I was in denial about the severity of my snoring and I failed to notice that gradually I was becoming increasingly tired and sleepy during the day. When I was not working I found it impossible to take sufficient exercise since I was exhausted after my normal day's work, and I used the weekends to recharge my batteries by listening to music and other sedentary activities.

This continued over a period of ten years, during which time my weight increased by at least 3 stones; I was also withdrawing from family life and became focused on retaining enough energy to enable me to keep working. My poor wife was therefore left to deal with family problems on her own, and was effectively deprived of my company. Often I would fall asleep on the train in the evening, sometimes missing my station, and when I reached home I would fall asleep and had to be roused to go to bed. The whole cycle of apnoeas and arousals would then begin again. Our social life became a joke and it was well known in our circle that at dinner parties I would be asleep before the sweet course. Sadly many people thought that I was simply being rude.

By morning I was exhausted and I had to face the journey to work. I have often stood outside the tube station feeling unable to make the final walk to the office, and having to gather my strength. My job required clear thought to unravel complex sets of circumstances and arrive at a clear strategy. I was unable to contemplate starting work before I had several cups of coffee, and even then it must have been obvious to my colleagues that I was not operating at a proper level. Matters came to a head one day when I was introduced to a new client with the assurance that I would solve all his problems: I actually fell asleep whilst he was outlining the details and had to be wakened by him! Fortunately he did not report the matter since my career might well have ended immediately.

The other trigger point which pushed me into seeking a diagnosis concerned driving. I was driving the family back from a break in Scotland and by the time we had reached the M6 in Lancashire they gradually fell asleep. I joined them for several seconds, my last recollection being of driving in the fast lane at 75mph. When I awoke suddenly the car had drifted over the entire motorway and was entering the hard shoulder. The

road was very busy with trucks whose drivers must have spotted the drift of the car and made way for me.

I resolved finally to find a solution to my problems (having no idea that I had sleep apnoea), but my GP was unable to help. Eventually my wife mentioned my symptoms to our local ENT surgeon, who made a preliminary diagnosis of sleep apnoea and referred me to Professor Stradling at Oxford Sleep Unit. Thereafter I was swiftly diagnosed and started CPAP therapy.

Benefits & Downsides of CPAP The benefits after only one night on CPAP were spectacular: I felt refreshed, my energy had returned, my senses were heightened and all was well with the world. I am told that my nature returned to its old self – I was no longer irritable and short- tempered. I was able to drive long distances without feeling fatigued and I was able to resume my career successfully for 10 years until my retirement. This spectacular result is a common feature found in many other patients with whom I have discussed the matter, although others take a few weeks or months to reach the same level. In short I had my old life back.

Compared with this result the drawbacks are minor. The most difficult part is learning to sleep with a nasal mask – patients can feel claustrophobic or suffer skin irritation; Others find that air being blown at slight pressure up their nose causes discomfort. All of these symptoms can be alleviated by careful medical attention from sleep nurses- I was very fortunate that Oxford Sleep Team took great care in fitting the mask and ensuring that I was given support when necessary. In fact I suffered only minor problems for the first 5 years when I began to have trouble with rhinitis, which was cured by adding a heated humidifier to my CPAP machine.

The other drawbacks concern travel. The machine has to be taken everywhere, and despite the claims by airlines it is usually impossible to use a machine on board aircraft. Although there are some lightweight models available, the next revolution will occur when someone invents a very small machine with a rechargeable battery sufficient for 1 or 2 nights. Until then we advise patients to limit their flights to a duration of 10-12 hours. The effects of CPAP wear off quite quickly, as I discovered last year when I was apart from my machine for 4 days. By day 3 I felt sleep – deprived and was unable to function normally.

Other Therapies I have no personal experience of other therapies, although I am aware that mandibular devices can be of some use where the sleep apnoea is mild.

Conclusion I believe that untreated sleep appoea is a dangerous and pernicious disease which impacts on the sufferer's ability:

- To work successfully
- To drive safely
- To carry on personal relationships and family life

Although all of these areas can be treated successfully with CPAP, if a sufferer remains undiagnosed for a significant time there are long term consequences for general health. For example I need drug treatment for hypertension and type 2 diabetes, both of which, I believe, resulted from the stresses imposed by untreated

sleep apnoea, and the weight gain which occurred during the ten years before I was diagnosed and treated. Although I have taken regular exercise for the past 15 years, I have been unable to reverse the weight gain.

I regard myself as exceptionally fortunate in having found effective treatment before it was too late. Many others have been less fortunate; I personally have spoken to several hundred people in the past 15 years, who have either:

- lost their careers and had their pensions wrecked because their employers assumed that they were "burned out" or simply indolent and inefficient
- lost their marriages or relationships, because their partners could not put up with the personality changes and sleep disturbance, or
- lost their partners or suffered severe injuries in road traffic accidents related to excessive daytime sleepiness.

It is self evident that there are many others who have not contacted me, but who have suffered the same life-changing events. To leave these people untreated makes no sense, as they will require treatment for consequential illnesses. This must have a appreciable impact on NHS costs (quite apart from the costs to the national economy).

I know that provision of CPAP is inadequately funded everywhere in England & Wales, and in many substantial cities is totally unfunded. As a result the level of treatment available is entirely random, dependent on where the patient lives. I am confident that a positive appraisal by NICE will improve that situation greatly, and I urge the Committee to reach a similar conclusion.

Frank Govan 6 August 2007