# SLEEP SOS REPORT

THE IMPACT OF SLEEP ON SOCIETY



#### THE IMPACT OF SLEEP ON SOCIETY

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# Introduction

In August 2003 John Stevens died in a road accident when driving to work. John was 41 years old, had been married to Alison for 17 years and had two young sons. As a motorway roadworks technical manager, John's job regularly involved driving long distances and as such he was an experienced driver. Yet according to witnesses of the accident, his car had veered off-course shortly before hitting another vehicle and spinning onto the verge.

For several years before the accident John had grown progressively sleepy during the daytime, despite regularly getting around seven hours sleep each night. However, John's sleep was marked by periods where he would briefly stop breathing altogether, before breathing normally again. He also suffered from heavy snoring, which had worsened as John had put on weight – one result of his sleepiness was that he exercised less.

Although John refused to see it as a serious problem, the snoring had reached the stage where Alison was forced to sleep in another room, while his sleepiness was leading to mood swings that were affecting their relationship.

If John and his family had been more aware of sleep disorders, and had received an earlier diagnosis and prompt treatment, then his life could have been saved.

John was also in denial about his daytime drowsiness, despite regularly falling asleep at home and occasionally at work, leading on one occasion to a minor accident. He eventually admitted to Alison that his reluctance to act was partly based on a fear that he would not be able to work. However, his employers were beginning to be concerned about his health and insisted on a medical check.

On hearing of John's excessive sleepiness, breathing pauses at night and heavy snoring, his doctor suspected obstructive sleep apnoea, a sleep condition that is more common in overweight men. With the right treatment almost all patients are able to live a normal life and John was referred to his local sleep clinic to confirm the diagnosis, receive advice and begin treatment. Unfortunately, as is common with many under-funded NHS sleep centres, his initial appointment involved a wait of several months.

Three months before the appointment, John suffered his fatal road accident. The other driver involved in the accident commented that John wore a vacant expression and did not react to the impending crash. John was almost certainly asleep at the wheel. If John and his family had been more aware of sleep disorders, and had received an earlier diagnosis and prompt treatment, then his life could have been saved.

John Stevens' case is just one example of the potentially devastating effect of sleep disorders on everyday life in the UK. Those who have ever suffered disturbed sleep will fully appreciate the immediate and damaging impact that tiredness brings. Losing just one or two hours in a single night can significantly affect our vigilance, co-ordination and thought processes. However, when a person suffers from the daily excessive sleepiness caused by a sleep disorder, the consequences can be damaging and far-reaching.

This report summarises the impact of sleep on society and explains how you can make a difference that will not only change lifestyles, but also save lives.

# **Executive Summary**

The Sleep SOS Report presents a comprehensive overview of how excessive sleepiness is damaging the health and economy of the nation. Sleep disorders are a major contributing factor to fatal road accidents, heart disease, strokes, lost productivity and the breakdown of marriages, in addition to impaired quality of life for hundreds of thousands of patients in the UK. Yet whilst the prevalence of sleep disorders is rising, the provision of medical services is in desperate need of attention.

- Approximately 6% of adults suffer from excessive sleepiness over 3.5 million people in the UK.1
- 20% of accidents on motorways are caused by excessive sleepiness.2
- Untreated cases of a single sleep disorder obstructive sleep apnoea are costing the NHS £432 million per year.<sup>3</sup>

The Sleep Alliance is calling on the Government and the NHS to commit to increased support for sleep medicine and improved funding of sleep services. Equally important is an improved awareness of excessive sleepiness and its consequences among healthcare professionals and the general public, and greater recognition of the impact of sleep disorders on health and quality of life.

#### Produced on behalf of the Sleep Alliance

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The report forms an integral part of the Sleep SOS Campaign, which brings together stakeholders with an interest in sleep and organisations concerned with the consequences of excessive sleepiness. The Sleep Alliance aims to create greater awareness of sleep disorders amongst the general public and the medical community and calls for a more proactive approach to reducing sleep-related morbidity and mortality. It also seeks to improve funding in an area where additional resources are sorely needed and will achieve a real difference to the everyday lives of individuals.

The Sleep Alliance is supported by an unrestricted educational grant from Cephalon UK Ltd.

# Taking Sleep Seriously — why isn't sleep medicine a priority in the UK?

Currently, an inadequate infrastructure exists within the NHS to support the diagnosis and therapeutic management of sleep disorders. This is partly a reflection of our society, which as a whole, is guilty of playing down the importance of sleep and the impact of sleep-related disorders.

Despite sleepiness being a common symptom, many who suffer from sleep problems are reluctant to 'trouble' the doctor – a decision that is usually cemented by an, at best, ambivalent attitude from their friends and family. At a time when the '24/7' attitude dominates western culture and time asleep is viewed as wasted time, many consider that a need for sleep indicates laziness or a lack of 'moral fibre'. Today's society demands a constant readiness to work and socialise, and as a result we often do not want to admit to sleepiness.

Another contributing factor is the tendency to trivialise symptoms. Heavy snoring may indicate obstructive sleep apnoea, but snorers often find themselves the target of jokes, and the symptom of a serious respiratory condition is often laughed-off.

In the UK, sleep disorders remain among the most under-diagnosed and under-treated group of medical conditions.<sup>4</sup> Sleep is considered by many within the medical community as an area that is arduous to investigate, reflecting perceptions that sleep medicine is a poorly understood, complex discipline. Certainly the time afforded to sleep medicine in today's medical schools could be improved. A recent study estimated the total time on average given to sleep disorders in undergraduate teaching at only five minutes.<sup>5</sup>

Importantly, sleep disorders are medically 'silent', initially producing 'negative' symptoms (e.g. sleepiness and poor performance) rather than 'positive' symptoms (e.g. pain,

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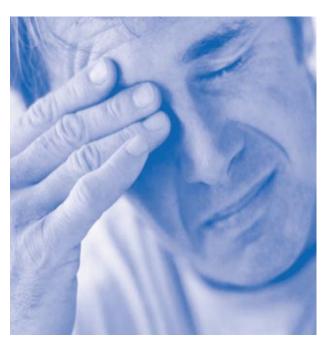
cough). The outcome is a 'silent epidemic' of excessive sleepiness, which can have profound consequences for the individuals affected and society generally. This report demonstrates that change is possible, beginning with a higher profile of sleep disorders and sleep medicine amongst healthcare professionals and the general public.

# Tough day at the office or excessive sleepiness?

From time-to-time we all experience some form of disruption to our usual sleep patterns and, for most of us, this takes the form of a short-term problem with obvious, specific causes — excessive alcohol consumption, hot weather, a restless young baby or a stressful period at work. However, the term excessive sleepiness is used when the sleepiness becomes so overwhelming that it seriously affects the individual's daily life.

Individuals with excessive sleepiness suffer from drowsiness, reduced concentration and an over-whelming desire to sleep when they need to be awake. Excessive sleepiness is seen in a variety of medical conditions (e.g. Parkinson's disease, depression, myotonic dystrophy and multiple sclerosis) and can also be an occupational hazard in jobs that involve shift work. In addition, it is the key symptom of several major sleep disorders such as obstructive sleep apnoea / hypopnoea syndrome (OSAHS) and narcolepsy.

It is therefore important to differentiate excessive sleepiness from the physical and mental tiredness that may result, for instance, from working too hard. Improved identification of the underlying cause of excessive sleepiness is a crucial step to improving the management of excessive sleepiness in those with other long-term medical conditions.



# Which sleep disorders can cause excessive sleepiness?

### **Obstructive sleep apnoea / hypopnoea syndrome (OSAHS)**

OSAHS is marked by obstruction of the upper airway during sleep. This causes pauses or breaks in a person's breathing, preventing air from entering the lungs and forcing the person to wake briefly to re-

initiate breathing before falling back to sleep again: the person is unaware of this. The interruption to breathing can happen hundreds of times a night, resulting in markedly fragmented sleep. As a result, people with OSAHS feel excessively sleepy during the day, potentially leading to dangerously reduced levels of concentration,<sup>6</sup> changes in mood and personality and a general reduction in quality of life.<sup>7</sup>

Approximately 1-2% of middle-aged men suffer from OSAHS in the UK, around 300,000 people, giving the condition a similar prevalence to Type 1 diabetes and double that of severe asthma. Women are thought to be less than half as likely as men to suffer from OSAHS. This still equates to a population of almost 80,000 UK women, particularly those in middle age.

Being overweight is one of several major risk factors for OSAHS<sup>7</sup>, in particular fatty tissue within the neck, which can compress the upper airway. Management of OSAHS is centred on a combination of Continuous Positive Airway Pressure (CPAP) therapy and the patient losing weight and avoiding alcohol. CPAP involves a mask and a small pump that raises air pressure in the upper airways, preventing them from closing and has proven effectiveness in the majority of patients. For other patients, dental devices can be beneficial and in a small number surgery may be appropriate. Pharmacological treatments are an option for those who remain sleepy despite good compliance with a fully functional CPAP system and once other sleep disorders have been ruled out.<sup>7</sup>

### **Narcolepsy**

Narcolepsy is a lifelong sleep disorder, which causes overwhelming, excessive sleepiness. People with narcolepsy may fall asleep at any moment – for instance whilst at work, in an examination, or even in mid-conversation. The effects on everyday life can be devastating.

Excessive sleepiness is usually the initial and often the most disabling symptom of narcolepsy. 9,10 Classic symptoms also include cataplexy (brief loss of muscle tone ranging from a sagging jaw to total body collapse), sleep paralysis, parasomnia, nocturnal insomnia and hallucinations. However, less than half of patients experience these last four symptoms.9

Although narcolepsy is perceived to be a rare condition, there are around 28,000 patients in the UK,<sup>11</sup> with almost 80% remaining undiagnosed.<sup>9</sup> Narcolepsy can affect men and women at any age, most frequently between the ages of 20 to 40, with an average age of onset of 20 years.<sup>9,12</sup> It is between 16 and 22 years, on average, after the onset of symptoms that a diagnosis of narcolepsy is made.<sup>13</sup>

Disease management currently focuses on control of excessive sleepiness and cataplexy through pharmacological agents and lifestyle changes such as scheduled short naps. These methods can be enormously beneficial, but for patients and doctors to capitalise on recent progress, an adequate infrastructure for the management of narcolepsy is vital.

#### Other conditions

As previously mentioned, excessive sleepiness can be a symptom of a range of chronic medical conditions, as well as motor disorders (e.g. restless leg syndrome, periodic limb movements in sleep). Although insomnia is a particularly common sleep complaint, it is important to recognise that it is not a sleep disorder in itself, but a symptom of another physical, mental or psychiatric problem. Additional conditions where excessive sleepiness can be a symptom are listed on page 14.

# The Impact of Sleep Disorders

The recently published Scottish Intercollegiate Guidelines Network (SIGN) guidance on the management of OSAHS commented that the condition's consequences "vary from annoying to life threatening."

# We are not talking about a life threatening illness, are we...?

Driving when sleepy is one of the most prevalent killers on our roads. <sup>14</sup> Whilst we are all aware of the accident risk related to drink-driving and speeding, less attention is given to the risks associated with driving when sleepy. Yet research has shown that:

- 20% of accidents on motorways in the UK are caused by sleepiness.<sup>2</sup>
- Death tolls from sleep-related accidents are three times higher than other accidents, presumably because the drivers do not swerve or apply their brakes.<sup>14</sup>
- More than 300 people a year are killed, and many more seriously injured, as a result of drivers falling asleep at the wheel.<sup>15</sup>
- OSAHS patients suffering excessive sleepiness have been shown to have a worse simulated driving performance than drivers in excess of the blood alcohol limit.<sup>16</sup>

Many drivers mistakenly believe that actions such as winding down the car window and turning-up the radio will prevent them from falling asleep at the wheel, but there is no proof that these methods are effective and for all of us there comes a point where sleep is inevitable, regardless of the environment. For those suffering from excessive sleepiness, this point can be reached relatively quickly – the nature

of their condition means that the need for sleep occurs repeatedly throughout the day.

Although the potential dangers of driving with untreated excessive sleepiness are obvious, more fatal accidents are caused by sleepiness each year than by drink-driving. Bouts of excessive sleepiness and reduced alertness can transform otherwise careful drivers into drivers who are at high-risk of causing a road accident, particularly when travelling long distances or on motorways. For instance, people with OSAHS have been shown to be 7-12 times more likely to have a road traffic accident than those without the disorder. <sup>7,18</sup>

The danger is not just confined to the roads. People with excessive sleepiness are at an increased risk of accidents at work and in the home. <sup>19,20</sup> In the United States, work-related accidents caused by sleepiness are estimated to produce 945,000 disabling injuries with 5,565 fatalities each year. <sup>21</sup>

It is not only patients who are endangered by their sleep disorder. As the introductory case study illustrates, accidents caused by untreated sleep disorders all too often involve fellow road-users, pedestrians, and even members of the patient's family. Low awareness of sleep disorders, reluctance to seek help and delays in diagnosis or treatment, place those people surrounding the patient at risk.

# What damage is excessive sleepiness doing to my relationships?

As with many chronic conditions, the patient's relationships are often the first casualty of a sleep condition. For example, whilst OSAHS patients suffer from excessive sleepiness, their bed partner experiences sleepless nights as a result of the patient's heavy snoring or because they are concerned about pauses in breathing. Symptom-related difficulties are common in the marriages of people with narcolepsy, with relationships deteriorating because of sleep attacks that occur during conversations, evenings out or possibly during sexual intercourse.<sup>10</sup>

The patient's excessive sleepiness may also manifest itself as irritability or a change in mood that damages relations between couples. OSAHS can also cause a decreased libido, placing increased pressure on what may be an already strained relationship.<sup>22</sup>

"Relate can see how damaging it can be for a couple when OSAHS is going undiagnosed. For a couple, coping with changes in their sex life can be difficult at the best of times. If one party is constantly being told by their partner that they're simply "too tired" for sex it is very easy for the issue to become a source of misunderstandings. Similarly the sufferer may be unable to explain their loss of desire to themselves, let alone their partner, if they are not aware that their tiredness is a result of an undiagnosed and treatable condition." Steve Bagnall,

Deputy Chief Executive, Relate.

The damage to the relationship is often compounded by the fact that family and friends refuse to accept sleep-related disorders as illnesses and attribute the sleepiness to boredom, laziness or psychological problems.<sup>10</sup> This can leave patients feeling misunderstood and unsupported by those closest to them. It is not surprising then that people who suffer from OSAHS and narcolepsy report having poor personal relationships.<sup>23</sup>

Yet for many, the strained and broken relationships that result from a sleep disorder are avoidable. Coupled with an accurate diagnosis, the treatment options for OSAHS and narcolepsy can significantly improve the condition, often leading to improvements in marital relations.

Research has demonstrated that CPAP (continuous positive airway pressure – see page seven), improves the quality of life for both the OSAHS patient receiving the treatment, and also their bed-partner. Following CPAP, both patient and bed-partner benefit from improved physical and mental health, and experience less sleepiness during the day.<sup>24,25,26,27</sup> As a result, partners play an important role in treatment compliance, with the patient encouraged to continue with therapy if their partner is also benefiting.<sup>28</sup>

In summary, sleep disorders, and OSAHS in particular, should be considered a community health problem, "impairing the quality of life and well-being of not only the individual patient, but the entire family and society." <sup>28</sup>

## How is the workplace affected by sleep disorders?

For those who suffer from a sleep disorder, knowingly or otherwise, the modern workplace only serves to exacerbate the effects of excessive sleepiness. The pressures of our 24/7 society are seen most clearly in the workplace, where the UK leads the European 'long-hours league' 29,30 and many people are constantly pushing themselves to keep up with their colleagues.

Changes in character and a drop in quality of work are common in people with sleep conditions. However, in our current working culture these signs are often misinterpreted and the person is mistakenly labelled as lazy and unmotivated.<sup>31</sup> For the untreated patient, the loss of sleep caused by conditions such as OSAHS and narcolepsy not only lead to poor performance at work, but also reduced job prospects and even loss of employment.<sup>32</sup>

The dangers of excessive sleepiness in the workplace have been demonstrated in clinical studies. A recent ten-year study of almost 3,000 men<sup>19</sup> concluded that excessive sleepiness and snoring, the main symptoms of OSAHS, increased the risk of occupational accidents. Shift workers have also been shown to be at particular risk of excessive sleepiness<sup>33</sup> because of the disturbance to their circadian rhythm (sleep / wake cycle), which can lead to shift work sleep disorder.

Sleep-related accidents can be particularly damaging if excessive sleepiness occurs in workers responsible for safety checks, operating heavy machinery or transport. People who drive for their occupation are especially at risk: transport statistics and National Travel Survey data indicates that about 30% of the miles driven on Britain's roads involve at-work drivers, not including commuting.<sup>34</sup> Indeed, very few organisations can operate without using motor vehicles. And many people work on or by the road – maintenance workers, refuse collectors, postal workers, vehicle breakdown employees, the police and so on. All of these workers are exposed to risks from traffic.

Research suggests that between 25% and 33% of all serious and fatal road traffic incidents involve someone who was at work at the time.<sup>35</sup> Based on this finding, RoSPA estimates that every year between 800 and 1,000 people are killed in road accidents involving an at-work driver.

A high prevalence of undiagnosed OSAHS is suspected amongst long-haul lorry drivers, as the condition is more common in middle-aged men who are overweight. This profile correlates with many lorry drivers who may gain weight as a result of their sedentary lifestyle whilst working irregular shift times, and so can exacerbate excessive sleepiness. With nearly 50% of lorry drivers admitting to falling asleep at the wheel, the consequences of working with untreated sleep disorders need to be taken seriously. 37,38

## How dangerous to my health is excessive sleepiness?

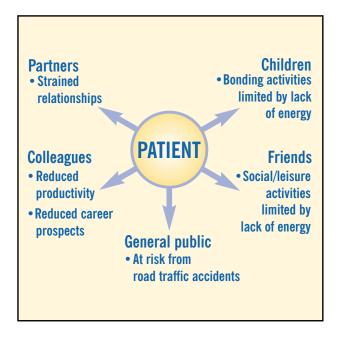
We have seen that excessive sleepiness can have fatal consequences in those situations that call for people to be alert. What has also been shown in clinical studies is that sleep disruption and excessive sleepiness as a result of medical conditions has an equally profound effect on our general health and well-being.

The breathing pauses experienced by people with OSAHS result in increased load on the heart and reduced oxygen in the bloodstream. OSAHS patients are at specific risk of serious health problems, such as vascular disease and a strong evidence base indicates that OSAHS patients are more likely to suffer from high blood pressure. Simply managing an OSAHS patient with CPAP treatment reduces blood pressure to an extent that the cardiac risk may decrease by 20% and stroke risk by 40% over five to ten years.

Patients may also experience problems with their mental functioning, caused by the disruptive nature of several sleep conditions. Mood swings, depression and personality changes are all common features of sleep disorders.<sup>7</sup>

Patients with OSAHS have been shown to experience reduced levels of attention, concentration, vigilance, manual dexterity and verbal fluency.<sup>26</sup> Narcolepsy patients in particular suffer from cognitive difficulties.<sup>42</sup> Since one-third of sufferers develop the first symptoms of narcolepsy under the age of 15 years,<sup>9</sup> academic performance is often compromised because of difficulty remaining awake during classes, exams and study.<sup>43</sup> In this way, the damage caused by excessive sleepiness in childhood can have severe implications later in life.

The knock-on effect of sleep disorders can reverberate throughout the patient's social network, impacting on the lifestyle and health of friends and family (see diagram below).



## What do untreated sleep disorders cost us financially?

The effective and timely treatment of sleep disorders could save the UK economy millions of pounds each year. Currently, untreated sleep disorders are incurring costs on a number of levels.

Untreated OSAHS is estimated to cost the NHS £432 million a year.³ This figure is based on the fact that 80% of patients are unaware of their condition and do not seek treatment, leading to hospital admissions and treatment for related conditions e.g. cardiovascular disease.³ Additional investment into sleep medicine and local sleep services would increase referrals, the speed of diagnosis and the availability of treatments, with long-term savings across the health service (see page 13).44

Undiagnosed sleep disorders can reduce productivity in the workplace, but in many cases productivity remains an issue following diagnosis. OSAHS patients are prevented from driving whilst awaiting treatment,<sup>45</sup> and any delay in treatment can have serious implications for employment. Those who continue to drive whilst awaiting diagnosis and treatment place themselves and others at significant risk.

The indirect costs of sleep disorders may prove to be an even greater drain on resources. The incidence of traffic accidents among people with an untreated sleep disorder remains high and the estimated cost to society of just a single fatal road accident in the UK is £1.25 million. $^{7,44}$  In the United States work-related accidents caused by sleepiness are estimated to cost between \$43.15 and \$56.02 billion every year, $^{46}$  with indirect cost as a whole totalling \$100 billion. $^{47}$ 

Tangible savings in these areas are achievable through a commitment

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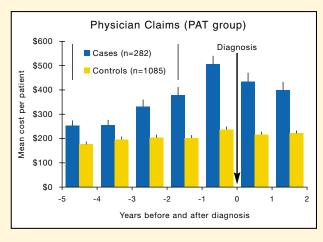
to strategic funding of sleep services at a local level and improved awareness of sleep conditions through professional and public education.<sup>48</sup>

# **Counting the Cost** – information for the NHS on how managing sleep disorders can save resources

A relatively small investment in the provision of sleep medicine services can provide significant short-term and long-term savings for health services. Appropriate diagnosis and treatment has been demonstrated to be cost-effective in a number of clinical studies.

#### **Indirect costs**

OSAHS leads to measurable increases in indirect costs and appropriate treatment reduces this excess cost. <sup>49</sup> For instance, prior to treatment, patients with untreated OSAHS are more likely to be hospitalised, incurring higher healthcare costs. <sup>50</sup> One report in Canada investigated healthcare expenditure for OSAHS patients five years before, and two years after receiving treatment. <sup>51</sup> The bar chart below demonstrates that patient adherence to treatment (PAT) significantly reduced patient costs.



A similar study of OSAHS in the United States produced comparable results,<sup>52</sup> reporting an unadjusted estimate of untreated OSAHS medical costs to be \$1,336 per year.

UK research clarified how prevention of sleep-related accidents can achieve significant cost-savings. Treating 500 OSAHS patients for five years could be expected to prevent one fatal road accident, 75 accidents that cause injury and 224 accidents that involve damage to property. This equates to £5.3 million saved against an estimated treatment cost of £0.4 million.  $^{44}$ 

Although studies have not been conducted into the cost savings associated with adequately treated narcolepsy, the financial benefits are likely to be of a similar order.

### **QALY-fying the impact**

The Quality Adjusted Life Year (QALY) is a measure that has been created to gauge a patient's quantity and quality of life. One year of perfect health-life expectancy is worth one, with the score dropping accordingly for anything less than perfect, to zero, which indicates death. Scoring in this way allows the impact on quality of life of unrelated medical conditions to be compared. It also enables the impact of interventions (including drug treatment) on quality of life to be evaluated.<sup>53</sup>

Several clinical studies have investigated the cost per QALY of treating OSAHS. In the UK, the initial cost of delivering effective treatment is estimated to be £1,000 per patient, which allows a sleep study, three outpatient visits and CPAP set-up. Annual maintenance following this is thought to be approximately £250.<sup>54</sup> At a very minimum, the QALY gain is estimated to be 0.1 per year,<sup>54</sup> whilst two recent studies demonstrate lifetime QALY gains of **8.0** (a 23% increase in health status).<sup>56</sup>

On the basis of these figures, the cost per QALY for OSAHS is approximately between £1,500 to £4,400, which reflects the inexpensive increases in quality of life that can be achieved.<sup>56</sup> To put this into perspective, the estimated cost per QALY for other interventions is as follows:

Chemotherapy treatment for non small cell lung cancer	£15,000 per QALY <sup>57</sup>
Bypass of left main coronary artery occlusion	£3,400 per QALY*58
Renal dialysis costs	£26,000 per QALY*58
Screening asymptomatic patients for carotid stenosis	£66,000 per QALY*58

<sup>\*</sup> based on US prices at \$1.8-£1 conversion rate

# Solutions to the Problem — the role and benefits of a local sleep service

For all sleep disorders, the straightforward route to improving patient care and quality of life is through a correct diagnosis, made at the earliest possible opportunity to allow appropriate management from specialist healthcare professionals.

The first step to achieving this goal is to raise awareness of sleep disorders in primary care and ensure that GPs and practice nurses receive suitable education about identifying excessive sleepiness and when to refer for further assessment.

Accurate diagnosis can be aided by tools such as sleep diaries and the Epworth Sleepiness Scale (appendix 1) – a validated patient questionnaire that assesses subjective awareness of sleepiness.

A GP will benefit from having access to a local specialist sleep service. This can also provide the focus for training primary care teams in that area and potentially develop GPs with a special interest (GPwSIs) in sleep.

If a sleep disorder is suspected, the patient should be referred for further investigation to the local sleep

Patient — Awareness

General Practitioner — Advice and referral

Local Sleep Service — Advice on sleep hygiene, shift work etc.
— Diagnose & treat conditions

Specialist Sleep Service — Diagnose & treat complex & severe conditions

clinic, usually based at the district general hospital. In some areas there are also multi-disciplinary specialist sleep centres / laboratories calling on the services of neurologists, ENT surgeons, anaesthetists, respiratory physicians, psychiatrists/neuropsychiatrists and psychologists. These specialist centres can provide detailed overnight investigations, but their numbers across the UK are limited.

The development of a local sleep service does not necessarily hinge on the costly formation of a new sleep laboratory – training of interested secondary care doctors with the necessary expertise will suffice for most patients, as long as a referral network is available to direct patients to more specialist sleep centres, if required. However, with the withdrawal of funding for sleep medicine in many areas, even the most basic services are being restricted.

An understanding of the diversity of sleep-related disorders is an important step to improving diagnosis and treatment. For instance, primary care teams may see patients with any of the following conditions that local sleep services (where they exist) are able to treat:

- Obstructive sleep apnoea / hypopnoea syndrome
- Narcolepsy
- Circadian rhythm disorders
- Restless leg syndrome / periodic limb movement disorder
- · Idiopathic hypersomnia
- Insomnia
- Other medical conditions where excessive sleepiness is a symptom (e.g. Parkinson's disease, depression, myotonic dystrophy and multiple sclerosis)

# **Call for Action**

The Sleep Alliance calls on the Government and NHS for a commitment to sleep medicine and improved funding of sleep services, to allow optimal diagnosis and management of excessive sleepiness, particularly OSAHS - the most common treatable condition. In addition, the Sleep Alliance calls for improved awareness of excessive sleepiness amongst healthcare professionals and the general public through education and greater recognition of the impact of sleep disorders on patients' lives and society as a whole.

# Call for action: What can you do?

### Are you an employer?

Employees, in particular shift-workers, with untreated excessive sleepiness are a greater risk and cost to your company because they are more likely to have an accident and be absent through ill-health.<sup>59</sup>

We should all be aware of the signs and symptoms that indicate an employee or colleague is suffering from excessive sleepiness. These may range from the subtle to the obvious e.g. a dip in performance to falling asleep in a meeting. Use of machinery, particularly repetitive operations, can be especially hazardous for people with excessive sleepiness.

Paying attention to the well-being of your workforce and colleagues makes for a safe, productive workplace with good morale. The employer also has legal responsibility for the employee suffering from excessive sleepiness whilst at work. The Health and Safety Executive (HSE) has published a new guide for UK employers, "Driving at Work", which makes it clear to employers that the Health and Safety at Work Act applies to employees when they are driving or riding on the road for work purposes. Therefore, UK companies and organisations are liable for road accidents caused by or involving employees who are

suffering from excessive sleepiness travelling to or from work. In America, the state of Pennsylvania sued a trucking company for damages caused to the motorway by company drivers who crashed their vehicles whilst asleep at the wheel – an out of court settlement of \$2.9 million was agreed. The HSE guide states:

"health and safety law applies to on-road work activities, as to all work activities, and the risks should be effectively managed within a health and safety system" http://www.hse.gov.uk/flist/september.htm

Employers need to assess and manage the risks faced, and created, by staff who drive, ride or walk on the road for work. They should conduct risk assessments, in particular reviewing features of the journey, vehicle and driver that increase the likelihood of an accident. The underlying principle is that every journey should be planned, not left to chance.

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Drivers diagnosed with OSAHS have a legal responsibility to inform the DVLA (Driver & Vehicle Licensing Agency). As a measure of the risk involved, Group 1 licence holders (drivers of cars, motorcycles, light vans) must cease to drive if they experience excessive sleepiness and Group 2 licence holders (drivers of trucks, buses and coaches) must cease to drive on diagnosis. For these groups, driving can only recommence when satisfactory control of symptoms has been confirmed to the DVLA by medical opinion and specialist / consultant opinion for Group 1 and Group 2 respectively.<sup>45</sup>

Employers can raise awareness of sleep disorders amongst employees by promoting understanding of the symptoms and dangers of excessive sleepiness among the workforce, who may not realise they are suffering from a sleep disorder. If you employ shift workers, especially drivers, consider developing a screening programme in conjunction with your local sleep centre. This could include regular, confidential driver-manager meetings on the issue, especially for new recruits.

You can find contact details of patient groups on page 21, whilst advice for employers on health and safety can be found at <a href="https://www.rospa.com/drivertraining">www.orsa.org.uk</a>. For more information about the risks of driving tired, including information sheets for drivers and their managers, the road safety charity Brake can also be contacted on 01484 559909 or email <a href="mailto:brake@brake.org.uk">brake@brake.org.uk</a>.

## Are you a GP, practice nurse or community pharmacist?

Primary care has a crucial role to play in the treatment of excessive sleepiness. Without an accurate diagnosis and early referral, patients can spend years unnecessarily suffering from symptoms that have a dramatic impact on their health status and quality of life. As well as improving patient outcome, appropriate treatment can save a practice time and money.

Excessive sleepiness is a medical symptom that can be associated with a range of conditions, many of which can be effectively managed. The first step is to improve awareness of sleep disorders in your practice by discussing the topic with colleagues. Ensure that all members of your primary care team are providing consistent advice and following a treatment protocol, which includes:

- Viewing persistent excessive sleepiness as a potential symptom of an undiagnosed sleep disorder or other medical condition.
- Taking a sleep history and using the Epworth Sleepiness Scale (appendix 1) on patients with a potential sleep disorder to help distinguish excessive sleepiness from general tiredness.
- Referral of the patient to your local sleep clinic to confirm the diagnosis (which should occur as soon as possible).

The British Sleep Society (www.sleeping.org.uk) encourages communication between GPs locally and sleep experts – networks such as this are invaluable as the basis for an improved sleep service in your area.

# Are you a member of a Primary Care Organisation management team?

Like many medical specialties, sleep medicine can claim to be under-funded and neglected at a PCO level. For instance, the Royal College of Physicians (RCP) Working Party Report on Sleep Apnoea concluded that 79% of physicians had encountered financial problems when providing a sleep service. In the case of nearly half, the NHS had imposed inappropriate restrictions on the number of CPAP machines provided or had rejected funding applications altogether.<sup>4</sup> Since the RCP report was published in 1993, the situation has not improved.

However, what makes sleep services more deserving of your budget than alternative services?

A survey <sup>60</sup> of the general public and clinicians to prioritise how NHS money is spent concluded that spending on healthcare should:

- Prevent future illness
- · Be available to everyone
- · Provide a better quality of life
- Be effective
- · Extend life.

Compassion plays a part in allocating resources, such as palliative care for cancer victims. However, it is often the case that medical conditions currently receiving adequate levels of funding do not meet these criteria. Conversely, the appropriate treatment of sleep conditions can successfully achieve all these aims.

The treatment of OSAHS represents better value for money for your PCO than many other conditions. A summary of QALY data on page 13 demonstrates that treatment of OSAHS is economical and produces large increases in quality of life, which are maintained for the rest of the patient's normal life span.

There remains a large, unmet need to treat OSAHS patients. As a result of the very limited sleep services available across the country, it is estimated that approximately 160,000 of the 380,000 people in the UK with OSAHS are unable to access treatment.<sup>61</sup> Currently the situation is only set to worsen, as sleep services around the country are either being limited or closed altogether.

Administering appropriate treatment UK-wide could potentially save the NHS over £400 million a year caused by hospital admissions, lost productivity, traffic accidents and treatments for related vascular conditions such as hypertension.<sup>3</sup>

However, increased support of sleep services does not necessarily require an additional sleep laboratory to be established in your area. Significant improvements can be achieved through the development of local sleep clinics and improved training of existing personnel, so long as patients and healthcare professionals have access to a central specialist sleep centre. Providing your local sleep services with £1 million per year would provide treatment for approximately 1,000 new patients or annual maintenance on CPAP for 4,000.54

The provision of an effective sleep service lies to a large extent in your hands. With waiting lists in most sleep centres rising, sleep disorders need to be viewed as a priority – you cannot afford to ignore funding of sleep services in your area.

## Are you a Member of Parliament?

Untreated OSAHS alone is costing the NHS £432 million pounds per year,<sup>3</sup> yet sleep medicine as a whole is underfunded and funding inequalities exist between centres.<sup>4</sup> A national survey by the British Sleep Society<sup>62</sup> identified 131 sleep centres in the UK, but very few offered the facilities that would allow them to be viewed as a specialist centre. From a sample of 127 centres, only 14 had three or more dedicated diagnostic beds. In your constituency alone there may be approximately 300 people on average with obstructive sleep apnoea needing treatment, but unable to access it. The rationing of such treatment effectively discriminates between patients in different areas, forcing only those who can afford it to buy the CPAP treatment.

The Department of Health should initially recognise the importance of sleep disorders in its policy papers. In addition, discussion should be initiated between the Department of Health, patient groups and interested parties about the possible terms of reference for the National Institute of Clinical Excellence (NICE) in producing guidelines on sleep-related disorders.

To alert the Department of Health and Government to these issues, a Commons Working Group of MPs, healthcare professionals and patient associations has been established to lobby for change in the field of sleep disorders, and a Parliamentary Bill has already been introduced calling for NICE to review OSAHS treatment as soon as possible. By joining this group, you will add to the voices in Parliament calling for improved awareness of sleep disorders and investment into sleep services.

## Are you a member of the public?

All of us face the implications of sleep disorders on a daily basis.

Those that live with a sleep disorder will have suffered (and may still be suffering) from excessive sleepiness and its effects on everyday life and health.

- Bed partners of patients may have endured sleepless nights and strained relations with their spouse or partner.
- Family and friends may notice personality changes in those potentially suffering from a sleep disorder.
- We may be concerned for a colleague whose productivity at work is dropping.
- As road users and pedestrians we are all at risk of accidents from those who are suffering from the overwhelming urge to sleep whilst behind the wheel.

Awareness of sleep-related disorders and their consequences needs to be substantially raised among sufferers and their families. For instance, sleepy people should be discouraged from driving, just as you would discourage someone who has drunk too much alcohol from driving.

Should you be concerned about anyone who is experiencing excessive sleepiness as described on page six, then encourage the person to visit their GP or contact one of the patient groups listed on page 21. It will help the GP if the Epworth Sleepiness Scale (appendix 1) is completed before the patient attends for an appointment.

# **Appendix**

### **Appendix I**

#### **Epworth Sleepiness Scale (ESS)**

How likely are you to doze off or fall asleep in the following situations, in contrast to just feeling tired? This refers to your usual way of life in the last few weeks. Even if you have not done some of these things recently, try to work out how they would have affected you. Use the following scale to choose the most appropriate number for each situation. Please tick one box on each line.

- 0 = Would never doze
- 1 = Slight chance of dozing
- 2 = Moderate chance of dozing
- 3 = High chance of dozing

Situation	0	1	2	3
Sitting and reading				
Watching television				
Sitting inactive in a public place (eg a theatre or a meeting)				
As a passenger in a car for an hour without a break				
Lying down in the afternoon, when circumstances permit				
Sitting and talking to someone				
Sitting quietly after lunch without alcohol				
In a car, while stopped for a few minutes in traffic				

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If by answering these questions, you score over ten, you may have a sleep disorder and should consult your GP.

### **Appendix II**

#### **Brake**

PO Box 548 Huddersfield HD1 2XZ

Tel: 01484 559909

#### **British Lung Foundation**

73-75 Goswell Road London EC1V 7ER

Tel: 0207 688 5555

#### **British Sleep Society**

PO Box 247 Colne Huntington Cambridgeshire PE28 3UZ

#### British Snoring & Sleep Apnoea Association

2nd Floor Suite 52 Albert Road North Reigate Surrey RH2 9EL

Tel: 01737 245638

#### **British Thoracic Society**

17 Doughty Street London WC1N 2PL

Tel: 020 7831 8778

#### Relate

Herbert Gray College Little Church Street Rugby CV21 3AP

Tel: 0845 456 1310

#### **Royal College of Physicians**

11 St Andrews Place Regent's Park London NW1 4LE Tel: 020 7935 1174

#### Royal College of Psychiatrists

17 Belgrave Square London SW1X 8PG

Tel: 020 7235 2351

#### Royal Society for the Prevention of Accidents

RoSPA House Edgbaston Park 353 Bristol Road Birmingham B5 7ST

Tel: 0121 248 2000

## The Sleep Apnoea Trust Association

7 Bailey Close High Wycombe HP13 6QA

Tel: 01494 527772

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