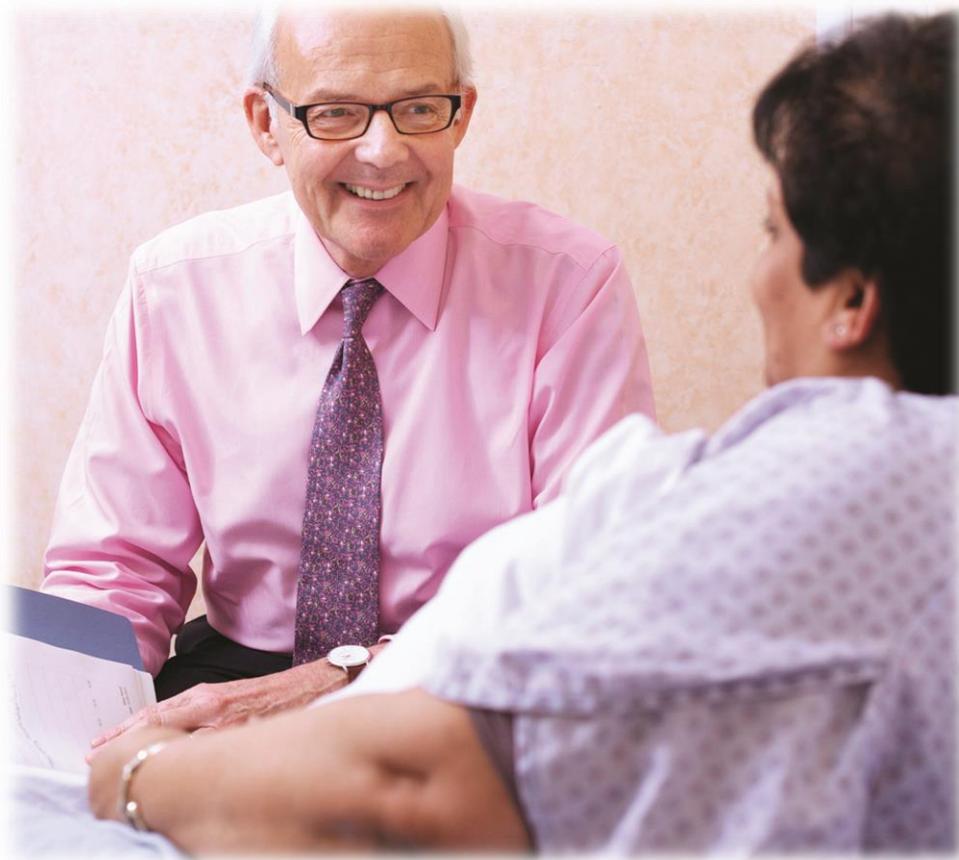




Having OSA in the UK: what the patients say



Summary report of the BLF's OSA patient experience survey 2013
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Introduction

Obstructive sleep apnoea (OSA), which occurs when the airway obstructs during sleep causing periods of breathing cessation, is more common than severe asthma¹, affecting up to two per cent of middle aged men and four per cent of middle aged women in the UK², although estimates vary, and OSA is thought to be on the rise due to increased prevalence of obesity³. It is estimated that about a quarter of a million men in the UK have severe OSA⁴, with about a million people across the UK affected by the condition. Older people are even more at risk, with 15 - 20 per cent of those aged 70 or over estimated to have the condition⁵.

Despite its prevalence, it is estimated that up to 80 per cent of people with the condition are undiagnosed⁶, and some studies suggest this figure could be even higher. Undiagnosed and untreated, OSA leads to an increased risk of hypertension, and is closely associated with cardio-vascular disease and stroke⁷. It also increases the risk of traffic collisions⁸ and other accidents e.g. work-place accidents, caused by excessive day time sleepiness which is experienced as a result of disrupted sleep. About half of people with OSA are obese⁹.

Treatment is effective and cost-effective¹⁰ and can change the lives of people with OSA and their families. However, it has been widely acknowledged in the UK that access to service provision varies, and that the quality and range of services and therapies offered also varies across the UK. There are not nationally agreed minimum standards for OSA referral assessment, diagnosis, treatment and management.

The British Lung Foundation (BLF) has led a major campaign since 2011 to raise awareness of OSA in the UK, and to improve access to services for people wherever they live. As part of this campaign they wanted to ensure that the patient voice was heard by reporting people's experiences of having OSA in the UK in 2013, and by recording and analysing their experience of receiving services following the introduction of the NICE TAG 139 on CPAP provision in 2008 and the IMPRESS service specification 2009.

Method

In 2012, a pilot survey took place with three clinics in England, using a questionnaire designed by the BLF with expert advice from the BLF's OSA advisory group. Patients and clinics who took part in the pilot were asked to provide feedback so that the methodology and questionnaire design could be amended prior to the nation-wide survey.

In 2013, sleep clinics across the UK were invited to take part in the OSA patient survey. Recruitment of clinics took place over a three month period, and under-represented areas were targeted to ensure that every region in England and every UK nation was represented. 57 clinics expressed an interest, 56 filled in registration forms and 53 clinics went on to take part.

Each clinic was sent a survey pack, comprised of a set of questionnaires to hand out to their patients, a poster to display in their clinic, a set of return envelopes to return completed questionnaires, and a guide on how to conduct the survey. Clinics were asked to collect surveys back from patients and return them in the envelopes provided.

¹ (Scottish Intercollegiate Guidelines Network, 2003)

² (National Institute for Health and Clinical Excellence (NICE), 2008)

³ (Young T, Finn L, Peppard PE, Szklo-Coxe M, Austin D, Nieto FJ, Stubbs R, Hla KM, 2008)

⁴ (National Institute for Health and Clinical Excellence (NICE), 2008)

⁵ (Martinez-Garcia MA et al, 2010)

⁶ (Won Lee MD, Swamy Nagubadi MD, Meir H. Kryger MD, and Babak Mokhlesi MD, M.Sc. , 2008)

⁷ (National Institute for Health and Clinical Excellence (NICE), 2008)

⁸ (National Institute for Health and Clinical Excellence (NICE), 2008)

⁹ (Won Lee MD, Swamy Nagubadi MD, Meir H. Kryger MD, and Babak Mokhlesi MD, M.Sc. , 2008)

¹⁰ (National Institute for Health and Clinical Excellence (NICE), 2008)

The survey was posted on the BLF website and the SATA website for people who preferred to fill in an online version.

The survey opened in May 2013 and closed in September. During this time, update emails were sent on a regular basis by the BLF to encourage and support participating clinics, and clinics were encouraged to raise any issues so that these could be dealt with.

Participation

Response numbers: A total of 2,671 responses were received: 2475 by post and 196 via the internet. This is believed to be the largest survey of people with OSA ever undertaken in the UK, and possibly globally.

Age and gender: The majority (82 per cent) of responders were aged between 40 and 69 years old. 1.2 per cent (n=31) were in their twenties and 6.5% were in their thirties (n=164). People in their fifties accounted for the highest numbers, at 31.7 per cent, and those in their sixties accounted for 30.2 per cent.

For the purposes of comparing age groups in the results, responders were grouped into three age groups: younger (20-49), Middle (50-69) and older (70+). Once grouped, younger people made up 27.4 percent of the cohort, middle aged people accounted for 61.9 per cent and 10.7 per cent were older people.

77.9 per cent of responders were male, and 22.1 per cent were female.

Driving experience: 82 per cent of responders held a current driving licence. 62 per cent drove a motor vehicle. 16 per cent held a professional driving licence, e.g. an HGV licence or drove for their living. At the time of diagnosis, 22 per cent had been doing a job that required them to drive regularly.

Other conditions / co-morbidities: Three quarters of responders said that they had at least one other condition in addition to OSA. Over 50 per cent had a weight problem, 40 per cent had hypertension and a quarter had diabetes. These three conditions are closely associated with OSA and these results are in line with research findings. 6 per cent of responders had suffered a heart attack and over 4 per cent had had a stroke.

Results

OSA awareness prior to diagnosis

44 per cent of responders said that they had heard of OSA before they were diagnosed. BLF surveys conducted in 2011 and 2014 indicate that awareness of OSA is rising in the population, with figures in 2014 suggesting that 58% of people have heard of OSA (53% of males and 62% of females). The lower figure from this cohort may reflect the fact that some of the people in the survey had been diagnosed many years ago.

50 per cent said that their partner was the first person to recognise that there was a problem while 22 per cent said a health care professional first noticed, and 19 per cent realised themselves. Some people remembered having a problem since childhood (under 2 per cent), while others did not realise that there was a problem until they were in their eighties. The mean age that people realised that there was a problem was 47, and the median was 48.

Patient pathway

Signs and symptoms

Symptoms that were asked about in the survey include those reported in the literature^{11 12 13 14 15}

Daytime symptoms:

- Sleepiness
- Waking feeling unrefreshed
- Actually falling asleep
- Poor concentration
- Dry or sore throat
- Poor memory
- Mood swings
- Depression
- Morning headache
- Fell asleep driving
- Had road traffic accident caused by sleepiness
- Other

The most commonly reported daytime symptoms experienced before diagnosis were daytime sleepiness (79 per cent), waking feeling unrefreshed (66 per cent) and actually falling asleep (53 per cent). Other common symptoms, experienced by at least a quarter of responders, were poor concentration, dry or sore throat, poor memory, mood swings, depression and morning headache. 11 per cent of people fell asleep driving, and 49 people (just under 2 per cent) admitted to having a road traffic accident caused by sleepiness. 27 per cent of these were professional drivers (n=13).

Almost all daytime symptoms were reported more frequently by women, apart from symptoms associated with driving. All daytime symptoms were reported most frequently by the youngest age group and least frequently by the oldest age group.

Night time symptoms:

- Loud snoring
- Breathing pauses
- Restless sleep
- Frequent awakenings
- Sudden or jerky body movements
- Needing the toilet often to pass urine
- Feelings of choking or gasping for breath
- Heartburn
- Other

The night time symptoms most commonly reported were loud snoring (87 per cent) and breathing pauses (79 per cent). Restless sleep and frequent awakenings were reported by over half of respondents. Sudden or jerky body movements and frequent awakenings were also common symptoms, occurring in 41 per cent and 40 per cent respectively.

Women generally reported more night time symptoms than men, with, for example, 38 per cent of women reporting feelings of choking or gasping for breath, compared with 28 per cent of men. The exceptions to this were loud snoring, reported by the same percentage of men and women, and breathing pauses, reported by more men.

¹¹ (Young, Terry, et al., 1993)

¹² (IMPRESS, 2009)

¹³ (American Thoracic Society Patient Education Series, 2009)

¹⁴ (Scottish Intercollegiate Guidelines Network, 2003)

¹⁵ (American Academy of Sleep Medicine, 2005)

Differences amongst age groups were smaller for night time symptoms and for day time symptoms, although once again, symptoms were most frequently reported by the youngest people, and least frequently by the oldest people.

These results highlight the need to ask people about a range of daytime and night time symptoms and they give an indication of the comparative frequency of these symptoms for the purposes of assessment. It is suggested that a symptom list could be used in OSA screening / assessment which includes these symptoms in order of frequency reported here, perhaps separated for men and women as the order would be slightly different, as a starting point to produce a validated screening questionnaire for OSA. The full list is included in the appendix.

OSA survey

Top ten symptoms

- Loud snoring (87%)
- Breathing pauses in sleep (79%)
- = Daytime sleepiness (79%)
- Waking feeling unrefreshed (66%)
- Restless sleep (57%)
- Falling asleep in the day (53%)
- Frequent awakenings at night (51%)
- Sudden or jerky body movements at night (41%)
- Poor concentration in the day (40%)
- = needing the toilet often at night (40%)



Referral

The time taken for responders to seek help after first noticing symptoms ranged from “immediately” to 50 years. The mean time was 38 months and the median time was 20 months. Women on average took six months longer to seek help than men, but this was not statistically significant. There were no significant differences between the age groups in time taken to seek help. However, those who had heard of OSA were more likely to seek help earlier, with an average difference of 10 months.

If people had not sought help immediately, the most common reason given for this was that they did not believe anything was wrong (68 per cent). The next most common reason, although this was only the case for six per cent, was that they did not want to admit they snored.

85 per cent of people went to their GP about their symptoms. 58 per cent were referred to a specialist or sleep clinic after one visit, with 81 per cent being referred to a sleep clinic and 8.7 per cent being referred to an ear, nose and throat clinic. 3.9 per cent of people were told not to worry and no further action was taken at that time, and a further 4.9 per cent were advised to lose weight with no further action taken. 1.9 per cent were given advice about snoring with no further action was taken.

Over 20 per cent of people visited their GP on three or more occasions with their symptoms, and 7.5 per cent of people visited the GP on five or more occasions.

These results highlight the need to ensure that GPs are made aware of the symptoms of OSA, understand the issues re health and safety of undiagnosed OSA and are involved in screening and assessment pathways for OSA services. The results confirm findings in the literature that OSA has suffered from poor understanding and recognition by the community at large and by health professionals, and that most primary care practitioners have limited experience of the condition despite the fact that GPs clearly have a role to play in the recognition of the problem¹⁶.

48 per cent of people did at least one thing to try and treat their own symptoms before diagnosis. 37 per cent tried to lose weight, 17 per cent tried to improve their sleep habits, and 11 per cent purchased a mouth guard or CPAP from the internet. Women were more likely to try and improve sleep habits and lose weight, while men were more likely to buy a product. Younger and middle aged people were more likely to try and do something to treat their symptoms than older people.

Diagnosis

The health care professional most likely to give the diagnosis of OSA was a sleep technician or physiologist (42.4 per cent) followed by respiratory physician (34.2 per cent), then nurse (7.7 per cent).

72 per cent said that they were told how severe their OSA was. This means that potentially, nearly 30 per cent of people were not told how severe their condition was, or at least have not remembered. Of those who were told, 49 per cent were told it was severe, 23 per cent were told it was moderate and 14 per cent were told it was mild. Another 14 per cent could not remember what they were told.

People were offered the list of words below and asked to choose the one which described most closely how they felt about their diagnosis. This list was compiled from previous interviews undertaken by the BLF with OSA patients who described their feelings using these words. The exception is “ashamed” - this word was recommended by a health care professional for inclusion in the list.

- Relieved
- Surprised
- Worried
- Hopeful
- Frightened
- Pleased
- Happy
- Embarrassed
- Awkward
- Sad
- Resentful
- Ashamed

The most common feeling at diagnosis was relief, felt by 46 per cent of responders, followed by surprised at 15 per cent and worried at 10.9 per cent. If the emotional reactions are grouped into positive (relieved, hopeful, pleased, happy), negative (worried, frightened, embarrassed, awkward, sad, resentful, ashamed) and neutral (surprised), then 62 per cent had positive reactions, 23 per cent had negative reactions and 15 per cent had neutral reactions. There were some variations in gender. Women were more likely to feel relieved, but also more likely to feel embarrassed and frightened, whereas men were more likely to feel worried, but also more likely to feel surprised, happy, pleased or hopeful. Generally, a higher percentage of women than men had positive feelings (71.6 per cent of women as opposed to 61.4 per cent of men).

There were also some age differences. Younger people were the group most likely to feel worried and frightened, middle aged people were more likely to feel relieved, and older people were more likely to feel surprised and hopeful.

¹⁶ (IMPRESS, 2009)

At the time of diagnosis, about 22 per cent had a job that required them to drive regularly. Of these, just over half said that their employer understood and reassured them about their continued employment and 13.8 per cent said they did this to some extent. However, 10.9 per cent said their employer did not understand, and nearly 20 per cent did not inform their employer.

92 per cent of people said that they were given information about OSA at diagnosis. The most common information given (to 82 per cent) was what happened to them during sleep, followed by what they could do to help themselves (66.2 per cent), with similar numbers being told about the causes and symptoms of OSA. 80 per cent were given information verbally, with 54.4 per cent reporting being given written information.

55.4 per cent of all people were told about informing the DVLA of a diagnosis of OSA. 62 per cent of those who drove were told to inform the DVLA, with 68 per cent of those who drove for a living being informed. Of those who reported sleepiness as one of their daytime symptoms and who were also currently drivers, 65 per cent of men and 58 per cent of women said they were told about informing the DVLA.

Treatment and management

The time gap between diagnosis and treatment initiation varied from the same day (25.6 per cent of responders) to over a year in 1.1 percent. 46 per cent had started their treatment within a week, 77 per cent within one month and 94 per cent within three months. There was no significant difference between people whose work involved driving and those who did not drive for a living.

People were asked about their first treatments (more than one could be indicated). The most common first treatment for this cohort of people was CPAP (92 per cent). A mouth guard was the first treatment for 3.3 per cent. 23.9 per cent were offered lifestyle advice as a first treatment.

There was no significant difference in the use of CPAP as a therapy between those diagnosed pre- and post- NICE guidelines.

When asked what difference the first treatment made, 75 per cent gave positive responses (It changed my life for the better; it helped a lot or helped quite a bit). Those first treated with CPAP reported much more positive outcomes than those whose initial treatment was not CPAP. Men were slightly more positive about their first treatment than women, but there were no differences between age groups.

95 per cent of responders said that CPAP was the best treatment for them. 74 per cent got used to CPAP within six months, with a further 29 per cent saying they got used to it, but that it took over six months. 52 per cent of these said that they were helped by their clinic to get used to it.

The IMPRESS service specification recommends:

- Facilities, equipment and experienced personnel necessary to initiate CPAP treatment
- Personnel and facilities to provide necessary support and training for patients commencing CPAP therapy
- Availability of a wide range of interfaces to allow provision of the most appropriate CPAP machine and interface, plus humidifier if required
- Regular monitoring and follow-up of patients
- Open access for CPAP-related problems or telephone help and support line, 9-5/Mon-Fri
- Provision of replacement machines and parts as required
- Monitoring of patient compliance, symptoms and side-effects of treatment¹⁷

Almost all responders (96 per cent) said that they received training and support on how to use their CPAP and fit their mask, and 93 per cent said they felt confident how to use it when they got home. However 43 per cent said that they had experienced some problems with their mask, tubing or machine. 92 per cent were given a helpline number to ring, and most reported that they received ongoing support; however 2.4 per cent said that they received no support at all. The results from this cohort suggest that the IMPRESS specification or equivalent is being implemented. However these results will be affected by the fact that the patients filling in the questionnaire were doing so

¹⁷ (IMPRESS, 2009)

at their sleep clinic, many of whom would have been attending a review appointment. Therefore these results will not necessarily reflect the whole population of people with OSA on treatment.

96 per cent of responders were using CPAP at the time of the survey, with 89 per cent of these reporting that they used it every night. 91 per cent used it for at least five hours per night, and 56 per cent used it for seven or more hours per night. There were no significant differences between men and women, between different age groups, between what types of information were given at diagnosis, or indeed between different emotional reactions at diagnosis. This indicates that these factors were not predictors for CPAP compliance.

Impact of treatment

Two sets of parallel statements were given about people's well-being and they were asked to score retrospectively how strongly they agreed with each statement before diagnosis and treatment and after diagnosis and treatment using a Likert-like 5 point scale. These statements were based on published research findings and literature^{18 19 20 21}.

- I slept/sleep well at night
- I got/get up feeling refreshed
- I felt/feel sleepy in the day
- I felt/feel safe driving
- My quality of life was/is excellent
- Partner's quality of life was/is excellent
- I felt/feel happy

For all seven statements, the improvement following diagnosis and treatment was highly significant.

For each responder an improvement score was calculated by subtracting the "before" response from the "after" response. For all statements the higher the score, the more positive the change, except for one statement "I feel / felt sleepy in the day", for which a lower score indicated an improvement.

Improvements were measured against various parameters:

- **Severity of OSA:** for all seven statements, the improvement was greatest for those with severe OSA and smallest for those with mild OSA and all of the differences were significant
- **Emotion when diagnosed:** there was a significantly greater improvement in well-being for those who reported positive emotions at diagnosis (except for the statement about feeling safe driving)
- **Age:** for all statements, improvements were significantly greater for those in the younger age group, and smallest for the oldest age group
- **Gender:** there were no significant differences in improvements for men and women
- **Weight:** For six of the statements (all except "My partner's quality of life was / is excellent"), those with a weight problem had significantly greater improvements in well-being scores
- **High blood pressure:** There were no significant differences between those with and without hypertension
- **Diabetes:** There were no significant differences between those with and without diabetes
- **CPAP compliance:** Those who used CPAP for more hours per night had significantly greater improvement scores, the greatest improvements being for those who used CPAP for seven or more hours per night, and the smallest for those who used it less than five hours.

These results indicate that improvements in well-being were greatest for those with severe OSA, those in the younger age group, those with a weight problem, and those using CPAP for seven hours or more per night.

¹⁸ (Mackay T (Scottish Sleep Forum), 2010)

¹⁹ (National Institute for Health and Clinical Excellence (NICE), 2008)

²⁰ (Flemons, 2004)

²¹ (Scottish Intercollegiate Guidelines Network, 2003)

Location of service provision

Current - 56 per cent of responders lived within 10 miles of their sleep clinic, with 44 per cent travelling over 10 miles. Within these groups, nearly a quarter of all responders were within five miles of their sleep clinic; however 12 per cent of the total number of responders needed to travel over 30 miles. 88 per cent of people reported that they were happy with the distance they had to travel, however this figure was much higher for those who lived nearer - 99 per cent of those within five miles were happy, whereas only 55 per cent of those travelling over 30 miles were happy with this.

Future - most people wanted services for assessment, diagnosis, treatment and ongoing management to take place in a local hospital or specialist sleep centre. Between 12.2 per cent and 16.9 per cent wanted their GP to look after them for these different services. Less than one per cent wanted telephone or video services with a sleep centre for their care, except just over one per cent chose this type of service for ongoing support. This may reflect the fact that most of these people did already access their services in hospital settings and so are used to this.

Finally, people were asked if they were due to visit more than type of clinic, whether they would want to attend one general clinic or to visit different specialist clinics for each of their conditions. Most (62 per cent) wanted to visit one clinic.

Conclusions

With a total of 2,671 responses received, this is believed to be the largest survey of people with OSA ever undertaken in the UK, and possibly globally.

The majority of responders were male and middle-aged. Three quarters of responders had at least one other condition: half had a weight problem, 40 per cent had hypertension and a quarter had diabetes.

Signs and symptoms, referral

For half of these people, their partner was the first to recognise there was a problem. Some had realised there was a problem since childhood, while for others they did not realise until they were in their eighties.

The most common daytime symptoms were sleepiness, waking unrefreshed and actually falling asleep. 11 per cent of people said that they had fallen asleep driving and nearly 2 per cent admitted having a road accident caused by sleepiness.

The most common night time symptoms were loud snoring and breathing pauses.

Women generally reported more daytime and more night time symptoms than men, and more frequently by younger people than older people.

The time taken to seek help ranged from immediately to 50 years. Women took a little longer to seek help. Those who had heard of OSA sought help earlier.

Over 20 per cent of people visited their GP on three or more occasions with their symptoms.

These results indicate the continued need to raise awareness amongst the general public and to ensure GPs are aware of the issue and have the tools to recognise

Diagnosis

72 per cent of people remembered being told how severe their OSA was, and most were relieved about their diagnosis. Generally, women were more positive about their diagnosis and men. Younger people were more worried and frightened, middle-aged people more relieved, and older people more surprised.

92 per cent of people were given information about OSA, including what happens at night, and what they could do to help themselves. Overall, only 62 per cent of drivers were told about informing the DVLA, the figure being higher, at 68 per cent, for those who drove for a living. Of those who reported daytime sleepiness and who were currently drivers, 65 per cent of men and 58 per cent of women said they were told to inform the DVLA. This highlights potential differences in practice between sleep clinics about what they advise patients.

Treatment and management

The time gap between diagnosis and treatment initiation varied from one day to over a year. There was no significant difference in time between those who drove for a living and those who did not.

Most people were receiving CPAP treatment and said that this was the best treatment for them. However, 29 per cent of people took over six months to get used to it. Nearly all responders had received training and support on how to use their CPAP and mask. Over half of these responders were using CPAP seven or more hours per night.

Being diagnosed and treated for SOA had a highly significant positive effect on seven aspects of well-being that were measured. Improvements were greatest for those with severe OSA, those who reported positive emotions at diagnosis, those who were younger and those who used CPAP for more hours per night.

Recommendations

1. Explore the possibility of developing a screening tool for OSA for use in general practice, based on the findings from this survey
2. Continue to raise awareness of OSA in the general public
3. Continue to raise awareness amongst GPs and encourage them to take part in local sleep pathways with sleep clinics
4. Campaign for minimum standards for screening, assessment, diagnosis, treatment and management of OSA including informing the DVLA and minimum time-frames for diagnosis to treatment time
5. Auditing of service provision at regional levels to ensure patients have access to the full range of services wherever they live

The BLF is continuing to contribute to these recommendations through its programme of OSA activities. However services will ultimately only improve across the UK if OSA is recognised as a national health care burden and services are commissioned accordingly.

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- BSS

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Appendix

OSA screening questionnaire - list of symptom prevalence from BLF survey

Symptom	Percentage affected	Rank
DAYTIME		
Sleepiness	79	1
Waking feeling unrefreshed	66	2
Actually falling asleep	53	3
Poor concentration	40	4
Dry or sore throat	39	5
Poor memory	31	6
Mood swings	31	6
Depression	28	7
Morning headache	27	8
NIGHT TIME		
Loud snoring	87	1
Breathing pauses	79	2
Restless sleep	57	3
Frequent awakenings	51	4
Sudden or jerky body movements	41	5
Needing the toilet often to pass urine	40	6
Feelings of choking or gasping for breath	30	7
Heartburn	14	8