AUGUST 2018

SLEEP MATTERS

THE SLEEP APNOEA TRUST ASSOCIATION

SATA*day* 2018 Moves North

SATA's Annual Conference and AGM moves to Stoke-on-Trent on 13th October

It has been SATA's goal for some years to hold our Conference & AGM in a place for those who find Oxford difficult to get to and give them the chance to attend the UK's biggest Patient and Partner Conference.

This year we will be holding the event on 13th October at the North Staffordshire Medical Institute, in Stoke-on-Trent, about 10 minutes from Junction 15 on the M6.

The Institute is located near the Royal Stoke Hospital and lies between Newcastle under Lyme and Hanley. There is ample parking and the new venue has very modern facilities, more akin to an IMAX Cinema. For those with limited access, the Institute has excellent facilities and is also the HQ of the Staffs Wheelchair Group.

It is not as large as the JR Academic Centre at Oxford, so places will be available on a first come first served basis for SATA members and their guests only.

"It does not mean we shall not be back to Oxford, but for this year, we must honour our commitment to hold a northern **SATA***day*. SATA has members all over the UK and needs to go out to the regions to allow those members access to this outstanding event. We are delighted that the manufacturers of CPAP machines will be supporting the event" states Bill Johnston, Chairman of SATA

"Sadly, in the past year we have seen the closure of another major patient support group in Hull and that follows the closure of the Bristol Group in 2016. If we are to get patients, specialists and equipment manufacturers together, SATA has to make itself more accessible. We are sure Stoke-on-Trent will be a success, so we do not see why we cannot organise large conferences in other areas of the country."

The programme is still being finalised and more details will be sent to members in the near future. Part of the theme will be focussing on alternatives to CPAP for those who are CPAP intolerant. At present their options are very limited and costly, so we hope to help that situation. It is also timely that NICE are reviewing their guidance on sleep disordered breathing, with special attention upon this area.

The brief details are that there will be formal presentations from noted medical leaders, an R&D update, a Question Time session and the AGM and the provisional programme will be released as soon as possible. There will be manufacturers stands, a specialist nurses area and a mask problem corner for those with serious mask fitment challenges (by appointment only).

You may well ask how SATA, with its constant request for help on the Committee, can consider doing this. As part of our modernisation programme, we are starting to outsource special activities and conference organisation is the first exploration into this scenario. We have engaged Executive Business Support of Lichfield to organise the event for us. It has an excellent reputation and track record in the medical business and runs the administration of the Association of Respiratory Technology and Physiology and British Sleep Society plus it organises their annual conferences.

SATAday 2018

A breathtaking experience

SLEEP APNOEA EVENT FOR PATIENTS

Saturday, 13th October 2018, 09:00–15:30

North Staffs Medical Institute
Hartshill Road, Hartshill
Stoke-on-Trent, ST4 7NY
(8 minutes from Junction 15, M6 and a
13 minute bus ride from Stoke-on-Trent Railway Station)

Find solutions to your problems with sleep apnoea

◊

Talk to specialist nurses

◊

Sort out your mask problems

◊

Hear about the latest medical developments

◊

See the latest CPAP equipment

◊

Participate in a SATA Question Time session

Meet other sleep apnoea patients & share experiences

◊

Lunch Included

◊

Members and their guests only

◊

£25 per person

◊

Book now by joining SATA (take a flyer to remind you)
Phone the SATAday Hotline 0800 025 3500 option 3 (Freephone)
Visit the SATA website www.sleep-apnoea-trust.org
Click on the SATA*day* tab, fill in some details and pay online

Medical Marijuana and Sleep Apnoea

Medical Marijuana or Cannabis has been in the news recently concerning a young boy and his epilepsy. Googling cannabis and sleep apnoea yields what initially seems exciting news. Some of you will have read about a synthetic marijuana extract being used for the treatment of obstructive sleep apnoea. Of course, most of this news emanates from the USA which is home to the world's largest healthcare business. So, if someone were to find a pill that could do the job of CPAP then unimaginable wealth would follow.

The particular drug concerned is called dronabinol and is a synthetic version of the molecule Delta-9 THC (tetrahydrocannabinol), which is in cannabis.

However, before you start lobbying your MP to declassify cannabis so you can grow your own, the guardians of safe sleep medicine in the USA, the Academy of Sleep Medicine, has issued the following position statement, which is a first class piece of common sense and will, we all hope, make sure that proper and large scale clinical trials are undertaken before any further SCIENTIFICALLY based news emerges.

SATA fully supports this statement and continues to recommend CPAP therapy as the best form of treatment for Obstructive Sleep Apnoea (OSA). We also hope that in the near future other forms of treatment, in particular MAD (Mandibular Advancement Devices) become regulated and find their way into the NICE review of Sleep Disordered Breathing that is about to commence.

This is an edited version of the position statement, the full version of which can be read in full on our website (or contact Chris Rogers for a printed copy).

Medical Cannabis and the Treatment of Obstructive Sleep Apnoea: An American Academy of Sleep Medicine Position Statement

The diagnosis and effective treatment of obstructive sleep apnoea (OSA) in adults is an urgent health priority. Positive airway pressure (PAP) therapy remains the most effective treatment for OSA, although other treatment options continue to be explored. Limited evidence citing small pilot or proof of concept studies suggest that the synthetic medical cannabis extract dronabinol may improve respiratory stability and provide benefit to treat OSA. However, side effects such as somnolence related to treatment were reported in most patients, and the long-term effects on other sleep quality measures, tolerability, and safety are still unknown. Dronabinol is not approved by the United States Food and Drug Administration (FDA) for treatment of OSA, and medical cannabis and synthetic extracts other than dronabinol have not been studied in patients with OSA. The composition of cannabinoids within medical cannabis varies significantly and is not regulated. Synthetic medical cannabis may have differential effects, with variable efficacy and side effects in the treatment of OSA. Therefore, it is the position of the American Academy of Sleep Medicine (AASM) that medical cannabis and/or its synthetic extracts should not be used for the treatment of OSA due to unreliable delivery methods and insufficient evidence of effectiveness, tolerability, and safety. OSA should be excluded from the list of chronic medical conditions for state medical cannabis programs, and patients with OSA should discuss their treatment options with a licensed medical provider at an accredited sleep facility. Further research is needed to understand the functionality of medical cannabis extracts before recommending them as a treatment for OSA.

Introduction

The American Academy of Sleep Medicine (AASM) is the leading professional society dedicated to promotion of sleep health. The AASM promotes sleep health and fosters high quality, patient-centred care through advocacy, education, strategic research, and practice standards. The AASM endeavours to advance sleep health policy that improves the health and well-being of the general public.

Obstructive sleep apnoea (OSA) is a sleep-related breathing disorder that is characterized by repetitive episodes of complete or partial upper airway obstruction during sleep.[1] Untreated, OSA is a potentially lethal disease that increases the risk of numerous health complications including hypertension, congestive heart failure, atrial fibrillation, coronary artery disease, stroke and type 2 diabetes.[2] Data show that untreated OSA is associated with an increased risk of all-cause and cardiovascular mortality, and that this risk can be reduced with effective treatment.[3,4] Therefore, the diagnosis and effective treatment of OSA in adults is an urgent health priority.

Cannabis and sleep

The flower from the cannabis plant has nearly 100 different active compounds called cannabinoids that work on the human endocannabinoid system through two main receptors, the CB1 and CB2 receptors. The two extensively researched cannabinoids are delta-9 tetrahydrocannabinol (THC) and cannabidiol (CBD). THC is the primary psychoactive component of cannabis that results in euphoria, hallucinations, anxiety, and tachycardia by acting on the CB1 receptor, while CBD counteracts the THC effects and has potential medicinal value of analgesia, neuroprotection, and anti-inflammatory action by acting on the CB2 receptor. To maximize the potential therapeutic applicability of medical cannabis, synthetic-based cannabis products have been developed such as synthetic THC (dronabinol, nabilone), CBD, and nabiximols (1:1 THC/CBD combination). Some of these synthetic cannabis products are approved by the United States Food and Drug Administration (FDA) for certain medical indications.

The effects of medical cannabis on sleep vary depending on acute versus chronic use, withdrawal after chronic use, the type of cannabinoids based on their effects on the CB1 versus CB2 receptors, and the types of synthetic extracts. Early animal studies demonstrated that cannabinoid agonists such as dronabinol improved respiratory stability through peripheral serotonergic antagonism activity, and thereby provide therapeutic benefit to treat OSA.[5] This led to human studies that assessed the effectiveness of dronabinol in pill form of different strengths from 2.5 to 10 mg to treat patients with OSA.[6–8] Prasad et al. reported a significant improvement in apnoea/hypopnea index (AHI) of 32% at 3 weeks compared to baseline (–14.1 ± 17.5; $P = .007$). Side effects related to treatment were reported in most patients, and somnolence was reported in 29% to 50% of patients. A recent placebo-controlled randomized trial in people with moderate or severe OSA found a similar response after 6 weeks of treatment using a 10-mg dose of dronabinol that reduced AHI by 33 percent with no change in the Maintenance of Wakefulness Test (MWT) latency scores. Eight percent of patients reported sleepiness and drowsiness.[8]

Importantly, the long-term use of these products on other sleep quality measures, their tolerability, and safety are still unknown. Dronabinol is not FDA approved for treatment of OSA. Medical cannabis and synthetic extracts other than dronabinol have not been studied in patients with OSA. Additionally, the safety and efficacy of other delivery methods (e.g. vaping, liquid formulation, oral capsule) have not been studied. Medical cannabis and other synthetic extracts may not only have differential effects on the CB1 and CB2 receptors; their delivery methods might also create differential effects. Therefore, further research is needed to understand their functionality before recommending them as a treatment for OSA.

Position

It is the position of the AASM:

- That medical cannabis and/or its synthetic extracts should not be used for the treatment of OSA due to unreliable delivery methods and insufficient evidence of treatment effectiveness, tolerability, and safety, and OSA should be excluded from the list of chronic medical conditions for state medical cannabis programs.
- That patients with OSA should be advised to discuss their treatment options with a licenced medical provider at an accredited sleep facility.

Discussion

Most states in the United States do not have laws legalizing the use of cannabis. However, certain states have laws that legalize it for medical and

recreational use. At least one state has announced that OSA will be added to the list of medical indications for the use of medical cannabis.[9] This is concerning as the announcement was based on limited evidence citing pilot or proof of concept studies with small sample sizes. Additionally, the duration of these studies was only 3–6 weeks, and therefore the long-term effects of use of these medical cannabis products and the effect on OSA is currently unknown. Also, treatment with the use of medical cannabis has shown adverse effects such as daytime sleepiness and may lead to unintended consequences such as motor vehicle accidents. Most studies only evaluated a specific synthetic cannabis extract (i.e. dronabinol). The effects of other medical cannabis products for treatment of OSA are currently unknown.

PAP therapy remains the most effective treatment option for OSA.[10] Adherence with PAP therapy is optimized by a patient-centred approach that includes pre-treatment education and ongoing follow-up.[11]

Dronabinol is one of the many synthetic medical cannabis extracts. The composition of cannabinoids within medical cannabis varies significantly and is not regulated. Therefore, synthetic medical cannabis may have differential CB1 and CB2 receptor effects, with variable efficacy and side effects in the treatment of OSA. There is a need for increased funding and further research on the use of synthetic medical cannabis extracts to treat OSA.

We need a better understanding of the pathophysiologic mechanisms on how synthetic medical cannabis extracts work differentially on the CB1 and CB2 receptors peripherally to help patients with OSA. This may also identify other potential synthetic extracts with higher efficacy and lesser side effects to treat OSA. Because of the potential for misuse and increased costs, the lack of evidence on beneficial effects, and risk of side effects including increased daytime sleepiness, which might lead to more harm than benefit, the AASM takes the position that medical cannabis should not be used for the treatment of OSA at this time.

Conclusions

Based on the available evidence, it is the position of the AASM that medical cannabis should not be used for the treatment of OSA. The AASM also advises state legislators, regulators and health departments that OSA should not be included as an indication for their medical cannabis programs. Further research is needed to better understand the mechanistic actions of medical cannabis and its synthetic extracts, the long-term role of these synthetic extracts on OSA treatment, and the harms and benefits.

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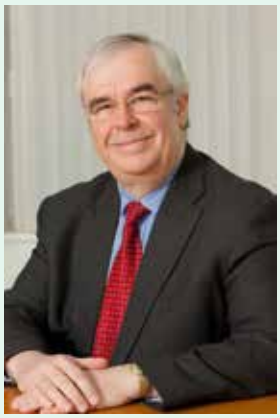
FROM THE CHAIRMAN



Bill Johnston, Chairman, SATA

I must apologise for the delays in getting Sleep Matters to you and had hoped not even to mention the DVLA in this edition, but the Committee and particularly the Helpline Volunteers have had to deal with what has been three years of confusion caused by this Government Department. Changes have occurred. They have a new boss and there is a new civil servant as Head of the Drivers Group. One might say it is not a hard act to follow, but there still many problems remaining. Why, without any consultation, having agreed to improve the forms SL1 & SL1V on line in March do they introduce major changes in April, which is causing chaos again?

If only it would consult on any changes with the people in the front line, the Clinicians who run Sleep Clinics and our charity's Helpline Volunteers, then this confusion would end. So, we are offering the DVLA the opportunity to meet with us and sort matters out.

I have to pay tribute to the hard work of my SATA colleagues, who have been the front line in helping confused patients through their own particular DVLA nightmare. The effect on the running of the Charity has been dramatic, with the level of work in dealing with the DVLA mess so great that other work such as the regular newsletter has suffered. We now have a self-help section on the website and a dedicated DVLA Helpline, and this has reduced calls.

Northern SATA*day*

We have referred to this in previous editions of Sleep Matters, and at last we have the opportunity to take our Conference and AGM to the North Midlands. That said, we must say a massive thank you to Oxford for hosting us almost continuously since 1997. We do plan to hold an Oxford Conference again, but it depends on how well the new location works and the development of a relationship with Executive Business Support.

ResMed – New HQ

We have been delighted to assist ResMed in their move from Milton Park, Abingdon to the Harwell Campus. Two events were organised for ResMed patients and SATA was there with a stand and providing advice and help. We wish ResMed the very best for the future and congratulate them on a move that has been accomplished so smoothly.

NICE

NICE has announced it is reviewing its guidance on Sleep Disordered Breathing and SATA was present at a scoping event held recently in London. It is clear that, for those who are intolerant to CPAP, they may well be receiving the collective focus of the NICE Guidance process. SATA has representation on the Guidance Panel and will keep you up to date.

Efficiency

The move to Direct Debit has been a major success. We set a target of 250 to be achieved by end of June and we have almost achieved 400. DD dramatically reduces the admin involved in our ever increasing membership. Almost everyone uses DD, for mortgages, council tax, utility bills etc. so why not SATA Membership? If you want to change NOW, just copy and paste this link into your web browser.

https://pay.gocardless.com/AL0000CXJN00FB

You are in complete control and will receive an email confirming the DD. We will liaise with you on how much you wish to pay and inform GoCardless. Two weeks before the DD is due, GoCardless emails you to state how much will be direct debited and when. If you disagree or choose to cancel, you can, at any time.

We are also going to make the first choice for new members to be DD, so making the process even more efficient.

Membership Benefits

We have decided to stop selling Medical Alert cards to non-members and make it a member-only benefit. Last year we sold 27 cards and not one of the recipients became a member, which was the original idea behind the sale decision.

We are looking at re-designing the MA Card to include other afflictions that a SATA patient may have, but nothing is definite yet.

As a trade-off, we plan to make our airline information, which is currently being completely overhauled by Committee Member David Graddon, available to all visitors to the website. It will increase visits and hopefully generate more members.

Sally Clent

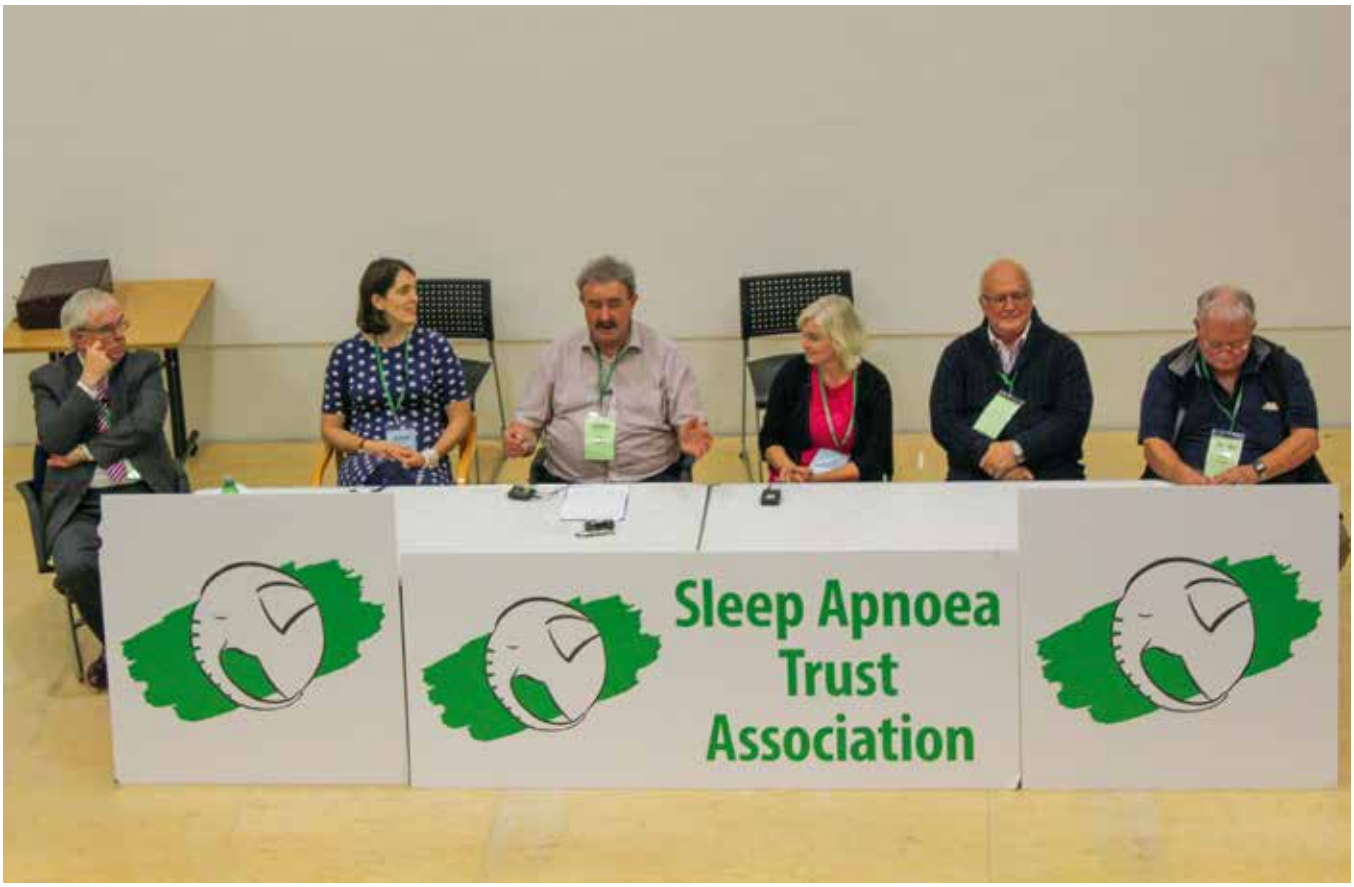
Sally has recently retired from the Oxford Sleep Unit and we wish her a long and happy retirement. Many of you will have got to know her as Oxford patients but also in her running of the Mask Corner at the **SATA**day Conference and AGM.

GDPR

All members who are recipients of Sleep Matters will have received a copy of our privacy statement. I am now delighted to state that we are GDPR-compliant. Chris Rogers is our DATA Controller and Rob Holt is our DATA Protection Officer and I congratulate them on doing such a thorough job. Also we must thank ResMed for providing guidance to us early in the run-up to the deadline.

Airline Information Update

I must thank David Graddon for the really comprehensive update to the extremely valuable information that affects many of us who fly, either on business or pleasure.



***SATA**day 2017 – The Question Time Panel*

Consumer Sleep Technology: An American Academy of Sleep Medicine Position Statement

(May 15th Journal of Clinical Sleep Medicine)

According to a position statement from the American Academy of Sleep Medicine (AASM), consumer sleep technology must be cleared by the Food and Drug Administration (FDA) and rigorously tested if it is intended to diagnose or treat sleep disorders.

Consumer sleep technologies are non-prescription devices such as wearables and mobile apps that are directly marketed to consumers to monitor sleep, improve sleep quality, or screen for sleep disorders. However, there is minimal data validating the ability of these devices to accurately perform these functions, and to date almost no consumer sleep devices have undergone review by the FDA. The lack of validation data and absence of FDA clearance raises concerns about the accuracy of consumer sleep technology. Therefore, it is important for health care providers to understand the capabilities and limitations of these devices.

"Given the heightened public awareness of the importance of sleep, and of diagnosing and treating sleep disorders, I believe we will continue to see more patient-generated health data," said lead author Dr. Seema Khosla, the medical director of the North Dakota Centre for Sleep in Fargo. "We need some guidance both for how to utilize consumer sleep technology in our practice and also how to communicate with our patients about the specific metrics their devices are measuring."

The position statement is published in the May 15th issue of the *Journal of Clinical Sleep Medicine*.

As the popularity of consumer sleep technology continues to grow, clinicians are increasingly asked to analyse patient-generated health data. However, health care providers must recognise that this data should be considered in the context of a comprehensive sleep evaluation and should not replace validated diagnostic testing.

"While technology is advancing rapidly, and we are following the trends closely, consumer sleep devices currently are unable to diagnose sleep disorders," said AASM President Dr. Ilene Rosen. "Individuals who are dissatisfied with their sleep, experiencing an ongoing sleep problem, or struggling with excessive daytime sleepiness or fatigue should discuss this important issue with a licensed medical provider, regardless of what their wearable or other consumer sleep technology device tells them."

Despite their limitations, consumer sleep devices may increase awareness of the importance of sleep and the potential presence of a sleep disorder. Therefore, this technology can promote meaningful interactions between patients and clinicians when discussed during an appropriate clinical evaluation. "I, like many of my colleagues, have seen more patients presenting to the sleep clinic to discuss their abnormal data," said Khosla. "They are looking for ways to improve their sleep and reaching out to their local sleep specialists for guidance. I believe consumer sleep technology allows us to partner with our patients to improve their sleep."

SATA Comment: This is an increasing trend in the UK and is apparent from the over-zealous self-monitoring of sleep performance appearing on some blog sites. From a medical point of view and for sleep apnoea patients, the key factor after a night's sleep using CPAP is whether you wake up feeling refreshed and symptoms, such as excessive sleepiness in normal waking hours, are eliminated. How many hours you need on CPAP has been discussed before in Sleep Matters (by *John Stradling MD FRCP, Emeritus Professor of Respiratory Medicine, Oxford University*) and there is wide variation between patients ranging from 2 or 3 hours to 8 hours plus. We are all uniquely different from each other, so it is an individual's assessment of how they feel after the night's sleep that matters. That is a personal judgement, not that of a machine.

REPORT ON SATA*day* 2017 – CONFERENCE & AGM

Saturday 7 October 2017, the one day in the year when SATA members and their families can get together to be advised about the latest events in the OSA world, be brought up to date with the latest products and technology, and most importantly are free to ask any question they like aimed at our panel of experts – all topped off with a much-appreciated lunch, teas and coffees. We've tried in this article to give a flavour of the hours of presentation, and the questions that were asked – fuller details will soon be on the web site in a SATAday 2017 section.

Introduction and Welcome, and the SATA AGM

Bill Johnston opened the conference and made some introductory comments. He also reminded us of Phil Lawrence, a long-time SATA member and leader of the Helpline who has recently died, and the immensely valuable contribution that he made. In Bill's official Chairman's Report (published in this issue), he made the comment that succession planning for Officers and committee members was still a major issue and asked for Members to come forward if they could offer some service. He advised that working with the DVLA on OSAS problems was occupying an enormous proportion of management time and the Helpline, and this was preventing us from taking more pro-active steps in other areas. He thanked Annabel Nickol for her work with the Trust and its initiatives. His Report was proposed, seconded, and passed unanimously. Rob Holt as Treasurer told us our funding was in an acceptable condition, although modest. The Report was proposed, seconded, and passed unanimously. The election of officers followed, and with the committee all available for re-election, the list was proposed, seconded, and passed unanimously. There was no Any Other Business, and the date of the next Meeting was pencilled in for Saturday 13 October 2018, and the AGM was officially closed.

Manufacturer's New Products

Graham Hill, Deputy Chairman, presented details of our manufacturers new products, and noted a trend to lighter machines. In alphabetical order –

Drive DeVilbiss	- the Blue CPAP range, and a new humidifier
Fisher and Paykel	- Masks for the Icon+ range of CPAPs - Brevida Nasal Pillows - Ison 2 Nasal Mask
Intus	- Transcend CPAP models - Tracer Lithium-Ion batteries - Mask Fit insurance – if the mask doesn't work, get a refund
Philips Respironics	- Amara View full face mask - Dreamwear nasal pillows
ResMed –	- AirMini CPAP - Air Touch F20 Mask (a very soft mask)

The Changing Face of UK Sleep Medicine

Dr Annabel Nickol, Consultant, Oxford Centre for Respiratory Medicine, explained to us how the NHS coped with OSA now, and how things might be done differently.

The current procedure should be that

- The GP notices the patient may have OSA
- The GP refers the patient to a Sleep Clinic
- The Sleep Clinic diagnoses OSA and issues a CPAP
- All subsequently goes well, and the patient is controlled

The actuality is that 50% of possible patients remain undiagnosed. We should be aiming for global awareness of the fact of OSA, and attempting to move the diagnostic service closer to home. There is, for example, a GP in Binfield, Berks specialising in OSA, serviced by the Oxford Sleep Clinic. There is also a cluster of GPs in Witney, Oxon, set up by John Stradling also relating to Oxford. However, there is still a long waiting list for referrals and sleep trials.

Oxford Clinic has a base of 11,000 treated patients and spent £1.4 million in 2016 on CPAP machines.

If we could increase the awareness of OSA, how could we meet the resulting demand, given cost restraints, i.e. a form of rationing? We could (but I would not recommend) -

- Only treat people showing an Epworth (ESS) score of 15+
- Give treatment only when the patient is "really bad"
- Give lifestyle advice (weight loss, etc) instead of treatment
- Just let a practice nurse give out a machine without the expensive consultation

A better approach might be to make use of the computing "Cloud" and use telemonitoring of sleep results by a nurse/physician. There are several programs that work with CPAPs, such as MyAir, USleep and others. Any problems showing up on monitoring would be fed back to the patient as feedback, and any remedial action can be taken. This would be good for patients, who often respond well to being involved; it is reported that 30+% of patients with CPAP give them up because they can't get comfortable with them.

Help and support is needed in the early stages of CPAP treatment. Annabel reviewed and commented on several US studies.

For mild OSA, Annabel looked at JAD (Jaw Advancement Devices), where a mouthpiece is used to hold the jaw forward and help keep the airway open. There have been some quite promising results, but precise and expensive fitting is needed for best results, and the NHS doesn't currently pay for this. JAD can be good for mild OSA, but CPAP treatment is still the gold standard for more severe problems. In summary, the patient's voice is central to shaping the future.

Sleep Matters – Why do we sleep, and what to do when sleep is unrefreshing despite effective CPAP

Dr Zenobia Zaiwalla, Consultant Clinical Neurophysiologist, Oxford Neurosciences, gave us a detailed look at the functions of sleep, and why they're needed for health.

What is sleep? It's an active restorative process, and a complex process. We estimate that 5 million Britons suffer from some form of sleep disorder.

Normal sleep comes in two categories – dream sleep (also known as REM sleep), and non-dream sleep (also known as deep sleep). A person spends a 60-90-minute period in each type of sleep, and cycles between one type and the other during the night.

Waking directly from deep sleep can be a problem, the person can be very confused. In dream (REM) sleep the body is effectively paralysed, so that the person can't "act out" any dream they may have. Waking directly from this state is much easier.

How much sleep is enough? According to the National Sleep Foundation, young people and adults have a recommended sleep period of 7-9 hours, and for over-65's it goes down to 7-8 hours. 6 hours may also be enough. Some highly-motivated people claim that 4 hours is enough, but in the longer term, a regular sleep period of 4 hours per night is probably not enough, unless supported by daytime naps.

There are two processes for falling asleep; the S-process, which becomes stronger the longer the period of staying awake, and the Circadian drive, where you feel awake in daylight, diminishing as it gets darker. The Circadian "clock" is not necessarily set at 24 hours. It's based on light, which affects the body's melatonin level. Melatonin secretion causes the sleeping process, but excess melatonin secretion makes it difficult to wake up after the sleep process.

In non-dream sleep, there are some body changes –

- Respiration rate changes
- Heartrate decreases
- The fight/flight hormone secretions should decrease
- The production of growth hormone increases

Sleep loss also has some physical effects –

- Irritability level increases
- Concentration fades, and memory processing is lost
- Pain processing improves
- Depression increases, and other psychological disorders

Among the beneficial functions of sleep are –

- Help with brain function, helping to process new memories

- To conserve energy (but only in non-dream sleep)

Specific memory functions are affected, as –

- Memories are consolidated in the sleep process, moving from short-term into long-term storage

Among people with OSA who are being treated with CPAP, 6% of people will still have sleepiness, particularly younger people; however, there are more sleepy people before treatment.

Lots of other sleep disorders may be involved, including medication. So-called Restless Leg Syndrome, where legs may kick involuntarily during sleep, may lead to full-blown sleep walking, and possibly sleep eating. Power naps may help with sleepiness, especially if planned into the day's schedule.

In conclusion, sleep is a really complicated business. Understanding normal sleep can help identify and management of disturbed sleep. The impact of sleep disturbance is pervasive. When sleepiness persists despite CPAP treatment, we need to exclude co-morbid other sleep disorders.

The World of Sleep Apnoea – an R&D update

Dr Chris Turnbull, St. Johns College, Oxford, has some updates on on-going trials for us – We know that CPAP significantly reduces blood pressure in patients with OSA; unfortunately many patients are unable to tolerate CPAP, particularly patients who are not sleepy, so we search for alternatives.

We have some early results from the Sox (Supplementary Oxygen) trial. This trial compares treatment with CPAP, treatment with supplementary oxygen, and treatment with sham oxygen (actually plain air). People in the trial start with 14 days on CPAP, to observe a blood pressure baseline. They then cease the CPAP, but switch to 14 days of oxygen, followed by 14 days of sham oxygen(air); part of the group follows CPAP with sham, then oxygen. At each stage the results on their blood pressure are measured.

In simple terms, treatment with CPAP reduces blood pressure by 2-3mm of mercury. Treatment with oxygen instead of CPAP slightly improves blood pressure, and treatment only with air makes it slightly worse. However, oxygen on its own without CPAP does not reduce the number of apnoeas/breath holding episodes, and oxygen on its own does not stop daytime sleepiness.

Another smaller trial on cardiovascular events (heart attack, stroke, etc.) treated with CPAP, found that CPAP treatment didn't help prevent second heart attacks or stroke.

A study (the STAR trial) has been conducted with implantable nerve stimulators. This is a form of pacemaker device, to stimulate the throat when breathing is being affected. This trial seems to show an improvement in patients, but since the trial is NOT randomised, the values may not be true. The results have been measured over 4 years, starting with 126 patients down to 95; improvement has occurred year on year, but the result is not definitive.

There is interest in Positional Therapy, where the patient wears a small box device on their back. This is uncomfortable and pushes the patient to turn over onto their side while sleeping. A study was done between the PT device, and a Jaw Advancement Device (JAD), both seen as non-invasive and relatively low-cost treatments. One result was a very high drop-out rate for the dental JAD.

In conclusion, either the Implantable or the Positional treatments could work, if more studies show this to be the case. However, CPAP treatment is still the best for sleepiness, even if it doesn't reduce blood pressure.

Driving and the DVLA

Chris Rogers, Managing Secretary, SATA brought the meeting up to date on the complex relationship between OSA patients and the DVLA – In general, the new rules are very confusing for patients, NHS clinicians and even DVLA staff, and licences are getting wrongly revoked. This is generating a problem for our Helpline, where 90% of available time is taken up with DVLA-related issues. We have a "friend" at DVLA, Dr Wyn Parry, Head of the DVLA Medical Group, and we are working with him to improve the wording, with a new version of the wording due for consideration for approval this month.

The SATA view is that –

- DVLA needs a specific OSA team of accredited clinicians to assess the situation, and an appeals procedure.

- DVLA needs an Action Line for rapid restoration of licences
- DVLA needs a new Advisory Panel for Respiratory Disorders, and
- The NHS needs to supply an "Advice to GPs" on how to contact the DVLA when the subject arises for their patients.

Chris was asked if any compensation might be claimable for wrongful loss of license? His answer, probably not, but give it a go anyway. Discussions between SATA and the DVLA, and other related groups are on-going, and changes will be published as soon as they can be added to the SATA website and the pages of Sleep Matters.

OSA Beginners Basics

Dr Maxine Hardinge, Oxford Centre for Respiratory Medicine gave a fascinating talk on the facts of OSA, the causes, treatments and outcomes for patients. We can all recognise the common symptoms of OSA

- Excessive daytime sleepiness
- Loud snoring during sleep
- Unrefreshed after a full night's sleep
- Choking sensations
- Restless sleep
- Passing urine several times at night

And we can anticipate some of the less common symptoms

- Morning headaches
- Changes in personality
- Poor concentration, memory
- Partner worried by apnoeic episodes
- Reduced libido

What causes the DVLA particularly to be concerned about OSA Syndrome (OSA with excessive sleepiness) is the measured effect it has on the ability to drive, compared both to "normal" drivers and drivers affected by alcohol. In a driving simulation to measure "wandering" away from a centre line, "normal" drivers varied by 25 - 150cm from the centre, in a tight grouping. With alcohol, the range varied from 50 - 450cm, quite widely spaced. The untreated OSAS entrants showed 44% approx. falling in with the "normal" group, but 56% in a long tail up to over 500cm, clearly a cause for concern.

Treatment techniques depend on the severity of the problem. For mild and some moderate OSA, weight loss and posture control may be enough, and a JAD (Jaw Advancement Device) may also help. In some cases, removal of tonsils may help, and treatment of other underlying medical disorders. The gold standard of treatment is still a CPAP unit, with a careful selection of a mask to help with patient compliance. For the grossly overweight, who might need bariatric surgery to enforce weight loss, the good news is that one survey shows that, after treatment, 90% of OSA patients had their symptoms resolved after 34 months of follow-up.

SATA Question Time

After lunch, the SATA panel convened for a question session, with all the main speakers, practice nurses, and members of the committee. For 90 minutes questions flew thick and fast from the floor for the panel to answer. The range of questions can be found on the web site, but here is a sampling of them –

Q. Do DVLA need to know about OSA, or just OSAS?
A. (Chris) OSAS with excessive sleepiness is the only requirement to advise DVLA
A. (Martine) the Sleep Clinic is the best source of information for contact with DVLA

Q. I've had a 15-month gap between CSA (Central Sleep Apnoea) diagnosis and first treatment, why is this?
A. (Annabel) CSA is more complex than OSA, and rarer in Sleep Clinics. There are more investigations for the causes of CSA, and other treatments may be relevant before CPAP. However, patients are always entitled to a second opinion. In this case, they should discuss this possibility with their sleep clinic, since any new doctor reviewing the case will need full access to all tests and key events.

Q. As an LGV driver, how often will I need a Clinic visit?
A. (Chris) As a Class 2 driver, there is an annual review.

Q. There are various sleep monitoring phone apps, is there any benefit?
A. (Dave) A mixed blessing – some patients like the breadth of information on treatment performance, others find their paranoia increased if treatment appears less than perfect.
A. (Maxine) Same goes for personal heart monitors.

Q. Is SATA working with GPs, via the Royal College or in core training?
A. (Chris) We have been to major meetings, passing on the message. Our experience is 30/30/30 denial, doubt, acceptance. There is NO formal training for GPs, it's voluntary not mandatory.

Q. I was diagnosed with moderate OSA a few years ago; should I be re-diagnosed?
A. (Annabel) If something has changed significantly for the better like losing weight, then it would be reasonable to try without CPAP. If your OSA symptoms don't come back over a couple of weeks, contact your sleep clinic, for confirmation regarding whether your OSA has resolved. If you move to a new clinic and are getting on well with CPAP without any significant changes such as weight loss, it is usually not necessary to repeat your sleep study.

Q. Can I drive overseas with OSAS if treated?
A. (Chris) EU directive was designed for commonality across Europe for CPAP for driving, but in practice the implementation has been very challenging. Check with national authorities.

A. Probably, since a licence to drive in one country is generally accepted in others; a UK-approved licence should be accepted elsewhere.

Q. What is the airline position on carriage of batteries for CPAP equipment?
A. (Dave) Each airline has its own policy, which can be seen on their website or the SATA travel page, and are all different. In general, for Lithium Ion batteries for a CPAP, up to 100 watt hours per battery is accepted. In some cases, up to 160 watt hours per battery. Some airlines expect spare batteries to be carried up to 150% of normal flight time, so check days before flying.

Q. What sort of water should I use in my humidifier?
A. (Chris) Tap water is mostly OK, with an occasional rinse with white wine vinegar every few weeks if there are signs of scaling. DEFINITELY no Olbas Oil or TCP in the water directly.
Q. If I take medicines to help me sleep, will it make my OSA worse?
A. (Annabel) It might do, as does alcohol, but since you have a CPAP you have the protection already.

SATA*day 2017 – The Conference Starts*

Sleep Apnoea Trust Association – Chairman's Report – 7/10/2017

This report covers the period from 15th October 2016 (our last AGM), until 7th Oct 2017

Trustees & Committee

We welcomed Steve Sawyer to the Committee this year, but Richard Yates sadly resigned due to other commitments. Richard has for many years been a very experienced Helpline volunteer and also took on the role of Helpline Coordinator. He was a valuable Committee Member with vast business experience, so his input to the Committee's work is already being missed.

Progress Report

Membership is growing weekly, with payments to us through subscriptions and donations increasing (see accounts for exact details) and the charity is in reasonably healthy financial position, but its business ambitions are constrained by finance. To offset this, we have requested assistance from organisations whose interest is very much sleep disorder orientated, such as the ARTP (Association of Respiratory Technology and Physiology), and we thank them for their generous support of our leaflet printing costs. ResMed is assisting us by distributing the leaflets to the various Sleep Clinics we supply, and we are working with Philips Respironics to look at ways of reaching GP surgeries with posters and leaflets. We are very grateful to these organisations and companies for their support. Cooperation with other like-minded organisations is certainly a way of spreading the SATA message and also utilising their skills and resources that our own size inhibits, but, we need more resources to be able to continue to increase awareness and that will start to dominate our activities over the coming years.

Activity Report

It has been a year totally dominated by the DVLA, almost to the exclusion of everything else. Over 90% of Helpline contact this year is the result of the confusion caused by the DVLA's revised guidelines. The summary of "Driven to Despair" by the Parliamentary Health Ombudsman, which was reproduced in the December 2016 edition of Sleep Matters, was scathing about the DVLA, who are now dealing with thousands of cases. The unprecedented publication of an emergency edition of Sleep Matters two weeks ago underlines the exceptional measures we are taking to try to steer a path through the confusion for all parties involved. We will provide a progress report today during the lunchtime sessions, so I will not pre-empt that. All this has involved a great deal of time and dedication by our Helpline volunteers, one of our Trustees, Professor John Stradling, Vice Chairman Graham Hill and above all by Chris Rogers, who has most definitely performed above and beyond the call of duty.

We had hoped by now to have started to get Sleep Clinics to provide all newly diagnosed patients with the leaflet "Living with your CPAP – Your Questions Answered", as part of a marketing initiative to encourage new membership. However, due to the time pressures on our small band of Committee Members, this has been delayed, but is now just starting. We look forward to an improvement in CPAP compliance and a growth in membership from this activity.

With the growth of some sleep apnoea-related closed group Facebook pages and the consequent risk of misinformation, we have also taken steps to relaunch our Facebook presence and are working closely with the manufacturers to expand our Facebook presence. So, if you use Facebook, look at our page, like it and share it. We are regularly updating our website and there is new content appearing all the time. We also have a Twitter page and we are now tweeting more. So our social media presence is growing.

Our involvement with both the OSA Partnership Group and the Four Week Wait campaign continues. Chris and Graham have between them attended Sleep Clinic based OSA support group meetings in hospitals in Portsmouth, Salford and Swindon, with another one on the horizon in Yeovil. We are

active members of the ARTP Sleep Consortium and Graham Hill represented us at the ARTP Annual Conference in Belfast. Chris Rogers has presented at the Worcester College, Oxford University symposium and the CARE Conference at Warwick University. These events are mainly attended by clinical staff from the NHS.

In cooperation with the Scottish Association for Sleep Apnoea we attended our second Royal College of GPs Annual Primary Care Conference in Harrogate last November to raise awareness about the seriousness of OSA, and next week attend this year's conference in Liverpool, Additionally, we will be present at the British Sleep Society conference, and next year's ARTP conference, both in Brighton.

Other activities conducted by Committee Members have involved being the patient representative on a number of current clinical trial steering committees.

Sleep Matters was subject to a delay in publishing between December 2016 and June 2017 because we had hoped, in vain, that there would be major changes to the DVLA rules that would need a dedicated edition. Our apologies for this lapse, but we are now restored to regular editions, albeit Lite Bite versions, as the human resource time to produce the glossy advert content editions doubles publication effort and time, our most precious commodity.

Let me close on the Helpline. We owe a major vote of thanks to Helpline volunteers Claire Mitchell, Sue Davies and Keith Nadin, who have been the frontline in dealing with the DVLA issues and we salute them, together with Chris Rogers, who has provided expert support on the driving issues. Sadly, Phil Lawrence, a founder member of the Trust and a long term Helpline volunteer passed away earlier in the year. We have paid tribute to his efforts for SATA but also as a unique person who spent his whole life helping others. To his wife, his children and all those who knew him closely, we extend our deepest sympathy.

But we desperately need more helpline volunteers. We have requested help from the Scottish and Welsh sleep apnoea associations, but we need more help from our own membership. Please let us know if you have the skills to help us and especially to help others who are going through the same problems many of you had to cope with when you started your CPAP treatment. We will train you and help you become established.

Risks

The main risk to our charity is a shortage of human resources, which is sadly true for many other mainly volunteer based organisations. The Committee is not getting any younger, yet the tasks they take on would challenge a significantly younger group. We do need younger people to help and share the load. Though we have developed the tools to assist sudden loss and emergency cover, especially using IT, we do not have the talented human resources to maintain continuity of the charity's business in the longer term.

With newer figures indicating that, rather than having 1.5 million adults with sleep apnoea in the UK, there are in fact approaching 3.9 million, it means our target market could grow by 160%. Let me remind you that, in terms of sleep apnoea treatment, the NHS is still climbing the mountain, as, to date only around 450-500,000 people in the UK are on CPAP, so that leaves up to 3 million still to be diagnosed and treated. For SATA this means memberships will continue to grow as more people are diagnosed. Since 2010, our total membership has grown by 70% and currently stands at 1,400.

In addition, my eighth year as Chairman is about to commence and there is a need to find a successor as I will be retiring at the end of March 2019, having by then been on the Committee for 18 years. Without naming names, but you can probably guess, a couple of our most active Committee members are now in their seventies, and with the best will in the world, cannot be expected to serve for ever.

I have to repeat last year's message that in the medium and long term we need new and younger volunteers to take on important roles and provide a wider and more evenly shared allocation of the business affairs of the Trust. But I must be blunt with you. If we do not get more support, and if some of the existing Committee feel the need to step aside on grounds of age or health, this Charity could fold within a couple of years.

If you feel, therefore, that you can help the Committee, please contact myself or Chris Rogers and we will arrange a discussion with you.

Outlook

We have developed a business plan for the next five years, which envisages a move from 75% volunteer and 25% paid labour initially to a 50% volunteer and 50% paid labour basis. Even that change dilutes the patient involvement element of our Charity which is so highly regarded in the wider world

I would very much like to congratulate and thank the Committee on what it has achieved, is achieving and will achieve through its excellent hard work. The support we receive from the Oxford Sleep Unit and the Oxford University Hospital Trust is fundamental and Dr Annabel Nickol and her colleagues are to be warmly thanked as is the Oxford University Hospital Trust who provide us with this venue and a regular meeting room at the Churchill Hospital. We also welcome the supporting clinicians from other Sleep Clinics here today and hope the inevitable collaborative discussions lead to even higher quality service in our wonderful NHS. Lastly we once again welcome the manufacturers, who so generously support this Conference. Please look at their stands during the various breaks – they will be very pleased to see you and to give advice on their equipment.

Bill Johnston, 7th October 2017

SATAday 2018

A breathtaking experience

SLEEP APNOEA EVENT FOR PATIENTS

Saturday, 13th October 2018
North Staffs Medical Institute
Hartshill Road, Hartshill
Stoke-on-Trent, ST4 7NY
(8 minutes from Junction 15, M6)

SPEAKERS INCLUDE

Bill Johnston – *Chairman – Sleep Apnoea Trust*

Dr Annabel Nickol – *Consultant in Respiratory Medicine; Sleep and Ventilation Lead, Oxford University Hospitals Trust*

Dr Aditi Desai – *President of the British Society of Dental Sleep Medicine*

Blake Marsh – *Sleep and Ventilation Physiologist, Oxford University Hospitals Trust*

Chris Rogers – *Sleep Apnoea Trust – DVLA Expert*

GDPR - SATA COMPLIANT – NEW PRIVACY NOTICE

ON 25th May 2018, all organisations that hold your personal data had to comply with new regulations that came into force throughout the EU. SATA was already well prepared with Chris Rogers as our DATA Controller and Rob Holt as our DATA Protection Officer working together to the various legal requirements, A major activity has been the depersonalisation of archive records, under the right to be forgotten. SATA has kept very good and accurate records, but information held on those people who are no longer members had to be audited and checked that we were not keeping information that we were no longer entitled to keep. For electronic data, this has been very straight forward. But, until 2010, SATA was an almost completely paper based operation and membership data was written on small cards in a card index system. This meant the safe disposal of major quantities of paper records by shredding and incineration. So, we are now compliant.

The new regulations have required us to update our Privacy Notice, which was previously on our website, so not accessible to all members. Therefore, we have reproduced it in this edition of Sleep Matters, so all members and prospective members do understand their rights and our position.

Sleep Apnoea Trust Association – Privacy Notice as of 24/05/2018

1. Introduction

This Privacy Notice explains in detail the types of personal data we may collect about you when you interact with us. It also explains how we'll store and handle that data, and keep it safe.

We know that there's a lot of information here, but we want you to be fully informed about your rights, and how the Sleep Apnoea Trust uses your data.

We hope the following will answer any questions you have but if not, please do get in touch with us.

It is likely that we'll need to update this Privacy Notice from time to time. We will notify you of any significant changes, but you're welcome to come back and check it whenever you wish.

2. What is The Sleep Apnoea Trust?

The Sleep Apnoea Trust Association, which we'll refer to as 'the Trust' in this document, is a UK charity registered on 29th June 1996 to promote the understanding and treatment of sleep apnoea in the UK.

3. Explaining the legal bases we rely on

The law on data protection sets out a number of different reasons for which a company may collect and process your personal data, including:

a) Consent

When you join the Trust we collect specific personal data and process your data with your consent.

The terms and conditions of membership, as explained in the joining email and welcome letter, clearly state that our primary communication with you will be by email. For those without email or not wishing to use email communication, you can opt in to use post as the primary communication. Members can choose to have both email and post if they wish.

The regular newsletter, Sleep Matters, has a separate choice, so a member using email can request Sleep Matters by post as well as or instead of email.

b) Contractual obligations

In one circumstance, we need your personal data to comply with our contractual obligations.

If you have registered with us for Gift Aid on membership contributions and donations, we are obliged by Her Majesty's Revenue and Customs (HMRC) to provide your title, first name, last name, first line of your address, postcode, the amount you

paid us and when, for each fiscal year in which we have made one or more claims.

There are no other circumstances when we would provide personal data.

c) *Legal compliance*
If the law requires us to, we may need to collect and process your data, such as details of people involved in fraud or other criminal activity affecting the Trust.

d) *Legitimate interest*
In specific situations, we require your data to pursue our legitimate interests in a way which might reasonably be expected as part of running our charity and which does not materially impact your rights, freedom or interests.

For example, we will use your personal data when you book a place at the **SATA***day* conference or any other conference or meeting we may organise.

Occasionally, we will email you an invitation to participate in some research and development being carried out by a third party. It is your decision to respond to the invitation and become involved and you decide how much of your personal detail you provide. NB We do not share any personal information whatsoever with that third party.

4. When do we collect your personal data?

When you joined the Sleep Apnoea Trust Association.

5. What sort of personal data do we collect?

a) From your membership application and medical alert card application: title, name, address, email, telephone number(s), sleep apnoea type, date of joining, how long on CPAP, Sleep Clinic attended, Gift Aid decision.

b) Also we collect notes of contacts with you, such as amendment to email address, registering for the SATAday conference and other details you wish to share with us.

c) Payment detail is kept for the 12 months following payment and deleted after the audited accounts of the fiscal year in which you paid are accepted at the Annual General Meeting in October/November, then deleted.

d) We do not keep payment card details when you pay us by phone.

6. How and why we use your personal data.

We use your data to manage your membership and to provide your membership benefits, e.g. Medical Alert card

Please be advised that if you choose not to share your personal data with us, or refuse certain contact permissions, we will not be able to continue to manage your membership, in which case your membership would end.

7. How we protect your personal data

We know how much data security matters to all our members. With this in mind we will treat your data with the utmost care and take all appropriate steps to protect it.

8. How long will we keep your personal data?

a) As long as you are a member of the Trust.

b) If your membership ends, we will keep records for 12 months following the cancellation for fiscal year auditing purposes and until the accounts for that fiscal year have been accepted by the AGM.

c) At the end of that retention period, your data will either be deleted completely or anonymised, for example by aggregation with other data so that it can be used in a non-identifiable way for statistical analysis.

d) In the case of Gift Aid, HMRC requires us to keep records for six years after a claim is made, irrespective of membership status. The information we collect is Title, First Name, Last Name, First Line of Address, Postcode, Amount Paid, and Date of Payment. Six years after the claim, the data will be deleted.

9. Who do we share your personal data with?

We do not share your personal information with any third party other than HMRC for Gift Aid Claim purposes.

10. What are your rights over your personal data?

a) You have the right to request:

i. Access to the personal data we hold about you, free of charge in most cases.
ii. The correction of your personal data when incorrect, out of date or incomplete.
iii. For example, when you withdraw consent, or object and we have no legitimate overriding interest, or once the purpose for which we hold the data has come to an end (such as the end of membership).
iv. You have the right to request a copy of any information about you that the Trust holds at any time and also to have that information corrected if it is inaccurate. To ask for your information, please contact **Data Protection Officer, Sleep Apnoea Trust, PO Box 60, Chinnor, Oxon, OX39 4XE** or email **info@sleep-apnoea-trust.org.**
v. To ask for your information to be amended, please contact the Managing Secretary by phone 0800 025 3500 option 3, email info@sleep-apnoea-trust.org or write to **Sleep Apnoea Trust, PO Box 60, Chinnor, Oxon, OX39 4XE .**
vi. If we choose not to action your request we will explain to you the reasons for our refusal.

b) Your right to withdraw consent

When you join SATA, you have given us your consent to use your personal data, but you have the right to change your mind at any time and withdraw that consent. However if you do so your, membership will end (see Section 6b above).

c) Where we rely on our legitimate interest

In cases where we are processing your personal data on the basis of our legitimate interest, you can ask us to stop for reasons connected to your individual situation. We will then do so, but your membership will end.

11. Checking your identity

To protect the confidentiality of your information, we will ask you to verify your identity before proceeding with any request you make under this Privacy Notice. If you have authorised a third party to submit a request on your behalf, we will ask them to prove they have your permission to act.

12. Contacting the Regulator

If you feel that your data has not been handled correctly, or you are unhappy with our response to any requests you have made to us regarding the use of your personal data, you have the right to lodge a complaint with the Information Commissioner's Office. You can contact them by calling 0303 123 1113. Or go online to www.ico.org.uk/concerns (opens in a new window; please note we can›t be responsible for the content of external websites)

If you have any questions that haven't been covered, please contact our Data Protection Officer who will be pleased to help you:

- Email us at: **info@sleep-apnoea-trust.org**
- Or write to us at **Data Protection Officer, Sleep Apnoea Trust, PO Box 60, Chinnor, Oxon, OX39 4XE.**

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Updating Our Airline Survey

In September 2013 we were getting a lot of enquiries from members relating to the carriage and use on aircraft of their CPAP machines, and it quickly became clear that there was little agreement between airlines on what an approved policy night be, and this meant problems and apprehension for our members, We therefore surveyed all the long-haul airlines serving the UK, and several of the commonly-used short-haul airlines like EasyJet and Ryanair; sorted them by the groupings they were in at the time, and published the results on our website.

Nearly five years on, there have been many changes. Airlines have replaced their planes, and the new versions are better equipped with in-seat power for laptops, iPads, etc., and there is now enough power to run a modern CPAP (not including a humidifier). Websites are now more secure, and almost all are protected by the https:// locking format, which in

itself required an update for us. There's also much more information on websites, organised in a more thoughtful fashion, which means that the old link may now lead to the wrong place, and there is new information not present before. There's also been new US legislation through the Federal Aviation Administration (FAA) outlawing discrimination against disabled travellers (including CPAP users) making flights into the US, forcing the airlines to rethink their own policies, to the long-term benefit of all.

However, the ability to make CPAP more usable doesn't necessarily change the ignorance of some airlines on what a CPAP does, or change their policy on how to use one, or the fact that a CPAP is a life-improving machine that you can use for a few hour's sleep, NOT a life-essential one which you need medical approval to use and has to be on as soon as you get on the plane. More airlines in our survey are happy to let you use in-seat power, and more will let you have some battery power rather than 150% of journey time (which is an awful lot of battery).

We have put the first grouping, the Non-Aligned airlines, onto the website in the new format, and the others (**one**world®, SkyTeam®, and Star Alliance™) will follow very shortly. The groupings are important, since with codesharing (ticket bought from one company, aircraft supplied by another) means the WORST conditions of each airline apply to the whole journey. Use the survey before you buy your ticket, and pick the airline that best meets your needs, and check who's actually supplying the plane you're going to be on, then enjoy your holiday as you should – and happy travelling.

SATA*day 2017 – Lunch in the Main Hall at Oxford*

R&D SPECIAL

The absence of Sleep Matters has left a gap in the normal reporting of R&D issues surrounding sleep apnoea and its treatment. So, we apologise and hope this section helps bridge this gap.

Do You Have Floppy eyelids? Your Sleep Apnoea May Be to Blame

A new study is providing further evidence that floppy eyelids may be a sign of sleep apnoea. The study, being carried out at Loyola Medicines Department of Ophthalmology in Chicago, Illinois, USA, found that 53 percent of sleep apnoea patients had floppy upper eyelids that were lax and rubbery. These are normally found in people who have one of three related conditions: lax eyelid condition (rubbery lids); lax eyelid syndrome (lax eyelids plus conjunctivitis) and floppy eyelid syndrome (lax eyelid syndrome in obese young men).

It is not clear why sleep apnoea is linked to floppy eyelids. One theory suggests the condition is associated with low-grade inflammation that causes degradation of elastin, a protein that allows skin and other tissues to resume their shape after stretching or contracting.

Obstructive sleep apnoea is a severely underdiagnosed disease, and without treatment leads to increased morbidity and mortality," researchers concluded. "It is the duty of today's ophthalmologist to be diligent in making the diagnosis of lax eyelid syndrome in the ophthalmology clinic. They are in the unique position to identify patients at risk for obstructive sleep apnoea and address this critical public health problem."

(*Mackenzie Sward, Clayton Kirk, Sunita Kumar, Nabila Nasir, William Adams, Charles Bouchard.* ***Lax eyelid syndrome (LES), obstructive sleep apnoea (OSA), and ocular surface inflammation****. The Ocular Surface, 2018; DOI: 10.1016/j.jtos.2018.04.003*)

Snorers Can Damage the Nerves and Muscles in the Palate

Researchers at Umeå University, in Northern Sweden have found that the recurrent vibrations from heavy snoring can damage the soft tissue in the palate, with both nerves and muscles the casualties. This damage can create problems with swallowing and contribute towards the development of sleep apnoea and its severity. They propose that early intervention with the development of snoring may be advisable, as it can both limit palate damage and also the development of sleep apnoea. Continued research is needed to see if early intervention can have the further benefits of mitigating this important health condition, which in linked to hypertension, cardiovascular disease and premature death.

Umea University. "Snorers suffer from nerve and muscle damage in the palate." ScienceDaily. ScienceDaily, 14 May 2018. <www.sciencedaily.com/releases/2018/05/180514095514.htm>.

Statins Found To Protect Blood Vessels From Substances That Cause Inflammation

Statins are drugs that lower your body's cholesterol level reducing your risk of heart and circulatory disease and are routinely prescribed to nearly 12 million people in the UK.

Cholesterol is a type of fat made in your liver. It does a lot of important jobs that keep you healthy. However, if you have too much 'bad' cholesterol (low-density lipoprotein or LDL) in your blood, it can cause fatty deposits to build up on the walls of your arteries. This is known as atherosclerosis – it's a condition that narrows your arteries, hence the risk of circulatory disease.

Normally, people have a protein called CD59 on the surface of the cells that line their blood vessels, which inhibits the build-up of inflammatory proteins on these surfaces. Inflammatory proteins can cause heart disease.

In sleep apnoea patients, the CD59 protein is found inside the cells and, as a result, the surfaces of their blood vessel lining cells have larger deposits of inflammatory proteins. This finding suggests that the interrupted oxygen flow during sleep affects the presence of CD59 on the cell surface.

The researchers found that, of those sleep apnoea patients being treated with statins, the CD59 was

preserved on the cell surface, similar to those without sleep apnoea. Further testing revealed that it is the cholesterol that draws CD59 away from the cell surface by a process known as endocytosis.

So, reducing the cholesterol level using statins, reduces the level of cholesterol in the blood, thereby limiting the endocytosis of CD59, so that it can continue to protect the lining of blood vessels from inflammatory influences.

"We were surprised to discover that these commonly prescribed drugs appear to reverse the process that leads to vascular injury and ultimately, heart disease, in people with sleep apnoea" said Dr Jelic. "This striking result provides support for the concept that statins may be considered as a primary prevention strategy for reducing heart disease risk in people with sleep apnoea, pending further clinical trials."

Jan. 6, 2016 online edition of Science Translational Medicine.

M. Emin, G. Wang, F. Castagna, J. Rodriguez-Lopez, R. Wahab, J. Wang, T. Adams, Y. Wei, S. Jelic. ***Increased internalization of complement inhibitor CD59 may contribute to endothelial inflammation in obstructive sleep apnoea****. Science Translational Medicine, 2016; 8 (320): 320ra1 DOI: 10.1126/scitranslmed.aad0634*

Losing Just One Night Of Sleep Can Increase Risk Of Alzheimer's Disease - Study

A small study from the United States has indicated that losing just one full night of sleep can elevate levels of a protein in the brain associated with Alzheimer's Disease.

The study examined a group of 20 participants aged between 22 and 72 years after a night of rested sleep and after a night of sleep deprivation, with the participants staying awake for around 31 hours.

Following the night of sleep deprivation, the researchers scanned each participant's brain using positron emission tomography (PET) and found that levels of beta-amyloid, a metabolic waste product found in the fluid between brain cells that is strongly associated with Alzheimer's, increased by about five per cent.

The increase of beta-amyloid occurred in the thalamus and hippocampus, two regions of the brain that are especially vulnerable to damage during the early stage of Alzheimer's Disease. A hallmark of Alzheimer's Disease is the tendency for beta-amyloid proteins to clump together to form amyloid plaques, which then negatively influences the communication between neurons.

While ongoing sleep deprivation can elevate brain beta-amyloid levels of mice, far less is known about the impact of sleep deprivation on beta-amyloid levels in the human brain. This study is one of the first to demonstrate just how important sleep is for clearing levels of human beta-amyloid.

Beta-amyloid levels are estimated to increase by around 43 percent in individuals with Alzheimer's disease, as opposed to healthy older adults. It is not known whether the higher levels in beta-amyloid among the study participants would subside after a full night of sleep.

Another interesting thing that the researchers found was that participants with the largest increases in beta-amyloid reported the worst mood changes after sleep deprivation. They noted that even though the study sample was small, the research demonstrates the negative effect of sleep deprivation on beta-amyloid burden in the human brain, but future studies are needed to assess the results in a larger and more diverse population.

It is important to note that the link between sleep disorders and Alzheimer's is considered 'bidirectional,' since elevated beta-amyloid may also lead to sleep deprivation.

The researchers said the study provides a new insight into how a lack of sleep can impact the brain, and that the results may help health practitioners better treat Alzheimer's.

SDA News (Australia) https://www.niaaa.nih.gov/newsevents/news-releases/lack-sleep-maybe- linked-risk-factor-alzheimer'sdisease

Thinning Of The Cerebral Cortex Linked To OSA

Recent research has found a connection between thinning of the brain's cerebral cortex and obstructive sleep apnoea (OSA) symptoms. By examining clinical records and magnetic resonance imaging (MRI) brain scans of patients who were recently diagnosed with OSA, researchers at the UCLA School of Nursing in the US made the link and found distinct changes in the brain structures and concurrent symptoms between men and women.

For example, they found that more regions of the superior frontal lobe were thinner in women with OSA than men or control groups. For these patients, an overall cortical thinning could lead to impaired regulation of the autonomic nervous system and impair breathing through the upper airway.

The researchers looked at cortex thickness of 12 women and 36 men with mild to severe untreated OSA and compared the findings to a control group who did not have OSA. The researchers then compared the clinical findings of each patient with evidence of cortex thinning.

This study is one of the first to determine significant differences between men and women with OSA, and outlines the need for appropriate treatments to tackle the varied symptoms. Although previous research has made links between gender, brain structure changes and general clinical signs of OSA, none of the research has definitively linked gender differences in brain structure with OSA.

Men are twice as likely to have OSA as women, and symptoms and brain function appear to vary between men and women. Regardless of gender, untreated OSA can damage the brain progressively over time. It is not clear, however, whether these physical brain changes precede OSA or worsen symptoms as the disorder progresses.

https://www.sciencedaily.com/releases/2018/03/180313093000.htm

Researchers Identify Neural Circuitry For Rousing the Brain In Sleep Apnoea Conditions In Mice

Often, but not always OSA is marked by regular loud snoring, then the pause as the airway collapses, then oxygen level in the blood dips, CO2 rises and the sleeping brain is alerted. BUT HOW?

The team at Harvard Medical School set out to identify the neural circuitry responsible for waking the brain up during the sleep apnoea, which is different from the part of the brain that controls breathing.

Professor Clifford Saper says, "If we could keep the brain from waking up during apnoea and activate only the part of the brain that opens the airways, people with OSA would still be able to get a good night's rest".

Using mice in an atmospheric enclosure, with adjustable O2 and CO2 levels, the researchers mimicked OSA by changing the ratio of the two gases every five minutes for about 30 seconds.

The genetically modified mice have neurons that can be switched on and off by light or drugs. They can actually be kept awake for many hours when they should be sleeping. The focus was on neurons known to show activity to elevated CO2 levels (PBel ^{CGRP}). By switching off the neurons connection to a key site in the basal forebrain, a nearly complete loss of sensitivity to CO2 arousal occurred. The researchers acknowledge that rising CO2 levels might not be the only factor that repeatedly rouses people with sleep apnoea during the night.

"The long term goal of this research is to come up with drugs that will affect specific pathways in the brain", Saper said. "The next step is to see if we can use drugs to prevent the wake-up response while augmenting the opening of the airway. That way, having an apnoea won't wake a person up.

But remember this is confined to the world of mice at present".

Beth Israel Deaconess Medical Centre. "Sleeping through the snoring: Researchers ID neurons that rouse the brain to breathe." ScienceDaily. ScienceDaily, 2 November 2017. www.sciencedaily.com/releases/2017/11/171102125028.htm

TALE END – UK or US medicine, which would you prefer?

Our contributor reports –

"I was in Florida over Easter on a golf holiday and discovered that I couldn't walk down the long hotel corridor to the breakfast room without stopping for a long breath (I am a CPAP user, which normally has me well controlled). My wife and I therefore decided to go to the nearest Emergency Room (the UK A&E), taking my CPAP with us just in case. We reported the apparent problem to reception, and within 5 minutes were taken into a diagnosis cubicle; an electrocardiogram machine (ECG) was wheeled in, and 5 minutes later I was told I had low levels of blood oxygen, and signs of atrial fibrillation, and 10 minutes later I was in a comfortable bed in a room of my own, waiting for some tests. Unlike the UK, blood tests, blood pressure tests and breathing treatments go on all night (a full staff crew), so the patient doesn't get much sleep. My CPAP was very useful, after some discussion on how it worked, and if it could be plugged in; they put a connector between the tube and the mask to connect an oxygen line, and a second connector to use for respiratory infusion. After a day of rest and recovery, I was scheduled for defibrillation (the scene in ER when a doctor holds up two electrical pads and leads and shouts "stand clear", while the patient jumps like a dead frog). I was sedated at the time, fortunately, and they put me back on the CPAP immediately during recovery.

After the op, I was prescribed a blood thinner – "it's called apixaban, it comes from the UK, it's really good, you're on it for life, and it costs $600 for each month's supply" – whaaat??

Still, I was out in three days, declared fit to fly home, and got all sorts of wheelchair help in Orlando and Gatwick airports.

So, which do I prefer, US or UK treatment? US is fast, friendly, comfortable, good hospital food, speedy effective treatment. The cost – three days in the low thousands of dollars (travel insurance paid for it, eventually), and the drug costs were extortionate. In the UK, I might have waited 4-5 hours in A&E, I might have got similar treatment in the right hospital, and the drugs are on free prescription since I'm over 60.

The NHS, best in the world? Maybe, and it's probably up near the best for treatments, and it's hard to argue with free medicines, but perhaps it could at least look at improving the quality of service?

SO COME TO

→ SATA*day* 2018 ←

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