



SLEEP MATTERS

THE SLEEP APNOEA TRUST ASSOCIATION

Dear SATA Members,

In my last year as Chairman, I never imagined that such life changing events would affect our world and with such potentially enormous consequences.

SATA was founded to help change and improve people's lives, primarily using a very simple piece of equipment, a small air pump attached to the face, invented by an Australian doctor who was fed up with sleepless nights due to his dog's snoring.

So it is extraordinary that 27 years later a relative to the humble CPAP machine, the ventilator, which acts as an electronic pair of lungs, has become a key piece of equipment in saving lives all over the world.

As we are all aware, it is the respiratory teams who have looked after us so well in the past, who are in the front line in dealing with corona virus, often putting their own lives at risk to save others.

My plea to you as fellow CPAP patients, as we have all become used to the very best support from our local hospital Sleep Clinic teams, is to be especially careful over the next few months, while the clinicians who serve us so well are diverted into the most important challenge of all, looking after very sick patients.

This means being especially careful with our CPAP equipment and its maintenance. Keep it scrupulously clean, wash the mask and tube carefully, in fact, treat it with the greatest care, and that will minimise any problems occurring.

If you do have problems, then email us on info@sleep-apnoea-trust.org, or if it is really urgent, then call us on 0800 025 3500 and we will try and help, as we do have direct contact with all the manufacturers.

For advice on cleaning and maintenance refer to the "Living with your CPAP" leaflet and patient information sheet, which you will find on our website.

Please all try your best to keep safe during this crisis by observing the Government and NHS advice.

Yours sincerely,

Bill Johnston

Guidance regarding coronavirus (COVID-19) and Obstructive Sleep Apnoea (OSA):

For people who routinely use continuous positive airway pressure (CPAP), their families and health care workers, published on 20th March 2020

Compiled by Dr Sonya Craig and Dr Sophie West with the OSA Alliance (incorporating British Thoracic Society, British Sleep Society, Association for Respiratory Technology and Physiology, Sleep Apnoea Trust Association)

General advice

Patients with OSA should follow the government advice re COVID-19:

<https://www.gov.uk/government/topical-events/coronavirus-covid-19-uk-government-response>.

There is no data yet regarding the risk of OSA alone in terms of COVID-19 susceptibility.

Home advice

- People with OSA should continue to use their CPAP at home as normal.
- There is no evidence that using CPAP makes you more likely to catch COVID-19, and nothing to suggest that CPAP will make you more unwell if you do catch it.
- If a CPAP user becomes unwell with symptoms suggestive of COVID-19 (new cough and fever > 37.8 C), please follow government guidance regarding self and household isolation.
- We do not know whether CPAP makes virus spread worse within a household. This will be something you will need to consider when deciding whether or not to continue using CPAP if you are self-isolating with symptoms of COVID-19. You may wish to distance yourself from vulnerable household members by changing bedrooms or stopping CPAP for a short time.
- Any respiratory infection, particularly with a blocked nose, can make it more difficult to use CPAP. Try and persist, but if wearing CPAP makes you feel worse (e.g. by increasing coughing and disturbing sleep), then stop using it until your respiratory symptoms improve. Sleeping more upright, avoiding alcohol and using a mandibular advancement splint if you have one, may help as alternatives to CPAP in reducing OSA a little in this period. Your OSA symptoms are likely to worsen over the week, but will resolve when you restart CPAP.
- Routine hygiene is adequate for infection control: changing machine filters routinely, cleaning surfaces, cleaning mask and tubing with hand-hot soapy water (washing up liquid) and washing hands regularly.
- Masks and machines should not be shared.
- Please use the telephone number/email address provided by your sleep centre for urgent issues with your equipment or sleep/OSA related symptoms. Do not attend in person unless instructed to do so. Please be aware the team may not be able to respond quickly, as staff may have been moved to Emergency Services.
- Please look after masks and tubing carefully as there may be a temporary shortage in the future.
- A reminder that DVLA says anyone with excessive sleepiness having or likely to have an adverse effect on driving must not drive.

Sleep out-patient advice for hospitals

- Routine out-patient visits should be avoided unless urgent.
- Remote monitoring and telephone consultations may be an option for some.
- Posting of masks and equipment from Sleep centres should be encouraged, without patients attending.

Advice for a person with OSA who routinely uses CPAP who is unwell and admitted to hospital due to suspected/confirmed COVID-19

- Bring your CPAP machine into hospital with you.
DO NOT USE YOUR CPAP UNLESS INSTRUCTED BY STAFF: you may be asked not to use CPAP for OSA on an open ward if you have suspected COVID-19, until COVID-19 screening results are back. If you use CPAP for Obesity Hypoventilation Syndrome (OSA, obesity plus respiratory failure) requiring CPAP to maintain ventilation, this should be continued but will need an isolation area (such as side room or negative pressure area), so please be guided by medical staff caring for you.
- To decrease any risks of infection from CPAP whilst you are in hospital: your usual mask, which has a vent to allow you to breathe out, may be changed. The new temporary mask will not have this vent, but a bacterial/viral filter can also be added along with an exhalation port in the tubing.
- DO NOT USE your humidifier with your CPAP machine in hospital due to increased droplet spread.

CLEANING YOUR CPAP EQUIPMENT –

USA FDA WARNS ON USE OF OZONE AND UV LIGHT IN CPAP CLEANERS & SANITISERS

SATA has never moved from its position on cleaning CPAP equipment and has always stated that hand warm water with a drop of plain washing up liquid has been enough to both sanitise and clean masks, headgear and tubing. Washing removes the skin grease contaminants that occur with any device that is connected to your skin. Our “Living with your CPAP” leaflet, designed for those newly diagnosed, clearly describes the whole process.

In the past few years, products have appeared in the UK using either ozone (activated oxygen) or ultraviolet light, claiming that they achieve the same or better effect. First of all, they do not clean, they only sanitise (kill any bacteria); skin debris and grease will remain on masks and headgear. This then has to be removed by washing in hand hot water with a drop of washing up liquid. Which then begs the question, why spend money on something that only does half the job?

At the same time, we became concerned about the safety of devices that generated ground level ozone and ultraviolet light, both of which are classified as potentially hazardous by the UK Government and both are covered by health and safety regulations, as follows:

- **Exposure to ozone** may cause headaches, coughing, dry throat, shortness of breath, a heavy feeling in the chest, and fluid in the lungs. Higher levels of **exposure** can lead to more severe symptoms. Chronic **exposure** may lead to asthma. Workers may be harmed from **exposure** to **ozone**: <https://www.hse.gov.uk/pubns/eh38.pdf>
- UV radiation can cause injuries and ill health either in the short term (e.g. sunburnt skin or conjunctivitis) or in the long term (e.g. premature skin ageing, skin cancer and cataracts): <https://www.hse.gov.uk/pubns/indg209.pdf>

Two CPAP manufacturers had already announced that their product warranties would be invalidated if subject to cleaning using these agents. Now, the US Food & Drug Administration has just published a communication about these products. Rather than rewrite the text, we have reprinted it for your guidance.

Potential Risks Associated With The Use of Ozone and Ultraviolet (UV) Light Products for Cleaning CPAP Machines and Accessories: FDA Safety Communication 27th Feb 2020

The U.S. Food and Drug Administration (FDA) wants to make consumers and health care providers aware that, to date, the FDA has not authorized for market any products using ozone gas or ultraviolet (UV) light to clean, disinfect, or sanitize continuous positive airway pressure (CPAP) devices and accessories (for example: hoses, masks, tubing and headgear).

CPAP machines are devices prescribed to patients with obstructive sleep apnea to keep their airways open during sleep. Most often, CPAP manufacturers recommend regular cleaning of CPAP device accessories with mild soap and water.

Important Recommendations for Consumers, Family Members and Caregivers:

- *Follow the CPAP manufacturer’s instructions and recommended cleaning and replacement guidelines for your CPAP machine and accessories. If you cannot find the owner’s manual or instructions, or have questions, contact the CPAP device or accessory manufacturer. You also can contact your health care provider with any questions.*
- *Be aware that the FDA has not evaluated the safety and effectiveness of ozone gas or UV light products claiming to clean, sanitize or disinfect CPAP machines and accessories in the home or healthcare setting.*
- *Understand the potential risks from exposure to excessive amounts of ozone gas or UV light as described below include irritation to breathing passages (that is nose, throat, and lungs), particularly for those who have respiratory sensitivity such as asthma or allergies.*
- *Seek medical attention if you suspect you have experienced injuries or irritation from using products claiming to clean your CPAP machine or accessories.*

Potential Risks Associated with Using Ozone Gas or Ultraviolet (UV) Light Products that claim to Clean, Sanitize, or Disinfect CPAP Machines and Accessories:

Using Ozone Gas Products that claim to Clean CPAP Machine Equipment and Accessories

Ozone (O₃), sometimes called “activated oxygen”, is a gas that can be used to kill harmful bacteria. However, for ozone to be effective in destroying harmful bacteria, it must be present at a concentration above levels considered safe for humans.

Although products that claim to use ozone gas to clean CPAP machine equipment are designed to keep the ozone generated inside the machine and its accessories, leaks can occur at tubing connections, filters or through fabric containers used to house CPAP accessories. When leaks occur, ozone gas in the nearby space may temporarily rise to unsafe levels, especially if the space is not well ventilated. Ozone gas concentrations within the CPAP machine and tubing can also remain above safe levels even after the recommended waiting periods for ozone gas products that claim to clean. If the CPAP accessories are used without first allowing fresh air to circulate through the entire CPAP machine to remove any remaining ozone gas, this could lead to nasal, lung or any other type of irritation to the user's breathing passages. Exposure to high levels of ozone gas also may worsen chronic respiratory diseases, such as asthma, or increase vulnerability to respiratory infection.

The FDA has received reports from patients experiencing cough, difficulty breathing, nasal irritation, headaches, asthma attacks and other breathing complaints when ozone gas-based products were used to clean, sanitize or disinfect CPAP devices and accessories.

Using UV Light Products that claim to Clean CPAP Machine Equipment and Accessories

UV light may be used to disinfect surfaces in a setting where UV light does not escape to the surroundings. If products generating UV light do not shield the user from exposure, they pose a potential health hazard depending on the wavelength, intensity, and exposure time.

Although FDA has not received any problem reports associated with using UV light products that claim to clean CPAP devices and accessories, unintentional or excessive exposure to UV light during cleaning may put a user at risk of eye injury, skin burns or even an increased risk of skin cancer. Additionally, when UV light is used with the purpose of disinfecting CPAP machine equipment and accessories, UV light may be unable to penetrate all areas of the CPAP accessories such as the hoses, masks and connectors. This may result in inadequately disinfected CPAP devices and accessories that may not be safe for reuse.

FDA Activities:

The FDA is working with manufacturers of products that claim to clean, sanitize or disinfect CPAP machines and accessories with either ozone gas or UV light to submit the recommended testing to support use of these devices as claimed.

Recently, the FDA conducted preliminary laboratory research on a few products claiming to use either ozone gas or UV light to clean, sanitize, or disinfect CPAP machines and accessories:

- For **ozone gas products** that claim to clean CPAP machines and accessories, tests performed in a minimally ventilated space with a volume representative of a small enclosed bathroom showed that several marketed ozone gas products generated ambient ozone levels above stated regulatory limits. Ozone levels were also elevated inside CPAP tubing even after recommended wait times in ozone gas products that do not perform an automatic clean air purge towards the end of the cleaning cycle.
- For **UV light products** that claim to clean, sanitize, or disinfect CPAP machines and accessories, tests showed the power of the UV light and the amount of time CPAP accessories were exposed to this light varied considerably among marketed UV cleaning products, based on the design of the product. If CPAP machines and accessories are exposed to insufficiently strong UV light, this could lead to inadequate disinfection and subsequent safety and performance issues.

The FDA will continue to monitor adverse events associated with the use of ozone gas or UV light products with claims to clean, sanitize, or disinfect CPAP machine and accessories. When new information becomes available, we will update this communication.

If you have one of these products all we can suggest is that you keep an eye on what is going on in the USA, which is the world's largest CPAP market. Their website is:

<https://www.fda.gov/news-events/press-announcements>

If you have any concerns you should contact the manufacturer of the product or the company from which you purchased it.

DIRECT DEBIT CAMPAIGN

Currently, just over 40% of our members are now paying by Direct Debit or Standing Order. Our goal is 70%!

For our administration, this reduces the renewal workload by at least 50% compared to all other forms of payment. In particular, we do not have to send out renewal notices.

It means our Committee members can:

- Devote more efforts in trying to improve the services you get from the NHS
- Deal with Clinical Commissioning Groups and Trusts that do not obey the legal implications of NICE TA139
- Influence decisions that will get many more sleep apnoea patients treated free of charge on the NHS, e.g. the new NICE Guideline
- Provide the best and most accurate patient information
- Continue to work with the DVLA to make driving regulations easier to understand
- Assist with many more research and development projects that could improve the way in which our condition is treated

Direct Debit is the most commonly used means of paying regular bills in the UK, from mortgages to council tax, from energy bills to insurance policies.

SATA's scheme is so easy, just fill in the online form with GoCardless, tell us how much you wish to pay and the rest is automatic.

You can change the amount or cancel at any time.

You are in complete control.

So please go DD and help make your membership renewal go much further in helping the charity

HOW MANY PEOPLE IN THE UK HAVE OBSTRUCTIVE SLEEP APNOEA (OSA)?

There is a dilemma in the UK; there are no accurately researched and peer reviewed estimates of the numbers of people with obstructive sleep apnoea, diagnosed or undiagnosed.

This article is not to undermine or criticise those who have attempted to quantify the situation; it is based on our position as a patient support charity, constantly getting feedback from its members and dealing with the many Sleep Clinics throughout the UK. We also gain from one of our members being on the current NICE Guideline Committee and benefitting from the intense scrutiny of all published information related to sleep apnoea and its related afflictions.

Data measurement on anything to do with sleep apnoea is difficult to find, but the following is a record of respiratory sleep tests in England from NHS data between 2006 to 2019¹. During this period 1.45 million diagnostic sleep tests were completed in England. The data from Northern Ireland, Scotland and Wales has to be estimated, bringing that figure up to 1.8 million. Add to that the estimated 200,000 for those tested before 2006 and that brings the final figure up to 2 million tested. It is then estimated that 50% of the sleep tests generate a CPAP prescription, and therefore 1 million people have been prescribed CPAP since treatment started in the UK in the early 1990s.

However, around 30% of those prescribed do not continue with their therapy², so at present there are approximately 700,000 people in the UK successfully established on CPAP.

As you can see, there are several estimates, but at least factual data is the starting point

When it comes to assessing how many of the UK population suffer from sleep apnoea, sadly, the starting point is based on an assessment in 1993 on a group of 603 people between 30 and 60 named the Wisconsin Sleep Cohort Study. The figures used for many years of 4% of middle aged men and 2% of middle aged women were derived from a 1993 American research paper³.

NICE in TA139 March 2008⁴, which mandated CPAP therapy free on the NHS for moderate and severe OSA confirmed these figures, so there was no question about their accuracy, despite being 15 years out of date and applying to a small group of people in America.

However, lurking in the background was the obesity crisis, with almost double figure rises in obesity. Almost no notice of its effect was detected despite the UK population putting on excessive weight for many years.

5% of the general population with OSAHS (OSA with symptoms) was confirmed as a general estimate across Europe in the 2013 EU Working Group study in driving and OSA⁵.

While recognising that obesity was the main driver of the increased prevalence, it was only studies on the data from the USA that showed evidence of the effect of the emerging obesity epidemic.

The excellent BLF (British Lung Foundation) study in 2014⁶ estimated 1.5 million adults with 330,000 diagnosed and this report did warn about increasing obesity rates.

At this point we need to illustrate that the increasing levels of human weight have become the main causal effect of the increase in the UK.

Between 1993 and 2018, adult obesity and overweight levels had risen from 53% to 64% of the adult population.⁷ Even worse, within those figures, obesity had doubled from 15% to 30%. One in every three people in the UK today is obese!

Reality hit SATA in June 2017, when, during a debate about anaesthetics at the CARE Convention in Warwick University, a leading anaesthetist stated that his hospital has introduced a screening policy, not based on the out of date 4% and 2%, but from their experience of it being three times those numbers. His justification was a research paper published by Dr Peppard et al in 2013, "Increased prevalence of Sleep Disordered Breathing (SDB) in Adults"⁸ in which he identified that between the ages of 30 and 70, 13% of men and 6% of women had moderate or severe OSA.

The data came from the same source as the 1993 figures, the Wisconsin Sleep Cohort Study in the USA as it existed in 2011!

These figures were confirmed by another paper from the UK and Ireland, "Epidemiological aspects of obstructive sleep apnoea" by Garvey et al.⁹

It was a shock for SATA and most people at the conference, but also a wake-up call. The SATA Committee discussed the implication of these results for the UK with our medical advisors. The obesity crisis in the UK is 10 years behind

the reality in the USA from 2010. It also confirmed reports we were getting that waiting times for sleep tests were growing at many Sleep Clinics, but as always, it is widely variable across the UK.

We immediately changed our figures to these new percentages, but also added in an estimate that extended the age cover from 30 to 75 rather than 70 (as people are living longer) and using the term “up to 13% of adult men” and “up to 6% of adult women” to make some allowance for variations.

The figures surprised us as they resulted in a total of up to 3.9 million people in the UK who had moderate or severe OSA, well over double any previous estimates. We published them in the Chairman’s Report at the SATAday 2017 Conference and updated our website. They have never been challenged!

SATA has reviewed more data than can possibly be comprehended and it is clear that the current estimate in the 2018 NICE SDB Scoping Document¹⁰ of 2.5 million with **undiagnosed** OSAHS is closer to reality but still underestimating what is a rapidly developing situation linked directly to the obesity epidemic. We challenged that figure in the 2018 NICE Consultation¹¹ and do so again now, as it is not sufficiently factoring in the rising obesity levels.

Today, on the factual data currently available in England, 29% of adults are obese and 35% are overweight. In simple terms 2 out of every 3 adults have a BMI greater than 25kg/m² (Parliamentary Briefing Paper No 3336, Aug 2019)⁷. According to the NHS, 67% of men and 61% of women are overweight and obese in England alone; this trend will continue for some time.¹²

Therefore SATA is sticking with its figures and has updated them taking into account the latest available population figures.

We now estimate that:

- up to 4 million people have moderate or severe OSAS (OSA with symptoms such as excessive sleepiness during waking hours)
- up to 6 million people have mild OSA, some with excessive sleepiness (Peppard 2013⁸)
- therefore up to 10 million people have Obstructive Sleep Apnoea, some with the most common symptom of excessive sleepiness during waking hours
- we estimate that 700,000 people out of the 1 million diagnosed are currently using CPAP regularly.

WHY IS THIS IMPORTANT?

The NHS works on big numbers to plan its resources to keep us all healthy and well treated. In order to plan the staff, facilities and budgets to support sleep apnoea patients, like any business, someone, somewhere has to estimate what the market is and what it will be in coming years.

The obesity epidemic is the biggest threat to public health in the UK.

The USA figures are from 2011 and with the 10 year lag, we may hit these levels in 2021 – NEXT YEAR!

The difference between NICE’s current undiagnosed 2.5 million OSAS, when added to the 1 million prescribed CPAP making 3.5 million and SATA’s up to 4 million moderate and severe is not so wide.

In terms of costs, the answer is simple. An undiagnosed patient with moderate or severe OSA will cost the NHS twice that of a patient diagnosed and treated with CPAP. Using the BLF 2014⁶ cost estimates it reckoned 80% of 1.5 million were undiagnosed and this was costing the NHS £28 million a year. Based on this, then, with 3 million still to diagnose, the current cost to the NHS is £96 million.

With mild OSA coming in at 6 million, based on Peppard’s 2013 figures⁸, of whom a number will have symptoms, it is time for the NHS to plan to deal with a much higher level of sleep apnoea patients. Treating them will, as NICE TA139 proved conclusively, save money, by preventing the development of expensive comorbidities

We take comfort that, with the new NICE Guideline due later this year, the NHS is getting ahead of the game and this will help all those engaged in resourcing what is required to meet the ever increasing demand.

1 <https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostics-waiting-times-and-activity/monthly-diagnostics-waiting-times-and-activity/monthly-diagnostics-data-2019-20/>

2 Identifying poor compliance with CPAP in obstructive sleep apnoea: Dipansu Ghosh Victoria Allgar <https://doi.org/10.1016/j.rmed.2012.10.008>

3 The occurrence of sleep-disordered breathing among middle-aged adults. Young DOI:10.1056/NEJM199304293281704

4 <https://www.nice.org.uk/guidance/ta139>

5 “New Standards and Guidelines for Drivers with Obstructive Sleep Apnoea Syndrome” EU working group 2013

6 <https://www.blf.org.uk/sites/default/files/OHE-OSA-health-economics-report---FINAL---v2.pdf>

7 <https://commonslibrary.parliament.uk/research-briefings/sn03336/>

8 <https://www.ncbi.nlm.nih.gov/pubmed/23589584> Increased prevalence of Sleep Disordered Breathing (SDB) in Adults-Peppard 2013 DOI:10.1093/aje/kws342

9 “Epidemiological aspects of obstructive sleep apnoea” by Garvey et al (DOI: 10.3978?j.issn.2072-1439.2015.04.52).

10 <https://www.nice.org.uk/guidance/gid-ng10098/documents/final-scope>

11 <https://www.nice.org.uk/guidance/gid-ng10098/documents/consultation-comments-and-responses>

12 <https://digital.nhs.uk/data-and-information/publications/statistical/statistics-on-obesity-physical-activity-and-diet/statistics-on-obesity-physical-activity-and-diet-england-2019/part-3-adult-obesity>

MAKING AN EXHIBITION OF OURSELVES

- Graham Hill, Vice Chairman SATA

You may have seen references to SATA attendance at Conferences, meetings or other events, and this article attempts to explain what we do and why we do it.

Chris Rogers or I, (or sometimes both of us) attend a whole range of events on behalf of SATA, from small patient meetings at individual hospitals to major annual conferences held by professional medical bodies.

Patient events are organised by individual Sleep Clinics, usually in the evening or on Saturdays. When Chris or I attend we usually give a short talk on whatever topic the clinic asks for, and then answer general questions about developments in the field of sleep apnoea, updates on what SATA is currently involved with, or on the latest situation regarding driving etc. Some of these events, such as those at Swindon or Yeovil, are very well attended and extremely successful, though others may only attract a dozen or so patients, which is a great shame, given the effort that Sleep Clinic staff put into organizing the events and giving up their time.

SATA is also a member of a couple of formal groups. Chris and I attend meetings of the OSA Partnership Group, a forum which includes representatives from the commercial vehicles sector, clinicians, and others. It exists to raise awareness of sleep apnoea but is particularly involved with issues relating to driving. I attend the DVLA Charities Forum, involving charities who represent medical conditions which may need to be reported to DVLA. Both of these groups meet twice each year.

Our other main involvement is with certain national medical organisations, in particular the Royal College of General Practitioners (RCGP); the Association of Respiratory, Technology and Physiology (ARTP); and the British Sleep Society (BSS).

As the name suggests the RCGP is the professional membership body for GPs in the UK, and which seeks to maintain the highest possible standards in general medical practice. SATA has long believed that the key to increasing rates of diagnosis and treatment for sleep apnoea is to increase awareness of the condition within the GP population. In a 5-year medical degree course sleep apnoea gets only a fleeting mention – I have heard varying estimates ranging between 15 minutes and a couple of hours.

For several years I have shared a SATA stand in the RCGP Conference exhibition with a colleague from our Scots sister organisation, SASA (Scottish Association for Sleep Apnoea), with whom we also share the costs. It gives us an excellent opportunity to discuss Sleep Apnoea with those GPs who visit our stand, give them leaflets etc. In fact at the 2018 Conference we arranged to have a SATA leaflet included in every delegate's conference pack; due to the extra cost, we can't do this every year, but it is something we will consider for the 2020 Conference after our next redraft of the GP leaflet. Some of these GPs have only a limited experience of dealing with patients who may have sleep apnoea, and some are still of the view that it is a condition which only affects overweight middle-aged males. They are surprised to be told that women, children, including some very young children, and younger, slimmer, males are frequently affected, and sometimes they take a good deal of convincing, though I can assure you that we are very persuasive!

Some GPs who come and talk to us suspect that they may have sleep apnoea themselves, so we advise them to go and see their own GP for a diagnosis and warn them not to drive if they have any symptoms of daytime sleepiness. At the most recent RCGP Conference, in Liverpool last October, one of these GPs came to our stand to thank us. He had visited us at our stand in Glasgow in 2018 to ask about his own possible sleep apnoea. He had followed our advice, seen his own GP, been referred to a Sleep Clinic and put on to CPAP therapy, and he told us how much better he now felt. Not only have we succeeded in getting someone treated, he will now be much more alert to the possibility of sleep apnoea in patients who come to his surgery with relevant symptoms. In addition, we take the opportunity to quiz GPs about the service in their area, for example what the referral time to their local Sleep Clinic is. We also stress the need for them to mark clearly on their referral form if their patient is a professional driver, so that the Sleep Clinic can fast track them and get them back on the road quickly.

Though it isn't our main objective, it is surprising how many people we see at the RCGP conference (as well as at ARTP and BSS) who are fellow exhibitors, and who come to talk to us about their own symptoms, or more likely those of a partner, family member or close friend, so we give them the talk, make sure they take some leaflets, and urge them to persuade their relative or friend to seek treatment as soon as possible. Finally it is an opportunity for us to talk to representatives of other medical charities in the exhibition, to compare notes, and to learn how their charities are funded.

The ARTP are the professional guardians of physiological measurement in respiratory medicine in the UK, and they provide the only national, professionally recognized qualifications in Respiratory Function Testing and Spirometry. Chris Rogers and I operate a SATA stand in the Annual Conference exhibition area. Many of the delegates at the ARTP Conference are staff from the respiratory departments at hospitals in the UK, and it gives us an opportunity to talk to them about sleep apnoea, and to find out how their own Sleep Clinic is coping with increased demand, what their waiting list is etc. For those hospitals who regularly take our leaflets it is an opportunity to find out whether they need more, and for those who don't it is an opportunity to sign them up for a supply of leaflets. We always stress the need to increase our membership and seek the support of these clinics in persuading their new patients to join SATA. The Conference is also a good opportunity to talk to the other manufacturers of CPAP or diagnostic equipment about developments in respiratory issues.

ARTP also has a committee specifically concerned with sleep apnoea, the Sleep Apnoea Consortium (SAC), made up of ARTP representatives, doctors, CPAP and diagnostic equipment manufacturers, with Chris Rogers and I as full members. Much of the discussion is about work carried out by ARTP in establishing technical standards for CPAP machines, very important since CPAPs are now arriving from the Far East. However you may be pleased to know that Chris and I usually make a fairly substantial input into the general SAC discussions. The SAC meets twice each year, once on the afternoon before the Conference and once at their offices in Lichfield. I must mention how grateful we are for the considerable financial support SATA receives from ARTP, especially in funding our range of leaflets.

The BSS is a professional organisation for medical, scientific and healthcare workers dealing with sleep disorders. It holds a biennial scientific meeting; this year's meeting was in Birmingham last November, and Chris and I were on the SATA stand in the exhibition area. The audience was slightly different to that at ARTP, with a different mix of exhibitors, but our objectives, and our discussions with delegates and exhibitors, were similar.

We occasionally attend other large-scale conferences, such as the British Thoracic Society, Care Convention etc, but this is usually when we are invited to give presentations.

Attendance at these conferences is not cheap. At the RCGP conference the cost of a stand, plus hire of a table and a couple of chairs, was over £1,600 to which must be added our travel and accommodation costs (After the Conference I complained to the organisers that this cost might be acceptable for big professional charities but was very onerous for small charities like SATA and SASA. I am pleased to say that they have agreed to a reduction of over 30% in the stand costs for smaller charities next year).

If members asked us to justify the cost of attendance at these events in terms of numbers of additional members gained, we would find it very difficult to do so. However SATA firmly believes that our presence at these events is a vital part of SATA's key objectives of raising awareness of sleep apnoea, and of education, and these objectives are at the forefront of SATA's activities at all these events. But beyond that, by our regular attendance and participation, SATA has become an integral part of the ongoing dialogue between the medical profession, equipment manufacturers, DVLA etc about sleep apnoea and respiratory issues, and I think it is fair to say that for a small charity we are punching well above our weight. By way of example, we have a list of at least 19 action points following the ARTP Conference in January, requiring further contacts with manufacturers, contact with Sleep Clinics, issues for our next *SATAday* etc.

I hope this give some insight into what Chris and I get up to when travelling round the country on SATA's behalf.

Graham Hill

**THE SATA WEBSITE HAS BECOME THE REFERENCE
POINT IN THE UK FOR THE MOST ACCURATE
INFORMATION, HELPFUL ADVICE AND NEWS ABOUT
THE WORLD OF SLEEP APNOEA THAT WE ALL SHARE**

www.sleep-apnoea-trust.org

SATADay 2019 REPORT - 19th October 2019

Introduction and Welcome

– Bill Johnston, SATA Chairman

Bill opened the event, welcoming 200 plus members to our latest event location, and running through the new facilities that the venue provides. He also thanked the manufacturers providing the exhibition for their confidence in SATADay, and hoped the greater area for the exhibits would make their life easier and more productive. Bill promised a packed day, with some cutting-edge research from our specialists.

MOSAIC, PREDICT, ROSA and MERGE – what have patients taught us over a decade?

Professor Mary Morrell, Imperial College and Brompton Hospital, London

Mary reported that research has been conducted by both Oxford and Imperial over the last decade, and there are seven broad sections of activity –

- 1) **“Things change”**. In the background, there have been changes in politics, and the technology employed, but the questions remain broadly the same.
- 2) **“CPAP works for some people, but not all”**. There are degrees of severity for OSA, and 10 years ago a CPAP was the best treatment for “severe” OSA – but it’s difficult to identify where “severe” starts. Another problem is that worldwide statistics suggest that there are 1 billion sufferers (to some degree), so who should be treated? The MOSAIC study conducted by John Stradling in 2012 took 170 patients per group (treated and untreated) who had relatively mild OSA. The outcome was that all patients had benefited at the end of the study. Real treatment helped, and 71% of treated patients opted to keep their machines. Untreated patients also showed improvement, and a questionnaire of “feelings” suggested that just the inclusion in the test program had made them “feel better” (the placebo effect).
- 3) **“We are stronger together”**. Over the decade a network of Sleep Clinics has been set up to improve treatments, starting with Oxford, then Taunton, then London and then nationally. This gives access to a wider range of test subjects and a more representative sample base. Mary set up the PREDICT survey concentrating on older patients. This is focussed on the different life needs of older people (grandparenting vs. work), and the costs of providing the benefit. Machines were given, or not given. The results show that all participants got a bit better (the placebo effect again) but machine users got much better at 3 months and 1 year. The government has a threshold on treatment cost of £20,000 (under £20,000, compared to added life quality); CPAP is shown as cost-effective at this level. NICE is reviewing the treatment at the moment, with an outcome expected in 2020, when new guidelines will be published.
- 4) **“Sometimes we need to be told twice”**. Both the MOSAIC and PREDICT studies say the same thing, that treatment is better than not. A new technique (known as Big Data) helps to confirm this; England and Spain joined forces for a 1000+ trial (actually 1206 patients), and this survey also confirms that treatment is better.
- 5) **“CPAP use varies”**. How much treatment is enough treatment? People with colds and flu may have difficulties with the machine, and there are other factors. 4 hours or more has been taken as a standard, but not originally based on scientific results. 4 hours treatment has some effect on improving blood pressure. However, treatment is not necessarily easy; many people have trouble with mask leaks and fitting, and persistence certainly pays for these patients; and some patients can’t get used to it at all. The MOSAIC study showed that, on average, patients got 2.5 hours of sleep. The PREDICT study raised this to 3.5 hours on average. Other studies have extended this to 4+ hours.
- 6) **“We have to keep going”**. Not all studies give positive results, but all results are valuable. Sophie’s test on OSA and Type 2 diabetes (the ROSA trial) where it was thought that CPAP treatment might also have a benefit to diabetes symptoms did not show this to be true. POSA, a current in-process trial (supported by government) is a “positional” treatment where a device supports side-sleep or back-sleep, without the use of a CPAP.
- 7) **“Everybody likes a happy ending”**. The MERGE study is a repeat of an earlier study by John Stradling on mild OSA, running over the years 2016-2019 (May), funded by ResMed and designed for NICE. To be published at the BTS in December, with 301 participants, results now show that 4+ hours of treatment can be achieved, and that the treatment does make a difference. The government will now have the evidence that CPAP treatment is a good treatment, and should be supported.



The New Venue



A full presentation - cabaret style



SATAday question time

Questions to Mary

Q. How does 4 hours occur – do people wake up and switch off?

A. An average is an average – some people sleep with the mask on for a couple of hours, then pull it off. Others use some nights, miss out other nights. Most current machines record sleep patterns, measuring nightly variations hour by hour.

Q. In the MERGE study, how many nights treatment per week were considered beneficial?

A. People were tested every night for 3 months.

Sleep Apnoea Research – What Next?

Dr. Annabel Nickol, Consultant in Respiratory Medicine, Oxford

Annabel updated us on the year's progress in on-going trials, and reminded us that while CPAP is a really good treatment, it's not for everyone. Other treatments may be possible in several areas –

- Physical treatment – weight loss, removal of giant tonsils, jaw advancement devices
- Opening the airway
- Increase muscle tone (using ave0118)
- Increase loop gain (using oxygen)
- Increase the arousal threshold (using eszopiclone)

Looking at the newest results in these main areas, we see both goodish news, and not so good –

- In the CPAP area, as Mary said earlier, the MERGE trial on CPAP usage is soon to be published, and confirms that CPAP does make a difference for mild apnoea, and that 4+ hours is an effective treatment level.
- Positional therapy – this might be a device on the back to deter back-sleep, or a chest device to encourage side-sleep. The POSA trials now being done will be done using a neck-mounted device, to measure real versus “sham” positional devices, and a second with a chest-mounted device, to measure results against CPAP.
- A decongestant trial (Otrivine) vs. placebo (just making the dummy packaging for the placebo cost £30,000!), while removing CPAP use for up to 28 days, to see if the decongestant can keep the airway sufficiently open that CPAP usage can be reduced.
- Pharyngeal dilators – this is a first “proof of concept” trial. Ave0118 has now been trialled in pigs, to see if airway collapse can be reduced. The trial has started but the delivery method failed to get the spray to the back of the throat, and the trial is now on hold.
- Loop gain (stabilising breathing with some oxygen) is tested in the SOX trial, doubling oxygen and air, and CPAP with no CPAP; it suggests that the observed blood pressure change is due to low oxygen, not sleepiness waking.

The Patient's Voice – Can we communicate better through our web site?

Sulaiman Alsaif, Imperial College, London

Sulaiman reminded us that 20 years ago, only 1 person in 10 had an internet connection, and now it's 9 in 10. The internet is now the primary means for getting health information, and in the field of OSA, then SATA should be a primary information provider. To achieve this, then SATA has to have better means of communication. We are looking primarily at Members' preferences for the web site. We have also looked at other sites as a comparison, such as Diabetes UK and the BLF (British Lung Foundation) and talked to sleep clinics, carers and others.

We also conducted an in-depth on-line survey of SATA members; of 351 responders, 70% were males; 93% were 45+; 72% had A-levels or a degree; 62% had severe OSA symptoms pre-diagnosis; and 84% had a smartphone or tablet.

44% of members aware of the site came to it through hospitals and sleep clinics, and 32% through browser sites.

In general, the members were happy with the content that the site provided; 60+% said they were satisfied or very satisfied, but 30% just thought it was OK, and a few people had criticisms.

Problems on our current site included –

- A “dated” appearance
- Difficulty in navigation
- Too much text on pages
- A “cluttered” design

Members also felt there were areas not well covered at the moment, such as

- OSA research and development information (covered in issues of Sleep Matters, but not searchable)
- Reviews and evaluation of new equipment, and on-going equipment maintenance
- Patient's experiences and stories (a support forum)

The net result – we have a clear understanding of what is needed, and work should begin as soon as practicable within our resources.

Questions to Annabel and Sulaiman

Q. What's the world map based on?

A. It's based on age and obesity levels, and more data is usually available where countries have sleep clinics. Even in the UK, we don't have good prevalence data, so poorer countries may be worse.

Q. How should we use social media?

A. There is work to be done in real-time Instagram and Twitter.

Q. Is there a link between OSA and dementia?

A. Does OSA influence cognitive decline? Work is currently being done in mice, but no evidence has been published as yet.

In Need of Help with Healthy Aspirations?

Kate Boys, Health Promotion Practitioner Specialist, Here for Health, Oxford

Kate Boys asked us the question "Looking for weight reduction when you have OSA – what really works? Extra weight is linked to OSA, especially around the neck, but how to lose the weight? Kate says that exercise is good, but your diet is also good. As an example, drinking a 138 calorie soft drink takes 26 minutes of walking to burn off, and a 420 calorie iced bun takes 1hr 17 minutes to remove. Might it be better not taking in the calories, compared to having to lose them? It's true that smaller portions contain fewer calories, but smaller portions may not be "satisfying" (i.e. removing your hunger). Being constantly hungry is not a sustainable solution for long-term weight loss. Extreme dieting also works, but usually only until your will power runs out. A better idea might be "feed yourself fuller". This is based on the principle of energy density, or calories per gram –

- Low-density foods – vegetables, soup, fruit
- High-density foods – fish and chips, wine, meat, cheese

The brain signals the stomach (and vice versa) regarding fullness, or satiety. It's food volume that makes you feel "full" rather than calorie content. This gives rise to a number of choices –

- "I need a snack" – you could go for low volume, high energy (2 pieces of chocolate) or high volume, low energy (a bowl of strawberries), both 50 calories
- "Eat when hungry, stop when not" – there's a difference between stomach hunger, which is slow to occur, and anything will do to satisfy it, and brain hunger which is quick-acting and requires particular foods to satisfy it. How to tell the difference? The broccoli test – "would I eat some broccoli right now?"
- "Eat slowly and mindfully" – a principle that allows body fullness to catch up to the brain (takes 20 minutes approximately). One example would be to eat 80-90% of your usual portions first, and then wait 20 minutes: if still hungry, eat the remainder, if not, reset your portion expectation. Another example is to eat while concentrating on something else (a match, a film): a whole can of Pringles can vanish when eating like this. A better way is to concentrate on the eating, and getting the best value from it.
- "Aim for grey" – picking the central "grey area" between eating everything and eating almost nothing helps you to build a food plan that can last. Ask yourself if you are able to stick to the plan long-term? Could you deny yourself a "favourite food" for 5 years if it's "bad" for you? If you couldn't, then keep it as an occasional treat, eat a bit less of it, or eat a lower-calorie version of it.
- "Start Small" – make a series of small changes rather than going for broke. Small initial "wins" build confidence for success in the longer term

And finally, repetition helps to build habits, and habits are what keep you on track for your goal.

Questions to Kate

Q. How much weight needs to be lost before OSA symptoms end?

A. What weight were you before you started noticing symptoms? At least as light as that, and probably more to account for ageing.

Q. Eat when hungry, not necessarily at standard meal times?

A. Old-fashioned eating habits (clean the plate, then have a “treat” dessert) tend to make things worse. Time of eating makes little difference.

Q. Alcohol as a useful social function?

A. Some types have differing calorie values – diluting them with low/no calorie drinks makes life simpler while protecting the social functions.

Q. Is there a good type of training?

A. Building a sweat, and upping the heart rate is the best form of exercise.

Manufacturers' New Products

Blake Marsh, Sleep Physiologist, Oxford

Blake reviewed new products from the manufacturers present –

SomnoMed	SomnoDent Flex – Jaw Advancement Device
Philips Respironics	DreamStation Go – travel CPAP with optional humidifier and optional battery DreamWisp masks – minimal contact nasal cushion, top-of-head tube fitting, in-frame airflow
Fisher & Paykel	Vitera mask – with better cushion, and new breathable headgear
Lowenstein	prisma SOFT – CPAP machine with PrismaLINE accessories prisma SMART – CPAP machine with two different APAP dynamics CARA – nasal cushion mask with soft cushion and very lightweight
ResMed	AirFit F30 – ultra-compact full-face mask, which fits under the nose AirFit N30i – nasal cradle mask with top-of-head tube fitting and in-frame airflow AirFit P30i – nasal pillow mask with top-of-head tube fitting and in-frame airflow AirMini – travel CPAP with waterless humidifier and smart phone control app

Part 1 - The Hidden Burden of Sleep Apnoea

Part 2 - Can Sound Waves help Diagnose Obstructive Sleep Apnoea.

Florence Barkats, Clinical Research Director, Imperial College/Acurable, London

Part of the work done at Imperial is to help calculate the costs of treatment, and the social costs of lack of treatment or delay. Florence reported on a survey conducted with SATA members to give patients a voice on these topics. All patients with access to the web were invited to participate and 477 members did so, with 34% of these being female and 66% male. The trial is slightly biased towards England (where most of the clinics are), and all responders have been diagnosed and treated. The results show –

- 25% had problems relating to delays in receiving treatment (including driving licence loss, job anxiety, relationship issues, depression and anxiety)
- 39% needed 3+ trips to the clinic to reach a diagnosis (not including preliminary GP visits)
- 71% of employed patients had to take days off work (from ½ day- 5 days)
- Only 25% were “fixed” (diagnosed, investigated, treated with CPAP, declared compliant) in 4 weeks, which is the target standard for professional drivers to protect their licences
- 12-44% waited up to 6 months from a GP visit to receiving treatment

There is a LOT of waiting time in the process; but if identifying and treating the condition is so important WHY is the wait for a machine acceptable? A 2004 study (Flemons et al) compared to our study now shows that waiting times remain broadly the same; time from GP visit to a sleep study is up to 4 months; time from study to receipt of CPAP was 4 months but is now 1-2 months; overall time from GP to receipt of CPAP did average 14 months, and is now 2-6 months. Although sleep clinics have increased in number, there is still work to do to improve the treatment timing.

Here are 2 case examples –

- Janet – diagnosed and treated in 1-4 months – considered as a successful process
- Eliot – treatment was delayed, he lost income and suffered anxiety, finally treated 7-9 months after suspicion that he had OSA



The excellent restaurant facility



A busy exhibition area



A new feature - the Here for Health stand

In an attempt to improve treatment times and decrease diagnostic costs, Imperial are turning to the use of sound waves in diagnosis of OSA. Florence agrees the estimate of approaching 1 billion worldwide breathing disorders (all causes), of which more than 200m may have OSA. At the moment conditions are under-diagnosed, partly due to the shortage of doctors and nurses. A new diagnostic technique, based on body sounds and conducted at home, could assist with speeding up the process. However, bodies are “noisy” in life and in sleep, so a mechanism is needed to separate the useable signal from the noise. The signal information (recordings from the throat area) can be sent electronically to the clinic, meaning more diagnoses can be made. The unit being considered is called “AcuPebble”, and should be launched next year. The app Imperial designed for it is specific, can be done by a patient at home, and results so far have been reliable: “Yes”, sleep apnoea may be present; “No”, SA is unlikely; or “Inconclusive”, do a revised test with the clinic.

Questions to Florence

Q. Could the test be given to all over-weight people as a screening process?

A. It’s possible, but it would need to be cost-effective.

Q. How can we get GPs to refer potential OSA to specialists?

A. Best way is for patients with knowledge to evangelise to their GP.

Q. Are there diagnostic tests on the SATA website?

A. You will find both Epworth and STOPBANG test sheets on the site, and both are indicative as a starting point

SATAday 2020
has been
postponed until
23rd Oct 2021
owing to the
COVID-19 pandemic

Chairman's Report – Review of the Year 2018-2019

Trustees & Committee

We welcomed Louise Mather and Chris Wade to the Committee this year. Sadly, former Committee Member, Gordon Waite died in December and our thoughts go out to his family and friends. Sadly too, although not a Committee Member, as we reported in the April edition of Sleep Matters, Claire Mitchell, founder member and Help Line Volunteer since 1993, has retired (and subsequently died).

Progress Report

The past year has been one of contrasts -

- The offer of help from Imperial College in looking at how we present ourselves to the public (primarily through our website) was accepted and today you have heard the first stage of that process.
- In terms of efficiency, we completed the challenge of going paperless on administration by 1st April and moving storage of data to Microsoft One Drive is continuing. A change in email provider has also been made to Microsoft Exchange and many of the problems we have been experiencing with our webhosting provider have been eliminated. A new webhosting provider is being sought as the current one falls short in many respects, but has been very cheap. The SATA Database is about to undergo a major revision and whilst this should have taken place earlier, finding the necessary and affordable software skills has been difficult. Ordering of leaflets by Sleep Clinics is now a web-based electronic process replacing an inefficient paper-based system. I must say thank you to Keith Nadin, as he translates the electronic orders into actual packages which ResMed then send to the Clinics, and to Chris Rogers and Rob Holt for all their efforts in this respect.

On now to the challenges -

- The telephone Help Line has been discontinued and we now have an email-based Help Service. Chris Rogers analysed the Help Line calls for a few months last year and found that almost all could be answered by looking at the detail on our website. Our replies now are very much, “click on this link” and read what is on our website. We still deal with very complex issues by phone.
- Last year we used an external event organiser to run the SATAday event at Stoke on Trent. The event was successful in terms of patient feedback, but we lost money as the accounts show. We decided to try this route again this year (with much more scrutiny of the costs involved), but the agency involved (EBS) could not come up with an affordable proposal. We therefore moved the planning of the event back ‘in house’ and thanks to excellent work by Graham Hill, (who found this superb venue at an affordable price) we are up and running.
- In April we were struck by an email problem that prevented us communicating with BT email addresses. The cause was our webhosting and email provider, discovered by Rob Holt and Chris Rogers after many hours of detailed detective work. As the company did not accept that they were the problem, this also prompted the move to Microsoft. We must apologise to Members for a less than perfect service from April to July.
- A growing concern is the increasing levels of late or non-payment of membership renewals by those using direct bank transfer and PayPal. The cost in terms of the time spent chasing payments was one of the main reasons for increasing membership fees. In administration terms, direct debit and standing orders cost us almost nothing, as no reminding or chasing is necessary. 40% of members now use Direct Debit. We do not think it is fair that the prompt payers subsidise the late payers, so we are looking at incentivising payment by Direct Debit and Standing Order.

Activity Report

- The first is a major thank you for assisting in surveys, mainly focussing on R&D. As you have learned today, these surveys assist the development or consideration of Clinical Trials. In the past year we have helped Imperial College, Royal Papworth Hospital and Oxford. Portsmouth is now also enlisting our help.
- Following several years of trying to initiate campaigns to raise awareness of sleep apnoea in GP surgeries, Graham Hill is working closely with the Royal College of General Practitioners (RCGP) on an exciting new



*Bill Johnston,
Chairman, SATA*

way of reaching GPs. We hope to announce more details soon. We still attend the RCGP Annual Primary Care meeting with the Scottish Association as this directly raises awareness.

- We continually support outside events with either Chris Rogers or Graham Hill or both attending and supporting the Sleep Clinics or medical organisations running the events. At the same time SATA is represented on the Charities Forum, ARTP Sleep Consortium, the OSA Partnership Group and more recently the new NICE Guideline Committee. This means the sleep apnoea patients' voice is being heard wherever and whenever we attend. SATA's advocacy is vital to progress in this sector.
- Thanks to the hard work of David Graddon, the Airline Survey has been updated and moved to the main public area of the website from the Members' Area. We have had a positive response from Sleep Clinics in this respect, as their patients expect them to be medical travel agents — SATA now assists this.
- In terms of providing the widest range of completely neutral but invaluable information for patients and clinicians, we launched the first UK Guide to "Dealing with CPAP Claustrophobia and Panic Attacks". It is amazing that, when you look at the web-based blogs, two thirds of the comments are about poor mask fit and machine problems, so this guide was needed. We are now looking at a mask fitting assistance guide.
- In terms of the DVLA, the SATA Guide to Driving and the DVLA has become a standard download and print handout from many Sleep Clinics to drivers in helping them understand the situation governing driving and OSA.

Risks

- Sadly, the shortage of human resources that I thought would be addressed last year by using EBS has not worked and we have had to take the organisation of *SATAday* in house again. Chris Rogers is looking at alternatives for the coming year, potentially using an experienced freelance.
- We do need more expertise on the Committee, especially IT, as this is a main pillar of an efficient charity business.
- The help we are getting from Imperial College is invaluable, but we have to act on their findings and recommendations. That requires expertise, especially when aimed at younger people for whom social media is part of everyday life.

The Future

- Planning, designing and commissioning a new website is the most important issue facing SATA today. The content of the current website is immense, but detail is difficult to find. Plus, it does not load well on smart phones. This work will start from the next Committee Meeting in December.
- At present I am in the process of changing the SATA Constitution to a Charitable Incorporated Organisation (CIO), from a charity governed by a Trust Deed. Currently, SATA Trustees are individually or collectively liable for the financial liabilities of the Trust. In an increasing litigious world, this is not good practice. A CIO has some similarity to a limited company, where the liabilities are limited to the assets of the organisation and Trustees have no personal liability, provided they have acted within the law. A significant change will be the more active involvement of all Trustees in the work of the Committee and some increase in administration work for the Treasurer and Managing Secretary.
- This year will be my last as Chairman, after what will be 16 years on the Committee, so at SATAday 2020, a new Chairman will be elected.
- During my period in the chair, I have watched the change of SATA from a card index paper-based charity of 600 members to a 1500 member, paperless, electronically based business with its website as its front window. All this work has been done by other members of the Committee; all I have done is to encourage and, in some areas, facilitate the changes.
- This Charity very much 'punches above its weight', and is and always has been "The Patients' Voice" - completely independent of any commercial pressure and answerable only to you, the Members.

Outlook

- The outlook is positive, but at the same time very challenging.
- We do have a business plan, but it has somewhat stalled owing to the lack of skilled human resources on the Committee.
- It is becoming increasingly clear that, if we are to continue to grow, we need to have our own fully-staffed office with a full time permanent CEO, and our funding model will have to change. We are now realising that there is a growth limit to a membership subscription based charity.

- The world is changing at such a rate that the business plan will have to adapt quickly to changes. Any plan, to be achievable, has to be based on the skill set of the team involved.

I would like to thank the Committee for its hard work during the past year. All members are contributing more than ever and that is why we have a successful event here today. Our thanks also go to our medical advisers, Dr Annabel Nickol, Blake Marsh and the team from the Oxford Respiratory Unit where we hold our regular Committee Meetings; and to have the precision of their medical guidance in everything we do is essential to us. It has been wonderful to see here today an NHS team from eight different hospitals working together to solve mask and machine problems. We are looking, with Dr Nickol's help, at escalating *SATAday* 2020 to a two day event – specialist sleep physiologists and nurses on the first day and patients on the second. No event like this takes place for NHS staff at present.

A huge 'thank you' is also due to the companies that have supported today's event, without which it would not take place.

Finally, once again my special thanks to Chris Rogers, who devotes a great deal of his time to working for the interests of SATA and all of us, its members. Chris is a real gift to us.



Bill Johnston,
Chairman

Sleep Clinics can order SATA's leaflets on line using the SATA website

**Click on the "Sleep Clinic Leaflet Orders"
tab, fill in the details we request and,
courtesy of ResMed, the boxes will arrive
soon after the order is placed.**

***The printing of SATA leaflets is generously funded by ARTP
(Association for Respiratory Technology and Physiology)***

TALE END

Claire Mitchell 30th May 1938 – 16th September 2019

In the April edition of Sleep Matters we carried an article about the retirement of Claire Mitchell, a founder member and Helpline Volunteer of this charity from 1993 to 2019. It is with the deepest sadness we have to inform you that Claire passed away on the 16th September 2019 after a short battle with cancer. It is difficult to say any more about this remarkable women, who gave 26 years of her life helping others with this dreadful illness, sleep apnoea.

So, in tribute, we are going to share with you some of her words that were published in Sleep Matters in its early days.

9th October 1993 – Founders Meeting – Report in Sleep Matters No 1 Spring 1994

I didn't quite know what to expect. What I was very sure of though was that when Sister Debby Pitson had written the first letter suggesting this meeting and the setting up of a support group. I knew that we would give our wholehearted support. We had never met anyone else suffering from Obstructive Sleep Apnoea. My husband's "bolt hole" was the Churchill Hospital where he saw his liberator, Dr John Stradling, and the comforting Debby Pitson. But I have always felt that he (we) needed more – "...a trouble shared...."

We moved to the lecture theatre where Dr Stradling opened the meeting. I was enthralled. I learned so much about CPAP and its interesting history and the work of other units throughout the world. He spoke of new developments and even an update on driving regulations. New diagnostic techniques, CPAP machines and many other related subjects were covered by Debby Pitson, Joanna Partlett and Dr Lyn Davies, the CPAP engineer. The questions from the floor that followed were fascinating, eminently thoughtprovoking and oh, so stimulating! I thought Sleep Apnoea was Sleep Apnoea - but I soon realised that the cases were so amazingly diverse.

The Fund Raising Concert 25th May 1995 with the Glasshouse Quartet – Report in Sleep Matters Autumn 1995

As we drove into Oxford, posters advertising our very First Fund Raising Concert seemed to overwhelm the City.

After the interval the audience were most touchingly made aware of what Sleep Apnoea is all about by Mary Doyle who eloquently told of her husband Seamus' suffering and recovery. We were all very moved. Dieter, our Chairman, really deserves the final fanfare though. He wanted to 'launch' us thus a year ago. The time wasn't quite right so he has been exceptionally patient, working extremely hard in arranging and organising the special event.



SLEEP MATTERS is published by the Sleep Apnoea Trust – THE PATIENTS' VOICE

The Sleep Apnoea Trust exists to improve the lives of sleep apnoea patients, their partners and families and is managed almost entirely by unpaid volunteers.

The editors and publishers of SLEEP MATTERS have no medical knowledge and therefore take no responsibility for the medical accuracy of the content of this newsletter. Concerned readers are advised to take professional medical advice. Queries concerning membership, SATAday, etc., should be addressed to the Secretary at the address below and not to the editors of SLEEP MATTERS.

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