In 2016, a research paper was published with disturbing evidence: -

“Obstructive sleep apnoea (OSA) is a common disorder, and continuous positive airway pressure (CPAP) is considered to be the gold standard of therapy. CPAP however is known to have problems with adherence, with many patients eventually abandoning the device. The overall CPAP non-adherence rate that was reported in studies conducted over the twenty year time frame was 34.1%, and there was no significant improvement over the time frame. The rate of CPAP adherence remains persistently low. No clinically significant improvement in CPAP adherence was seen even in recent years despite efforts toward behavioural intervention and patient coaching. This low rate of adherence is problematic, and calls into question the concept of CPAP as gold-standard of therapy for OSA.”

In essence out of every three patients diagnosed and on CPAP, one abandons the therapy; a 30%+ failure rate that increases costs on the NHS and shortens lives. Whilst some of the patients discontinuing CPAP may be those in whom obstructive sleep apnoea was only mild or symptoms minimal, simply ‘giving it a go’ in case it helped, others with significant sleep apnoea may be left with burdensome symptoms.

It stimulated SATA to produce its “Living with your CPAP - Your Questions Answered” leaflet designed for those newly-diagnosed and starting their journey with CPAP. The leaflet has been a great success with 50 Sleep Clinics using the leaflet regularly. The feedback from the Association for Respiratory Technology and Physiology (ARTP), which sponsors the leaflet, has been a major reduction in the “trivial questions” that Sleep Clinics receive from new patients plus higher levels of compliance.

Therefore, SATA has started to look at other reasons for non-adherence and to address issues we have not dealt with before.

Poor mask tolerance is frequently the perceived problem by patients struggling to settle with CPAP.

Sleep Clinics should always remember that, according to the National Institute for Care and Health Excellence (NICE) Technology Appraisal (TA) 139, CPAP therapy be legally-mandated and free-to-patients, since the cost of non-treatment of sleep apnoea is almost twice the cost of treatment (Guest 2008). A theoretical saving by restricting mask choice for a patient can lead to non-adherence and will cost the Hospital Trust and Clinical Commissioning Group many thousands of pounds more in dealing with the other illnesses that may develop as a result of untreated sleep apnoea. It is an economic no-brainer!

Associated with this, the editor of Sleep Matters (who has been temporarily manning the telephone helpline over the past 18 months) observed that claustrophobia and panic attacks whilst using CPAP therapy are common.

With the health and economic basis of our case underpinning further investigation, we initiated action. According to NHS England, Claustrophobia is the irrational fear of confined spaces and a Panic Attack is a feeling of sudden and intense anxiety.

It’s normal to fear being trapped when there’s a genuine threat, but people with claustrophobia become fearful in situations where there’s no obvious or realistic danger. They’ll go out of their way to avoid confined spaces, such as lifts, tunnels, tube trains, etc, or when confined and limited as with a CPAP breathing mask. However, avoiding these places often reinforces the fear. The most common experience is a feeling or fear of losing control.

Panic attacks can also have physical symptoms, including shaking, feeling disorientated, nausea, rapid irregular heartbeats, dry mouth, breathlessness, sweating and dizziness. The symptoms of a panic attack are not dangerous, but can be very frightening. Most panic attacks last somewhere from 5 minutes to half an hour.

This was enough to prompt SATA to do some research and come up with some ideas on how to deal with this threat to CPAP therapy adherence.
THINGS TO REMEMBER IF YOU HAVE CPAP CLAUSTROPHOBIA

CPAP claustrophobia is a natural occurrence at the start of CPAP treatment for some people. If you have this you may feel you are struggling to breathe with the mask, hose and pump attached to your face, and have surges of the stress hormone, adrenaline. Getting past this initial hurdle can be a challenge for some, so here is a summary of tips that will help you deal with CPAP claustrophobia.

**CPAP masks will not suffocate you**

From the start, let’s make it clear that ALL the CPAP masks supplied in the UK are vented, to facilitate carbon dioxide escape. This allows patients to breathe through the mask even if the pump is not running and saves your life if there is a power cut. If for any reason the vents were blocked, due to lack of proper care and maintenance, your body will react and cause you to take your mask off. The CPAP mask will not kill —try to love your CPAP mask!

**CPAP is providing you with all the air you need.**

When asleep the CPAP machine is actually pushing air into you. While there may be a slight claustrophobic feeling at first, this is soon overcome as the CPAP machine is providing you with air to breathe!

**CPAP is like brushing your teeth regularly.**

Use the machine regularly and gradually establish a routine to assist in coming to terms with this daily activity and overcome the fear of using it.

**Wear the CPAP mask while awake.**

Wear a CPAP while awake and practice breathing through the mask during free periods during the day. At the same time, read a book, watch TV or text friends. This helps to imprint the process and create familiarity.

**Develop a Positive attitude to CPAP.**

Your relationship with CPAP will be long term so, by starting to consider it as part of your body to create a positive relationship. By caring for the equipment, washing the mask regularly, keeping it clean, checking the hose for leaks, changing the filter, you will build a positive attitude towards CPAP.

**Be patient with CPAP therapy.**

Do not get discouraged if it doesn’t work instantly for you. It can take some time to get used to the therapy. There is an initial period when making small adjustments will help to find the most comfortable settings and mask position. This is a time-based process, so cannot be rushed. If there is a real struggle, then going back to basics and refitting the equipment as if it had just been received can help. This can be started by loosening and tightening the straps in small steps. If it feels impossible, contact the Sleep Clinic for help.

Mask type is vital to help your CPAP claustrophobia.

Research studies show that a poor fitting mask is the main cause for CPAP claustrophobia. Getting the best possible mask fit is vital in overcoming mask claustrophobia. All good sleep clinics will offer a good range of mask types and sizes, and the specialist sleep team have expertise in helping find the right one for you, depending upon the shape of your face and whether you breathe through your nose or mouth.

Patients may prefer a nasal mask, that just covers the nose, or nasal pillows that sit below the nose, because they know they can always breathe by opening their mouth. But this only treats the sleep apnoea if they can prevent mouth breathing when they are asleep. For some this comes naturally and for others an adjustable soft chin strap to hold the mouth closed can assist.

If someone breathes through their mouth when asleep and therefore has to wear a full face mask, then there can be a problem due to mask fitting, cushion leakage and dry mouth issues that can appear when they wake up.

If the patient does have these issues, they will still be able to breathe as the mask is vented and will always let air into the mask if the CPAP machine is switched off. With the CPAP machine on, the patient will receive air from the machine.

**CPAP Ramp Facility**

All CPAP machines have a Ramp facility. This can contribute to the feeling of claustrophobia, if it is not set properly or not needed. The ramp helps the patient get used to the pressure by starting low and climbing slowly to the set pressure, by which time the patient is hopefully already asleep. Auto CPAP, where the maximum pressure can vary, operates in a similar way. Both can contribute to the claustrophobic feeling, because at very low pressure there may be a feeling of insufficient air supply. The Sleep Clinic should demonstrate to the patient how to adjust this and they can find whatever suits them best. The Ramp facility can usually be switched off by a Sleep Clinician, if the patient doesn’t find it helpful.

**EPR**

This is an abbreviation for Expiratory Pressure Relief and is adjustable on most CPAPs. It controls the variation in pressure on a breath by breath basis and is a very personal setting, which the patient can adjust as they get used to using the machine.

**CPAP Mask Panic Attack**

Panic attacks may be common amongst patients who are new to CPAP therapy. According to a 2012 study at the University of California, Berkeley, when a person has an apnoea (a breathing pause) the body releases certain hormones that cause anxiety and panic, to try to restore breathing. This can initiate the panic attack.
In addition, people who routinely suffer panic attacks are more likely to have them while trying to fall asleep or while sleeping.

Having a CPAP mask covering their face is a new sensation which can understandably lead to feelings of suffocation. The reality is, though, that if diagnosed with sleep apnoea and not wearing a CPAP mask, the risk from suffocation is much greater. An adjustment period is therefore necessary.

**Slow and very gradual conditioning process**

Some of the suggestions in the Claustrophobia section will be useful, but there is also specific advice that is pertinent here to panic.

1. For panic attacks, perhaps the most usefully suggestion is for the patient to increase the time spent with their mask on a very gradual basis. To be precise, wearing the mask for a few minutes during the day, until the feeling of panic starts and then remove it. This will gradually condition the patient to get used to the mask. Then try again later in the day.

2. Start to increase the amount of time the mask is worn, say up to an hour. Avoiding panic attacks is a step by step and sometimes a very slow progress and cannot be rushed.

3. The next stage is to turn the CPAP on to experience how the body reacts to the feeling of the pressure. This will allow the patient and their brain to develop an understanding of how the machine will work and feel when in use.

4. The next step is to plan a sleep during the day for one hour with the CPAP machine switched on as getting used to the pressure for a longer period can be as challenging as wearing the mask.

5. The next step is to schedule a 3 to 4 hour night sleep with the CPAP therapy and see how it goes.

6. Gradually increasing the time until the patient feels they are getting really refreshing sleep and their energy levels feel restored. The number of hours needed on CPAP is entirely personal and varies hugely from patient to patient as everyone is uniquely different.

**Breathing Exercises**

Another way to become more comfortable with mask choice is by doing breathing exercises. Slowly inhale for four seconds, and then exhale for four seconds. Count to ten and focus on breathing if the feeling of panic occurs with the mask on.

When the body realises it can breathe through the mask, it won’t instinctively tense up and seize when it’s supposed to be relaxing and sleeping.

Additionally, turning the CPAP on to feel the experience of air pressure, will allow the brain to understand how the machine works and feels while in use.

**Generally speaking,** CPAP panic will go away as soon as the patient gets used to the mask and the air flow. It just takes some time and patience.

**Repetition is the key to Success**

CPAP therapy is unusual in that its management is quickly transferred from the NHS Sleep Clinic to you. This brings its own challenges, as some Clinics are good, and some are bad at helping you; but there is no answer other than the patient has to take responsibility for managing their therapy.

Practise, repeat, make changes, make notes of the changes, if necessary return to the default position and start again. There is no substitute or quick fix and for the foreseeable future no alternative to CPAP. We strongly advise patients NOT to give up, unless their doctor has advised them they are using CPAP simply as a trial to see if it helps their symptoms. This may be the case if their sleep apnoea was only mild, or they were not too bothered by symptoms.

Once being able to sleep with CPAP, in general the quality of life will drastically improve. In the end, the struggle is worth it. This is the experience of most patients

**Information gleaned from the following sources**

Alaskan Sleep Clinic
American Sleep Apnea Association
Claustrophobic Tendencies and Continuous Positive Airway Pressure Therapy Non-adherence in Adults with Obstructive Sleep Apnea. Edmonds, Young, King, Sawyer x 2, Rizzo – Heart-Lung 2015 Mar-Apr 44(2) 100-106
NHS England
NICE UK
& other sources that have briefly written about these issues

**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.**
FROM THE CHAIRMAN

This is becoming a bit of a habit, noting the delay in the publication of Sleep Matters. But it does underline the subject I have referred to continuously over the past three years, we need more Committee Members with skills. I am glad to report that we now have two new members of committee, but there continues to be future need. I will address this later in my comments, although it is certainly outlined in my AGM Annual Report included in this edition. In January, we had a major challenge, in that Claire Mitchell, our long serving Telephone Helpline Volunteer had decided to retire. When SATA was formed in 1993, and the first Sleep Matters was published in spring 1994 she was an inaugural member of the team. There is more about Claire and her long service to SATA in this issue.

Gordon Waite
It was sad news that we also received in January, that long serving Committee Member Gordon Waite had died in December following several years of battling cancer. Gordon provided us with wise counsel as he was involved with running other charities. His attention to detail combined with his sheer professional knowledge will be sorely missed. Our sincere condolences go to his family and friends.

Telephone Helpline Discontinued.
At one time, when CPAP was a rare and sought after treatment, yet little was known about its effectiveness, there were seven Helpline Volunteers. But more recently significant changes have taken place. First of all, there is the introduction and development of our excellent website, which is now packed with nearly all the information you need to know about OSA. Secondly, the calls have become much more complex, often overlapping other illnesses, and have become impossible for anybody other than a specialist clinician to answer, not patient volunteers. Some are nothing at all to do with OSA. Combine this with only three Helpline Volunteers and Claire Mitchell’s retirement meant we had to take a hard decision and terminate the telephone helpline. The email service will continue, but searching our website is now the first line of enquiry. Quite frankly over half of the calls we were getting are answered in the “Living With Your CPAP-Your Questions Answered leaflet” which is why we are targeting all Sleep Clinics and hoping to get all major Sleep Clinics to issue this to new patients when they are set up on CPAP.

Website and Leaflets
Thanks to a lot of work from Graham Hill, the front page of the website has been tidied up, the DVLA and Driving information has been simplified and he has started to bring conformity of style to the leaflet range as we redesign them following the changes to our Helpline. We do recognise that while our website is packed full of information, nearly all of which is checked by senior NHS Clinicians, it is not always easy to use, or find information quickly and not well adapted to smart phones. We are, therefore, upgrading the website to make it more modern and easier to use, especially from a phone, but we do need more funds to do this which brings me to the next item.

Increase in Membership Fees
Faced with ever increasing demands for our services and with a gap in the skill set needed on Committee of volunteers capable of dealing with the digital age, we now have to use external suppliers to meet this challenge and that requires financing. While revenue is increasing due to membership growth, it is not enough to meet this new financial demand.

Therefore, the Normal Membership fee will rise from £17 to £20 from 1st April 2019, and the Supported Membership fee will double from £5 to £10. These rates continue to offer superb value for money and helps us to meet our rising expenses, which we keep to a minimum through the work of dedicated volunteers. We are very grateful to all those who pay by direct debit, as this is the cheapest option for us to administer. The supported membership fee of £5 was set in 2001 and has never been increased, despite the current actual administration cost of £10.

Our request for members to consider payment direct debit is doing very well, as this is the least costly in administration terms.

NICE
As mentioned in the last issue, NICE, at the request of NHS England, has established a new “Obstructive Sleep Apnoea/hypopnoea syndrome and obesity hypoventilation syndrome in over 16s” guideline committee. SATA Managing Secretary Chris Rogers was appointed as a lay member, and Annabel Nickol representing Specialist Sleep Centres. Meetings are now taking place and a lot of hard work is going on, to see how existing standards can be widened and improved to provide a more comprehensive approach to what is an area of health problems which
Sleep Matters is growing in line with the obesity crisis. The draft report is expected to be published in August 2020. Brief details can be found on the NICE website.

**SATAday 2018**

Fulfilling a long promised commitment to hold an event further north, last year’s SATAday took place in Stoke on Trent on 13th October 2018. Feedback from delegates has been excellent, but we were a bit disappointed at the turnout, about half of what we would get at Oxford. The support from other Sleep Clinics and the manufacturers was, as always, superb and our thanks go to guest speakers Dr Sonya Craig from the Aintree and Dr Aditi Desai from the BSDSM (British Society of Dental Sleep Medicine) for their excellent presentations.

Dr Annabel Nickol and physiologist Blake Marsh from the Oxford Sleep Unit also presented. This event was organised for us by an external supplier for the first time and we are indebted to Executive Business Support from Lichfield in Staffordshire for the excellent work they did. This edition of Sleep Matters has a lot of detail from this event, which I hope you will enjoy.

**Airline Survey**

Committee Member David Graddon has done an amazing job in both expanding and updating the Airline Survey. He has introduced a colour coding for airlines, so it is easy to see with which one you can fly with a CPAP with confidence and which ones possibly you should not.

We also moved this information onto the main public area of the website in response to requests from Sleep Clinics as they have increasingly been questioned by CPAP users about which airline is the best to fly with if you use CPAP. We always advise, check this area of the SATA website before you purchase your ticket.

**Supporting Outside Events**

The SATA Committee is becoming increasingly involved in supporting an ever increasing number of events. At present Chris Rogers and Graham Hill are covering all such demands, but it is becoming difficult for them at times owing to pressures from their other Committee work. Soon we will be circulating outline volunteer job descriptions of the skills needed to assist us with representation in some regions. The main requirement will be to stand in front of an audience and speak accurately and effectively about sleep apnoea.
Introduction & Welcome: Bill Johnston, SATA Chairman

Bill formally welcomed the members to the Conference. He thanked the organiser, EBS, for assembling the conference, the manufacturers for supporting it and providing the exhibition, and the North Staffs Conference Centre for the facilities at relatively short notice.

OSA & Diabetes: Dr. Sonya Craig, Consultant in Sleep Medicine, Aintree Hospital, Liverpool

Sonya focussed her presentation on any particular linkage between OSA (Obstructive Sleep Apnoea) and diabetes; can the use of a CPAP for OSA also help to control diabetes; can CPAP help to control another disease of the eye (retinopathy) which is linked to diabetes; and finally can we help to reduce both OSA and diabetes.

5% of the global population is estimated to have some level of diabetes, going up to 10% by the age of 60. The risk factors for diabetes include age, family, weight, activity, and diet – and possibly OSA? Statistics from the Department of Health (DoH) suggest that 2-25% of the UK population have OSA primarily due to obesity, varying by UK region.

In the North West region where Sonya works, there are believed to be around 23,000 people with moderate to severe OSA. Of the population with Type 2 diabetes, 23% of people with diabetes also have OSA. 56% of this sample (diabetes and OSA) also have retinopathy, vs only 36% for diabetes alone. Another survey (of obese patients with Type 2 diabetes) suggests that 89% of diabetics also have OSA, but the OSA has been undiagnosed and is untreated.

A collection of diabetes factors (central obesity, high blood pressure, high triglycerides, low HDL cholesterol, and insulin resistance) has been called Metabolic Syndrome – a checklist covering these factors may act as a predictive instrument identifying who might either have or be prone to getting diabetes.

It is thought that 24% of the U.S. population exhibits Metabolic Syndrome, which might show a dramatic increase in future diabetes.

Sonya showed a series of charts showing the linkages between OSA, body chemistry and physiology and the severity of the impact on the diabetic population. Measurement of neck size tends to predict OSA – the bigger, the more likely. However, most indicators of linkage are anecdotal – what’s required are randomised trials generating real evidence.

An Oxford trial compared 36 patients with Type 2 diabetes, switching between real CPAP treatment and “sham” CPAP treatment, showed that the real CPAP treatment was no better than the sham in improving insulin sensitivity.

In a bigger trial, the results suggested that CPAP treatment can help with blood pressure in diabetics, but not the diabetes itself.

Another trial linking OSA with retinopathy suggested that the oxygen shortage through AHIs might have an impact, and that CPAP usage might have a positive impact.

A randomised trial using CPAP plus standard eye care vs. standard eye care alone showed no difference in outcome.

A study in the New England Journal compared weight loss, weight loss and CPAP, and CPAP only for effects on insulin sensitivity. The results showed weight loss + CPAP worked best, weight loss alone next, and CPAP alone last.

Looking forward, the best potential treatment for diabetes, pre-diabetes and OSA control seems to be the Blood Sugar Diet. This diet works to reduce liver fat and is good for diabetics. There are also new medications, affecting so-called GLP1 receptors, which help to lose weight.
The ROMANCE study, looking at liraglutide medication is an interesting study, comparing a control, liraglutide alone, in conjunction with CPAP, or CPAP alone.

The various bariatric surgery techniques very much help with diabetes and may have an effect on long-term OSA.

The journal The Lancet have recently published a Newcastle study using a very low calorie liquid diet that does promote weight loss in the short term – the Blood Sugar Diet does a similar job, but with the wider range of food types and texture allowed is probably a better long-term solution to maintaining the weight loss.

Questions to Dr. Sonya Craig
Q. Does CPAP help with eyesight?
A. CPAP has no effect on eyesight, but there are drugs that do work. CPAP only works for OSA.
Q. Is the Lancet diet a liquid-only diet, or does it contain other foods?
A. The Blood Sugar Diet is the solid food version of the Lancet diet. People need vegetables, broccoli, and proteins; NOT bread; fats are good, and better than sugar.
Q. Is there any research into CPAP and migraine?
A. Anecdotally yes, seems to be the improvement in sleep quality.
Q. Are brown rice and brown pasta lower in sugar?
A. Yes, a bit better than the white versions, but are still carbs, which turn into sugar. Protein is better.
Q. I’ve had a kidney transplant, and am not allowed certain veg.
A. There is a list of safe veg for kidney problems, but no broccoli – talk to your specialist.
Q. Is the Blood Sugar Diet of general value, or is it just for weight loss?
A. It seems to be good for long-term use for weight maintenance as well as loss – the Lancet diet at 850 calories per day is more for loss rather than maintenance.
Q. Is my CPAP or my diet that gives me acid reflux?
A. People with OSA can get acid reflux, but weight is more likely – a bit chicken and egg.
Q. Can you keep liver fat, and still lose weight?
A. There are drugs to help lose liver fat.

The Role of Jaw Advancement Devices for OSA: Dr. Aditi Desai, President, British Society of Dental Sleep Medicine (BSDSM)

While CPAP is widely identified as the Gold Standard for OSA alleviation, it is true that many people prescribed a CPAP find themselves intolerant to it and need to be treated by other means. Problems usually arise relating to the mask, including poor mask fit, leakage, skin rashes, high pressures causing eye and sinus problems, and claustrophobia; but there are other factors including the embarrassment factor for younger and female patients.

The requirement is to keep the airway open during sleep; a CPAP does this by air pressure, but there are other methods. The Carioli Study in 2017 showed that 28% of patients couldn’t cope with a CPAP, but if all the range of alternative treatments were used, only 3% were left with no treatment at all.

There are guidelines for the use of oral treatments – snorers and mild to medium OSA, and moderate to severe OSA if CPAP treatment fails – a combination therapy including an oral treatment. Oral Advancement Therapy (OAT) follows the principle of airway management by mechanical means. There is a principle called Mean Disease Alleviation (MDA) where different techniques can be rated together. As an example, CPAP may be the Gold Standard, but other techniques like OAT can improve the health outcome.

MDA measures efficiency versus compliance. So –
– if CPAP is 90% effective, but for only 56% of patients, and
– if OAT is 56% effective, but has 91% compliance, then the MDA score will actually be very similar.

What’s required for an effective OAT treatment? There are three areas making up the decision.

1. The identification of patients who are eligible for OA Therapy is a key factor, because the overall success rate of OA Therapy is lower than that of CPAP. OA works better for the young, females, people with low BMI, people with small neck size, and people with positional sleep problems.

2. The second factor is the nature of the OA device. The device needs to be carefully selected, and carefully adjusted to the patient. Supervision and follow-up are also necessary, or pain may follow. A suitable appliance can be made quickly, faster than a CPAP can be supplied.

3. The final factor is the requirement for a suitable OA provider. The dental practitioner must have sufficient knowledge and skill, and be supported where necessary by medical professionals.

The process works as follows – the dentist can provide a full clinical consultation, to be passed to the GP. The GP will then contact a dental specialist to install the appliance, and then follow-up will be required. Fitting is important, as is the content of the mouth. The base of the tongue is a major factor. Tongues can accumulate fat, which may need to be lasered off. There are lots of different mouth shapes, and a wide range of tongue-ties.

In conclusion, OAT can help some people as well as a CPAP, except for the reduction of AHIs. OAT works well for Quality of Life (QoL) factors, such as depression. OAT may be better for mild to moderate OSA, CPAP better for moderate to severe OSA.
There are many types of oral devices available; the best are adjustable bi-bloc devices. There are over 120 devices to pick from. The best gives incremental protrusion of the mandible, which gives the jaw a chance to adjust to the device a little at a time.

**Questions to Dr. Aditi Desai**

Q. Does the DVLA accept OAT for OSA?
A. Yes, if the treatment is effective, and the patient shows “no excessive sleepiness”

Q. I have severe OSA, but my CPAP is insufficient to make me legal for driving?
A. OATs have been shown to be effective in mild-OSA. Safe driving is dependent upon resolution of excessive sleepiness at the wheel.

**The World of Sleep Apnoea – An R&D Update: Dr. Annabel Nickol, Consultant in Sleep Medicine, Oxford**

Annabel brought us up to date with the latest research results in the OSA area, which covers CPAP, diet, weight loss, Bariatric surgery, Tonsillectomy, and Oral Advancement Therapy (OAT).

We used to think of treatment for all OSA patients in the same way. We increasingly recognise that there are different types of OSA or ‘phenotypes’, meaning it is possible in the future that OSA treatment can be better tailored to the individual patient. For example: does the airway block very easily during sleep and is it severe? If so a physical therapy like CPAP may be necessary. Alternatively is it mild, with the airway being less vulnerable to blockages? An alternative option may be viable. These could include a drug to increase airway tone, a drug to simply help maintain sleep or supplementary oxygen.

It is well know that CPAP is highly effective in moderate and severe OSA, however its effect in mild obstructive sleep apnoea is not certain. The CATNAP (USA) and MOSAIC (UK) trials suggested a Quality of Life (QoL) improvement. The MERGE trial (UK) has recently finished recruiting and will address this.

Forthcoming trials include –
- POSA – positional device vs. CPAP, or vs. no treatment with @ 150 patients in each of these two studies – due to start 2019
- DOSA – decongestants based on Otrivine – patients take two weeks off CPAP with Otrivine, to see if CPAP pressures or usage can be reduced.
- Pharyngeal dilators – relating to muscle tone – AVE0118 – drug to reduce airway collapse and increase muscle tone.
Manufacturers’ New Products

Blake Marsh, Respiratory & Sleep Physiologist, Oxford

Blake reviewed the manufacturers’ latest equipment;

**Philips**
- Dream Station Go
  - Travel CPAP, with battery giving 13 hours run time at 10cm pressure.
- DreamWear mask
  - Fits under nose, airflow through mask top

**Fisher & Paykel**
- SleepStyle CPAP
  - Includes humidifier, plus app for personal data

**Loewenstein**
- Cara mask
  - Lightweight mask, quiet in operation
- PrismaSOFT and PrismaSMART CPAPs
  - Supported by PrismaLINE accessories

**ResMed**
- AirTouch F20 full-face mask
  - Memory foam mask, needs replacing 4-6 weeks
- AirMini CPAP
  - Travel machine with waterless humidifier + app for AirMini (battery not provided)
- MySleep membership
  - Customer help line, hints, tips, discounts

**DVLA Update: Chris Rogers, Managing Secretary, SATA**

Chris brought us up to date with the latest status of OSA and the DVLA. We have had three years of chaos, but we all share the same goal of safety for the public. Up to October 2017, licences were being revoked unnecessarily, causing a SATA Helpline meltdown; DVLA crisis calls were forming up to 90% of all Helpline calls.

On 17 October 2017, DVLA changed its Guidance Document (Assessing Fitness to Drive – Guidance for Medical Professionals) to “excessive sleepiness” which made understanding much simpler for sleep clinicians; at the same time, DVLA said they would change the wording of forms SL1 and SL1V, the public pages and those for people renewing 70+ licences.

In March 2018 the new forms were brought in but did NOT contain the simple wording agreed with us and other parties. Chaos came back, SATA re-drafted the two documents but DVLA made no response.

In April 2018, SATA issued guidance to those dealing with the DVLA, and produced a self-help package for DVLA contact on our website.

Currently, relations with the DVLA have improved somewhat, and more licences are being restored. Sleep clinics are providing patients with SATA-designed texts. Our help calls are reduced down to those patients who still are calling the DVLA rather than writing.

The next step is that there are now two relevant physicians advising the DVLA on wording; changes are being made to the relevant section of “gov.uk” in the DVLA area; and there will be a review of the 3-year and 1-year annual review process for licence maintenance.

Our recommendations remain the same –
- Always communicate by letter
- Do NOT phone the DVLA or use the on-line system
- Keep copies of everything
- BUT if a doctor says don’t drive, then don’t – you are personally responsible

SATA will be updating website advice as the situation changes, and we hope to make a demo video on how to complete the necessary forms.

Questions to Chris and Annabel

Q. Should I have septum realignment, and would it help?
A. Annabel – it might do, but see an ENT specialist.

Q. On the 3-year rule, I’ve not been seen since 2004 except for new machines?
A. Chris – DVLA will need to know and review at next licence renewal.
A. Annabel – requests a review from your clinic, or discuss remotely.

Q. What is excessive sleepiness?
A. It’s a judgement by your doctor, defined as “likely to impair safe driving” i.e. cause an accident, have a near miss, an episode of sleepiness, requiring cold air, or slow reaction time.

Q. A review – what does it involve?
A. Annabel – it might involve questions from your Sleep Clinic on your situation, i.e. is your CPAP working for you, or not.

**SATAday Question Time**

The panel comprised Dr. Annabel Nickol (Oxford), Dr. Ashwin Rajhan (Royal Stoke), Blake Marsh (Oxford), David Graddon (SATA Travel), Chris Rogers (SATA Managing Secretary).

There were a LOT of questions, some challenging and others looking for small detail improvements.

All the questions and answers are in the SATAday 2018 entry on the SATA website, and the majority are detailed below:

Q. I have lost a considerable amount of weight – I was expecting to reduce my CPAP requirement?
A. Even if losing weight has not reduced your CPAP requirement, then it will certainly have other advantages so, keep going! As we age, we lose muscle tone throughout the body, and this can be another reason besides weight that sleep apnoea tends to worsen with age.

Q. A Sleep Apnoea Nurse Specialist – is she allowed to tell a patient not to drive?
A. Yes – any appropriately-trained health professional in the Sleep Clinic can and should give advice about Driving, and informing the DVLA, car insurance company and...
employer. If there is any uncertainty, they will discuss the case with their Sleep Consultant.

Q. What's the purpose of the Epworth Sleepiness Scale?
A. This is not a diagnostic tool; however, it is useful to help track improvements in sleepiness in response to treatment of OSA. A high score may indicate a significant impact on quality of life. It may also suggest the person is putting themselves or others at risk during "vigilant critical" tasks such as driving. It is quite normal for many people to fall asleep in relaxed settings, such as watching TV, even though many of these people would be fine and remain alert driving.

Q: Any research on use of CPAP in a care setting? Husband takes mask off and drops it. Wife is deaf and doesn't hear him having a problem.
A: We are not aware of a research paper; however, clinicians have substantial experience looking after people who need help using their CPAP or home-ventilator. An individual case assessment must be carried out taking into account the potential benefits and burden of using CPAP. If CPAP is to be continued, then it should be part of the care plan for that individual, and all staff should be appropriately trained and supported.

Q: When will there be a USB charging port which can power an OSA machine?
A: Manufacturers will have to answer this. There could be travel CPAP in the near future, that may have a USB port. Patients should be encouraged to tell manufacturers what they want. A USB provides 5 Volts and up to 900 milliamps, which is 4-5 watts and not currently enough. A bathroom shaving point provides 20/40 Watts, which might be enough (but not a humidifier). An airplane seat provides 75W which should be enough, if you're allowed to use it. SATA are revamping guidelines for airlines and we advise you not to book a ticket before reviewing what you need for CPAP and the flight.

Q: For many patients, the main reason for stopping using CPAP is the starting pressure. What can be done?
A: If the starting pressure is too high, it can be started at 4 cm H2O and slowly ramped up. Is it the combination of the mask and the CPAP? Suggest wear the mask without the machine on to get used to the condition of the mask on its own, and then after a while switch on the machine. some people like the ramping procedure where the machine takes some time to get up to pressure, others more comfortable to go straight to it.

Q: How can sleep data on CPAP be monitored night to night?
A: Newest CPAP machines have a modem to send data to a secure ‘cloud’, which can be viewed by both the patient and the sleep centre. It is proven when patients have data feedback, it encourages better use. A Fitbit™ may help to tell if sleep is less restless on treatment, and overnight oximetry can help show if oxygen dipping is improved.

Q: Any way to avoid the lines on face – still have them at midday?
A: Possibly look at masks with less pressure. Some use cotton wool/memory foam. Check the routing of the tubing, which may help.

Q: What devices are there to move jaw forward, as I feel mask pushes jaw down and back?
A: Use a chin strap, or there are different types to look at.

Q: Do I only need to use the mask when in bed? What about sitting up?
A: If you sleep sitting up, obstructive sleep apnoea may be less severe, but for the best quality sleep it’s worth using CPAP during all sleeps if possible, even during power-naps.

Q: More hotels on the Continent are moving to USB adaptors – what if no mains plug?
A: There is almost always a plug somewhere, if only for a vacuum cleaner. We advise to always take an extension lead if the plug socket is far from the bed. Hotel Standard lamps may still use old small 3 pin sockets to prevent theft, and these plugs can still be purchased. One person suggested that, for Disability Discrimination, there must always be an electric socket.

Q. I have fibromyalgia – does CPAP help the symptoms?
A. Treating obstructive sleep apnoea with CPAP improves sleep quality and sleepiness. Being less sleepy can make it easier to cope with other symptoms, for example managing pain, low mood or anxiety. Sometimes people are told they have another condition

SATA Leaflets are available free of charge to NHS Sleep Clinics. If they are not available in your local Sleep Clinic get the staff to contact Chris Rogers and he will arrange supply.

SATA leaflets are generously sponsored by the ARTP (Association for Respiratory Technology & Physiology UK) for printing and ResMed for delivery.
such as chronic fatigue syndrome, and they later find out it is sleep apnoea.

Q. Is it true many people have vivid dreams after they start CPAP?
A. Any sort of sleep disruption, including OSA or being critically unwell with use of sedation in intensive care can interfere with dream (Rapid Eye Movement) sleep. When the sleep disruption is overcome, for example by treatment of OSA with CPAP, or recovery post intensive care, then there may be rebound REM sleep. That is to say – excessive dream sleep, to compensate for the previous lack of REM sleep. During this short-lived phase, an individual may have excessive, vivid dreams. Not everyone experiences this, and it is by no means a marker of CPAP success.

Q. How often should I have a deep sleep in one night?
A. People start the night in light sleep (stages I and II), then go into deep sleep (stages III and IV) 2 or 3 times, plus dream (REM) sleep. Some people try and monitor occurrence of deep sleep using a Fitbit™, or similar device. It is not important to monitor stages of sleep; the main question to ask is: is CPAP controlling OSA.

Q. How many people in the UK have OSA?
A. There are thought to be up to 3.9 million people with some degree of OSA, which represents 13% of adult males (30-70), and 6% of adult females (30-70).

Q. I have been using CPAP for 2½ years. I unconsciously turn off the machine in my sleep. What can I do?
A. Perhaps move the machine further away from the bed? Use an extension lead? Lock the machine in a cupboard.

Q. I was diagnosed eight years ago with OSA. Since turning off the machine in my sleep, what can I do?
A. It's partly due to cost – normal CPAP is cheaper than travel CPAP, not counting the travel battery. The travel CPAP does not have water humidification, which many patients find useful on their regular machine.

Q. Why are there only sales people here, and no technical people? My mask has holes (in the expiratory ports) and if I face my partner in bed, it blows air at her. I put a filter over the holes of the mask to diffuse the air, but the sales reps have advised me not to do it.
A. This is very ingenious, and we’re glad to hear it works. However, we don't recommend tampering with masks in case it changes their function, e.g. not allowing sufficient air to flush through the mask. In general, we welcome technical questions, which could be put on the SATA website, and also put to manufacturers directly.

SATA AGM
Bill conducted the SATA Annual General Meeting, as follows –

1. Minutes of the AGM meeting October 2017. The Minutes were presented to the meeting, and proposed, seconded and approved.
2. Chairman’s Report. Bill reminded the meeting that the committee was ageing and requested increased support from the Membership. In the absence of this, it was likely that more help would need to be bought in, with clear effects on our finances. The Chairman’s Report was presented to the meeting, and proposed, seconded and approved.
3. Treasurer’s report. Bill provided a copy of the accounts to Members and said that we had made a small surplus for the year. Income and expenditure were broadly in balance and he expected this would remain the case. The accounts were proposed, seconded and approved.
4. Election of Officers. Bill reported that all Officers were available for re-election, and the list was proposed, seconded and approved.
5. Any Other Business. A Member stood and requested a vote of thanks to the Chair and the Committee, which was appreciated.
6. Date of next meeting. To be decided, as is the venue, but will probably be part of the next SATAday in October 2019.

There being no other business, the meeting closed at 15.30.
This report covers the period from 7th October 2017 (our last AGM), until 13th Oct 2018

Trustees & Committee

We welcomed Peter Balham to the Committee this year, but Michael Mosely, a long serving member has had to resign owing to ill health. We record our thanks to Michael for his contribution.

Progress Report

I just want to say a few words about an activity which you support as members, but hear little about and that is our advocacy on your behalf. SATA is involved in many committees, organisations and campaigns which strive to give sleep apnoea patients a better outcome. It is time consuming and involves a high level of dedication to detail. In the past year we have stopped several Clinical Commissioning Groups (CCGs) from restricting access to CPAP therapy, (which is illegal), and we have assisted NICE with a consultation that will now form the basis of a Sleep Disordered Breathing review and a SATA member will be on the review committee.

Membership is growing quickly, with payments to us through subscriptions and donations increasing (see accounts for exact details) and SATA is in reasonably healthy financial position, but our ambitions are not only constrained by finance, but also human resources. We are getting some help from some external organisations, but for the first time, we have engaged an external supplier to run our Annual Conference and AGM. Executive Business Support has a long history of helping other organisations in the medical field and also working with other charities.

A major challenge in the last year has been to make the charity compliant with GDPR by the end of May 2018. Our thanks go to ResMed for their assistance and training in this area. It has involved a large amount of work with an audit of all our records over from the past 20 years of operation. The benefit is our record keeping is now efficient and legal.

This focus on improving efficiency in everything we do is crucial and to that end we are continuing to modernise the database operation and looking at a redesign of our website. Many of you will know about our drive to get memberships onto Direct Debit as a means of paying subscriptions, as this method of payment represents a 50% saving in time. Progress is good and almost 30% of members are now using DD.

Activity Report

In October last year, just after our Conference in Oxford, after almost three years of lobbying by us and other interested organisations, the DVLA finally changed the wording in its Guidance for Medical Professionals, and brought the focus of legislation for driving and sleep apnoea back to excessive sleepiness. The results have been substantial. Helpline calls relating to the DVLA have fallen to about 75% of total, which is to be welcomed. However, the DVLA failed to cascade these changes of wording into the public arena and we still have a degree of chaos here. Recent staff changes in Swansea indicate that, at last, they are listening to us. We now have comprehensive guidance about dealing with the DVLA on our website and many Sleep Clinics now print this and give it to their patients who drive.

Demand for our information leaflets is growing and we must thank the ARTP for funding printing costs. To make distribution of the leaflets more efficient we have taken a small storage facility in Witney, to allow us to manage this activity more effectively. The “Living with your CPAP – Your Questions Answered” leaflet is a major success and is now being given to newly diagnosed patients in many Sleep Clinics as it seeks to address the “tedious but essential” enquiries patients have in their early days on CPAP.

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 Cardiff, Yeovil, Leigh and Swindon. We are active members of the ARTP Sleep Consortium with Chris Rogers and Graham Hill representing us at the ARTP Annual Conference in Brighton. Chris also presented at 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, Graham attended our third Royal College of GPs Annual Primary Care Conference in Liverpool last October to raise awareness about the seriousness of OSA, and last week attended this year’s conference in Glasgow.

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 July 2017 and Aug 2018 due to pressure of work
Some of the Manufacturers supporting SATAday 2018 Conference

Dr Annabel Nickol of Oxford presenting her R&D Update
on the Committee. We have, however, found a solution in the way we distribute news by email in a much more efficient manner and it is GDPR compliant, so the plan is to try to get back to quarterly Sleep Matters.

Last year I closed the Activity Report on the Helpline and this year I do so again. We desperately need more helpline volunteers as we are down to three. 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 provide training.

Risks
The main risk to our charity is the same as last year, a shortage of human resources. By appointing EBS to run our Annual Conference and AGM, we have taken the first step in what I believe will be the move to establishing a SATA Office based organisation, but that will mean a substantial change to our funding requirements. We need younger Committee Members who can take on some specific duties, we are not short of ideas, but we are short of person power. The continued growth of our charity depends on this.

The obesity crisis is fuelling the growth of sleep apnoea and we see nothing to mitigate this. Some estimates indicate that there are 4 million people in the UK with obstructive sleep apnoea, with less than a million who are diagnosed. The extra cost to the NHS will be huge as an undiagnosed person costs the NHS twice that of a patient on CPAP.

The Future
As I mentioned last year, as I enter my ninth year as Chairman of SATA, with fourteen years on the Committee, I am looking to step down from the role. I have agreed to carry on (health permitting) to the AGM in 2020, but will definitely withdraw at that point. 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. If we do not get more support, and if some of the existing Committee feel the need to step aside on age or health, this Charity will be under serious threat.

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

Outlook
I want to finish on a positive note. We have developed a business plan for the next five years, which envisages a move from 75% volunteer and 25% paid support model, initially to a 50% volunteer and 50% paid labour basis. The danger of this change is that it dilutes the patient involvement element of our Charity which is so highly regarded in the wider medical and administrative world (e.g. DVLA).

I would very much like to thank the Committee (Chris, Graham, Rob and David in particular), and congratulate it on what it has achieved, is achieving and will no doubt continue to 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 which provides us with a regular meeting room at the Churchill Hospital, and in previous years a Conference venue. We also welcome the supporting clinicians for other Sleep Clinics here today and hope the inevitable collaborative discussions lead to even higher quality service in our wonderful NHS. As always we 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, 13th October 2018

DIRECT DEBIT MAKES SATA MORE EFFICIENT AND YOUR DONATION GO FURTHER

Direct Debit means we do not have to send annual reminders for membership payments. Standing Orders also work well as we do not have to send annual reminders for membership payments. Membership reminding is now the biggest single unnecessary administrative cost for the charity.
It was such a sad day for SATA when in January Claire Mitchell, a founder member and major support volunteer for SATA decided it was time to retire. In fact, with the loss of this unrivalled expert, with changing information requests and the rise of the website as the prime information source, it was time to call it a day for the Helpline.

Claire was part of a group, along with CPAP user husband Bob, who founded the Sleep Apnoea Trust on 29th September 1993 and attended the first meeting on Saturday 9th October with many other people to set up a CPAP Support Group. She joined the Committee immediately with her husband as a Counsellor.

She contributed to the first issue of Sleep Matters in Spring 1994, brilliantly summing up the spirit of adventure of the Oxford Sleep Clinic and its pioneering activities.

“I was very touched listening to the conversations around me while we ate. There was a hunger to talk as well - to swap experiences and discuss the advantages and disadvantages of the various machines used. The almost unbelievable trauma and bewildering desolation caused by this Sleep Apnoea thing, their lives ruinously affected before Dr Stradling and the CPAP” (Sleep Matters Vol 1 Spring 1994).

In issue 3 published in Spring 1995, husband Bob won the competition to design SATA’s logo, and Claire wrote enthusiastically about the SATA First Birthday Party.

The second anniversary conference was reported by Claire in the Spring 1996 edition with the words “Thus ended our Second Anniversary Celebration. “It was lively, stimulating and exciting – a thoroughly nice day” Sleep Matters in Autumn 1997 saw Claire enthused about the Summer Gathering:

“In a distant meadow, hazed by dust, a tractor turned hay. Coot and moorhen scurried and called, but the sound, as all others, was subdue by the heavy atmosphere under the shade of the willows. It almost had a dream-like quality. A truly English scene in a setting unchanged for centuries. We had, all of us, enjoyed the relaxed, delicious gathering, in the height of summer and the sultry heat. We are looking forward to our next meeting in November and perhaps again, next year, another Summer Gathering”.

This pinpointed both the social and medical camaraderie that SATA created and still does today.

She also wrote about Social Security and Sleep Apnoea, offering advice to people who had lost their livelihoods through sleep apnoea and helping them to deal with the social services, an area where her career expertise was invaluable.

The millennium edition saw Claire reporting on the SATAday conference:

“Warm thanks to the speakers for a most stimulating day and to conference committee for organising such a successful event. The whole thing went so smoothly that such a result is only achieved by a lot of hard work. The numbers attending the conference have been growing from year to year. To some extent this may reflect the increased knowledge of Sleep Apnoea among the medical profession (and hence an increase in diagnoses) but it also reflects a continuing enthusiasm for the conference amongst its longer serving members”.

She also started a GP awareness campaign targeting seven health authority regions.

As the Committee grew and more people came forward to help, Claire concentrated on running the London telephone Helpline service. With increased awareness of sleep apnoea, SATA was certainly at the centre of national and international discussions and the campaign to get free CPAP treatment on the NHS was dominating the Committee’s work.

Claire now concentrated on providing the very best information to literally thousands of enquirers.

More recently, with the way in which Government Departments have mismanaged their handling of sleep apnoea, from Bedroom Tax to DVLA, Claire has been the citizens’ friend, sorting out MPs, DWP, DVLA, NHS, and local authorities with her extensive and expert knowledge. She got things done, with her tenacity and expertise often outflanking “more than my job’s worth “and “tick box” attitudes that pervade civil society today. Thanks to Claire, drivers have got their licences back, people who have lost benefits have had them restored and on a personal basis, they have received the finest possible caring advice in managing their sleep apnoea and all the complications it brings with it.

All this has been done on a voluntary basis and this illustrates better than ever, the ethos of empathy, care and a dedication to helping everyone whose lives have been affected by sleep apnoea.

The Sleep Apnoea Trust, its Committee and all its members, plus the many thousands of people she has advised, thank Claire for 25 years of dedicated volunteer service.
You are on CPAP, but your eyes are giving you problems. They are itchy, sore and you have red eyelids that stick together. Your eyelashes are crusty or greasy and give you a burning, gritty sensation. You have an increased sensitivity to light (photophobia), especially xenon car headlights at night. You have swollen eyelid margins and, if you wear them, you are finding contact lenses uncomfortable. At worst, you have abnormal eyelash growth or loss of eyelashes in severe cases. It must be a leaky mask, with your CPAP blowing cold air into your eyes while you are asleep, or is it Blepharitis?

Your editor recently had new glasses, so there should be fewer mistakes on membership renewals etc, but after the test, his optician said “You have Blepharitis”. Oh My Goodness, will I go blind, do I ring Moorfield Eye Hospital now, and how long have I got to live? This issue is serious. Typical Man Panic! At this point she did say it was probably incurable, so my panic increased and then she said, but it is easily treatable. Utter relief swept through me. She then went on to explain.

**What causes blepharitis?**

There are three main types of blepharitis:

- **anterior blepharitis** – where the inflammation affects the skin around the base of your eyelashes
- **posterior blepharitis** – where the inflammation affects your Meibomian glands, found along the eyelid margins behind the base of the eyelashes
- **mixed blepharitis** – a combination of both anterior and posterior blepharitis

Blepharitis isn’t contagious.

**How blepharitis is treated?**

Blepharitis is usually a long-term condition. Most people experience repeated episodes, separated by periods without symptoms. It cannot usually be cured, but a daily eyelid-cleaning routine can help control the symptoms and prevent permanent scarring of the eyelid margins. There are three main steps to eyelid hygiene that should be performed once or twice a day:

- using a warm compress – to make the oil produced by the glands around your eyes more runny
- gently massaging your eyelids – to push the oils out of the glands
- cleaning your eyelids – to wipe away any excess oil and remove any crusts, bacteria, dust or grime that might have built up

More severe cases may require antibiotics that are either applied to the eye or eyelid directly, or taken as tablets.

At this point, emerging from the optician’s treatment room, I said to my 18 year old grand-daughter I have itchy eyes and have to use a liquid to treat a serious condition called Blepharitis.

She replied, “Oh yes, I use that liquid to make sure all my eyeliner is removed as it can be irritating when it’s dry.”

At this point, despite being over 6 foot tall, I felt like a child on the naughty step for stealing some icing from the Christmas cake.

The lesson – make sure you do not blame the CPAP mask until checking you are not a victim of BLEPHARITIS.