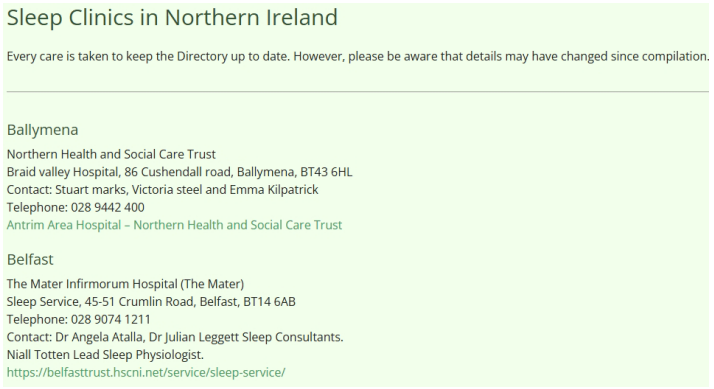
SUMMER 2026

# SLEEP MATTERS

SLEEP APNOEA TRUST – THE INDEPENDENT PATIENT VOICE

# THE SLEEP APNOEA TRUST WEBSITE – UPDATING AND IMPROVING!



Sleep Clinics in Northern Ireland

Every care is taken to keep the Directory up to date. However, please be aware that details may have changed since compilation.

Ballymena

Northern Health and Social Care Trust
Braid valley Hospital, 86 Cushendall road, Ballymena, BT43 6HL
Contact: Stuart marks, Victoria steel and Emma Kilpatrick
Telephone: 028 9442 400
Antrim Area Hospital – Northern Health and Social Care Trust

Belfast

The Mater Infirmorum Hospital (The Mater)
Sleep Service, 45-51 Crumlin Road, Belfast, BT14 6AB
Telephone: 028 9074 1211
Contact: Dr Angela Atalla, Dr Julian Leggett Sleep Consultants.
Niall Totten Lead Sleep Physiologist.
https://belfasttrust.hscni.net/service/sleep-service/

The Sleep Apnoea Trust website probably has more information regarding the various forms of Sleep Apnoea within its pages than any other in the UK. However, our members and other patients and users, when asked, told us that sometimes it's quite hard to find. We are taking these comments on board, and have embarked on an updating program to make searching more efficient, so you can find what you want; make the language easier to read and understand; and to make sure it's as up-to-date as is possible with our resources. We're pleased, therefore, to announce an update to our Northern Ireland Sleep Clinics page, courtesy of our friend Chloe Gibson from the Sleep Service at Ulster Hospital. See the page in total at Northern Ireland - The Sleep Apnoea Trust

We also give you access to include a range of technical and educational video/webinar presentations via the News and Events section of our website.

The SATA Members Area - already has access to our own past SATAday video presentations (have you used your own access recently?

## IN THIS ISSUE

We have a great mix of personal stories, the latest medical news, the activities of Trust Officers and a reminder to pop **SATA*day* 2026** into your diaries

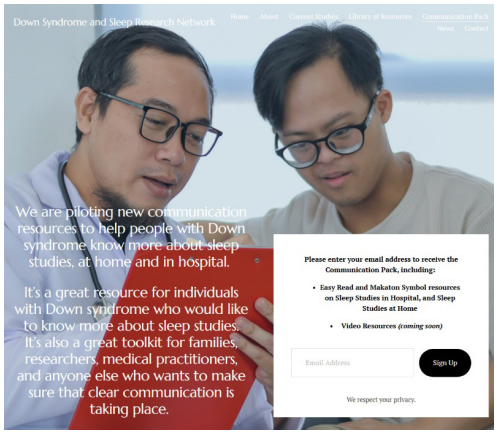


***Enjoy this Issue!***

# FROM THE MANAGING SECRETARY

**Claire Allen** - Gosh, I can't believe it's that time again. Time to update you all on my activities and give a warm welcome all our new members who have joined us since the last edition. Did you know that past editions of our newsletter can be found on our website here – Sleep Matters Newsletter - The Sleep Apnoea Trust? On that page you can search all our past newsletters on any topic.

Lots has happened over the last three months, including giving presentations and attending meetings to raise awareness of sleep apnoea and the Sleep Apnoea Trust. In the last edition I gave you a taster of what was coming and, in this report, you'll find out how I got on!




On 23 March I listened to a webinar from the Down Syndrome Sleep Research Network and this made me very aware of the fact that many people with Down Syndrome also have sleep apnoea. Subsequently I travelled to Guildford in early June for their face-to-face meeting, and we agreed to link out to some resources for that audience that have developed. These resources are also available in Makaton and if you aren't aware of what that is (I wasn't!), it's a language programme that combines signs, symbols, and speech to support communication and language development in individuals with Down Syndrome. I hope to be able to upload these resources in the next few weeks.

I've been delighted to work with Chris Turnbull to finalise the agenda for **SATA***day* on 3 October. I hope that our existing members will have marked that date in their diary, and this is a call out to our new members to ask you to 'save the date', as you'll be receiving an invitation to it in the coming months. I think it'll be very different to the last **SATA***day* having taken your feedback into account. I'm also excited that most, if not all, of the presenters will be live in a studio rather than pre-recording their presentations. We'll have two 'fireside' chats and I look forward to receiving your questions in real time as the conference proceeds. And I'd like to thank the commercial sponsors who have supported us so far – you'll be seeing their logos in the next edition of Sleep Matters, as well as during **SATA***day*.

In April I was delighted to be invited to be a speaker at the inaugural NHS conference – LungVision 2026. I got to know some of the staff of Respiratory Departments across the country and after my presentation was involved in a 'skills clinic' which involved a small panel discussing all things sleep apnoea. This was swiftly followed by being invited to attend the Vivisol Study Day where I met many people I'd only corresponded with before. Swapna Mandal, who leads the Royal Free Hospital's sleep and ventilation service, gave us information about how she had reduced the waiting list for CPAP treatment by providing 'group setup' which some of you may have had. In a single day the service can set up around 150 patients using this model rather than the 13 or 14 a day previously. It was interesting to hear that with a group set up, there is better compliance of CPAP, perhaps because patients could talk to each other and support each other throughout the session.


*Claire, Dr Chris Sleight, and Dr Gurnak Dosnajh at LungVision 2026*

Tom Chambers (of Theta Sleep), who wrote a piece on consumer wearables in the last edition of Sleep Matters, and will be speaking at **SATA***day*, spoke about the fact that sleep needs to move up the national agenda, and that sleep apnoea is a perfect fit for the 10 year health plan for England as it fits the criteria for digital, community and preventative care. I'd like us all to support him by doing our bit and sharing stories of sleep apnoea where we can.


Meantime I was approached by ExtraCare, a charity providing retirement villages with a very healthy health focus! They have asked me to give talks to their villages, and we're starting in July with villages in Hughenden, Milton Keynes (two villages) and Bedford. I'll be supported in these by Mike McEwan of Sefam who will demonstrate CPAP machines to those who are interested. After this, the next tranche of presentations will include Bristol, Gloucester and Evesham in September.


Later in May came the Association for Respiratory Technology and Physiology (ARTP) conference – it was the 50th anniversary and was held in Belfast. I enjoyed connecting with both manufacturers and health professionals – again, many of whom I've only ever met online. I also enjoyed reconnecting with people I've met in person and took the opportunity wherever possible to raise the profile of the Trust. I enjoyed my very first face to face Sleep Apnoea Consortium (SAC) meeting where we received a lot of support. I was very grateful to them to receive, on behalf of the Trust, a grant of £3,000 to support leaflet production for our NHS sleep clinics. I'm sure I can speak on your behalf when I say a huge thank you to them.


Many of you will have received our leaflets when visiting your sleep clinic. As a reminder all the leaflets are available on our website to download at your leisure. This report is peppered with the photos that were taken during the conference and include staff from ResMed, Philips, Lowenstein, Inspire, Sefam, and Hope2Sleep. If I had to name check everyone to send my thanks to you'd still be reading in a week's time but suffice to say I was welcomed with much enthusiasm for which I'll always be grateful.

Recently I've also connected with the Paediatric team at Southampton. We're looking to have some generic support on our website for parents of children with sleep apnoea. Did you know that often, sleep apnoea is familial? And in other new connections, I've been meeting with Sudden Cardiac Arrest UK and Diabetes UK to explore ways in which we can work together given the association between sleep apnoea, cardiac events and diabetes. Before our next edition of Sleep Matters, I will have attended the Philips Study Day at the Sofitel Hotel on the Gatwick Airport site talking to acute care (NIV) nurses about how we support both patients and sleep clinics.

I hope the summer months will be a little quieter so that I can work on updating the website. Related to this, I'd like to thank Jen Troath, who is helping me to update the diagnosis and treatment pages (for sleep apnoea), Zainab Al Lawati and Lesley Langdell for supporting me in developing some 'in memory' pages





and all those who work at sleep clinics who help keep our list of UK sleep clinics up to date. If you'd like to volunteer to do some 'desk-based' work with me or know anyone who might be interested in doing this, I'd welcome any help! As you can probably tell there is a pretty big job of work to be done to achieve our goals of education, advocacy, awareness raising, and research & development.

My last message to you is that the most important thing for me is to support you by providing a service that's efficient and effective as well as responsive. Thank you for your continued support and encouragement. Your messages are always welcome, and I'm always interested in your ideas for improvement and how we can support you better.

**PLEASE PAY YOUR SATA MEMBERSHIP BY DIRECT DEBIT**

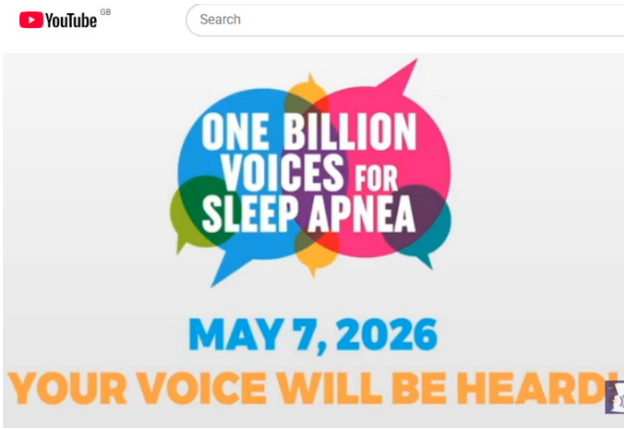
# SATA IN SOCIAL MEDIA – ONWARDS AND OUTWARDS

**David Petrie** – Hello, I hope you're all having a nice summer. I thought this might be a good opportunity to talk a bit about what the thinking is behind the material which we post on our social media channels (currently Facebook and LinkedIn). Our posts fall into three categories.

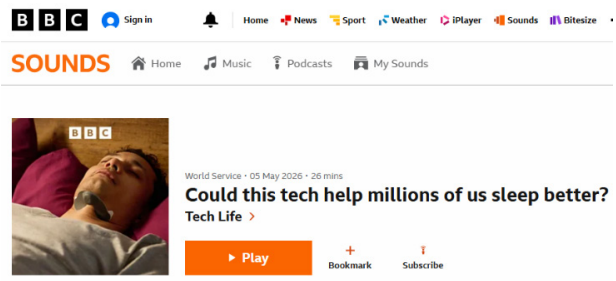
Firstly, there are those that might be described as "information". A good example of this is when there are weather warnings for a winter storm or for unseasonably high summer temperatures. In these circumstances we will publish a post which reminds you to take care, and will point you to a website such as the Met Office or the NHS where you can get more detailed information.

We also post a lot of information about transport issues. Recently we've shared information and advice on railcards, concessionary travel passes and travelling with your CPAP. We also communicate updates from DVLA as and when they become available. Other information posts have included reminders to check the opening times of GP surgeries, pharmacies and Sleep Clinics ahead of a Bank Holiday.

The second category is the work of the Trust itself. Our Managing Secretary Claire spends a great deal of her time meeting with a range of people connected with our work and this as a constant source of material for both Facebook and LinkedIn. We've recently shared some great pics of Claire at the ARTP Conference in Belfast and at a Vivisol Study Day. My fellow Trustee Louise also provides lovely photos and updates on her work with our volunteers across the country. We also post information about our work with partner organisations; for example. the recent One Billion Voices for Sleep Apnoea campaign.




The third category is links to stories about OSA which have appeared in the media. I find it really encouraging that the mainstream media now seems to be paying much more attention to Sleep Apnoea and related issues. Coverage which we have shared over the last few weeks includes –




- BBC Sounds, a couple of episodes of the what's up docs podcast looking at OSA and snoring
- The Economist, a look at the growing use of sleep trackers
- Good Housekeeping, a feature on snoring
- Health Services Journal, alternatives to CPAP for treating sleep-apnoea
- BBC World Service, a report from the Tech Life programme about the use of new technology in OSA treatment, including an interview with yours truly!
- The Times, a feature on orthosomnia (in case you didn't know, orthosomnia is an unhealthy obsession with getting a good nights' sleep)

Although we can generate a great deal of material for social media by the methods above, we're well aware of the fact that we don't know everything! So, please get in touch if you have a story that you think would be of interest. If you are a clinician, a volunteer or a patient we would love to hear from you. You can send us a Direct Message on Facebook, or send an email to info@sleep-apnoea-trust.org . Enjoy the rest of the summer.

# FROM THE CHAIRMAN – BILL JOHNSTON

Before I stand down from the Chairman's role at the Sleep Apnoea Trust, I'd like to share some memories with members on the history of the Trust from my time as Chair, and my own personal experiences as a long-term CPAP-treated OSA patient.

I became conscious in my late 40's that I often felt tired, and just put it down to getting middle aged. Eventually, I chatted to my GP who initiated some tests, but nothing was identified.

I did fall asleep during the day, but was generally managing OK.

In 2003, when I was 50, I was referred to a specialist dentist for some extended treatment. He commented that I had slept through most of the treatment, and that my breathing was uneven. He thought I might have OSA, and told me to speak to my GP.

I did as was suggested and my GP referred me to the local Sleep Clinic. As I live in West Buckinghamshire, this turned out to be the Churchill Hospital in Oxford. After an overnight sleep study on site, I was diagnosed with severe OSA, and met Prof John Stradling who arranged provision of a CPAP machine. During my discussion with him, he suggested that I might consider joining the committee of the Sleep Apnoea Trust Association. I, like a lamb, agreed, and the rest is history.

I am very fortunate that, from day 1, I have been very tolerant of using CPAP, and apart from overnight flights, have used it ever since November 2003. I usually manage at least 7 hours sleep. During the last 23 or so years, I have had a series (4, I think) of fixed pressure ResMed machines.

I am very conscious that, at the time I was diagnosed, the Sleep Clinic seemed to be under less pressure than now, in terms of work load and available resources. As an example of this, I was called in to the clinic on an annual basis to check the machine and monitor my progress. Clearly the number of people being diagnosed has increased substantially, but the resources provided have not kept pace, so waiting lists have expanded, although I do not question that very high-quality care is still being provided.

## Work with the SATA Committee

When I started to work with the Committee, meetings were always in person and held at the Churchill hospital. Frank and Wilma Govan were leading lights, as Chairman and Treasurer respectively, and Prof Stradling and several of his colleagues attended the meetings. Two Committee Members then (Tim Healing and Rob Holt) are still on the Committee today, having pre-dated my time in office.

During the 20+ years since that time, practice has changed a bit, although overall objectives have not. In the early 2000's almost everything was analogue, and it was not for a few years that a comprehensive website was created. Members did, however, have access to a helpline which was enabled by a volunteer group who were invariably OSA patients. Much of that work was superseded by the website.

Two significant achievements have been made. First is that SATA was very prominent in lobbying NICE to mandate the provision of CPAP machines for diagnosed patients. Up until that time, whilst some Sleep Clinics (including Oxford) did so, provision across the NHS was not uniform.

The second area of real help was in relation to DVLA and the rules related to driving. The number of interventions which SATA has made on behalf of patients when dealing with DVLA has been substantial.

Frank and Wilma were so active in management that, when they stepped down from the Committee, we needed to appoint a Managing Secretary, although that was initially a mainly administrative role. Unfortunately she had to withdraw at short notice due to change in family circumstances, and it looked as though the in-person **SATA***day* conference planned for that year would have to be abandoned. Chris Rogers had just joined the Committee at that time, and offered to run the conference, which he did very

successfully. Chris had newly retired from Honda UK, and had a Marketing background. He then volunteered to take on the Managing Secretary role, and for the next almost 20 years was the public face of SATA, and also did an enormous amount of work behind the scenes. For a lot of this period, I was Chairman of the Committee, and always found him to be an excellent colleague. We didn't necessarily agree, but always managed to find a constructive was forward. As many of you will recall, Chris became very unwell, but continued to work for SATA right up until a few weeks before his death.

During the period before COVID, SATA held an annual in-person conference, **SATA***day*. For most of the time, this was in the academic centre of the Oxford Hospitals, on the John Radcliffe Hospital site, but latterly was in a conference centre in Wyboston, Cambridgeshire. As well as being a great gathering to hear medical developments, hold Q&A sessions with experts, consult sleep nurses with practical problems, and look at sponsored exhibitions at which suppliers and manufacturers were pleased to be present, it was also an opportunity for older members to renew acquaintances and swap experiences.

*SATAday 2012 Oxford*

Unfortunately, COVID made the in-person 2020 conference impossible, but the on-line substitute conference was well attended and appreciated. The Committee has decided in subsequent years to maintain the on-line format, but this is constantly being reviewed, as whilst it serves part of our purposes very effectively and efficiently, not meeting in person clearly does lead to some loss of experience.

When SATA was established it followed the then-normal practice of being constituted as a Charitable Trust. Whilst this is still a very common way of running a charity, Charitable Law changed a few years ago to establish a new form of structure (a Charitable Incorporated Organisation or CIO) which suited small charities which sought to provide limited liability to Trustees without the extra administrative burden of becoming a limited company. SATA undertook this transition about 5 years ago.

During my time on the Committee there have been many committee members who have done a lot of work valuable to SATA; Treasury (managing the accounts), preparing Sleep Matters, liaising with Sleep Clinics, ARTP, NICE, organising volunteers, running social media, giving travel advice, to name but a few. I particularly want to thank our Clinical Trustees. John Stradling has been mentioned before, and he not only gave very valuable advice to SATA, but was also one of the founders of the charity. He also encouraged participation in the charity by sleep nurses, as well as being a regular speaker at **SATA***day* conferences. Since he stepped back, we have greatly benefitted from the contribution of Dr Annabel Nickol, and Dr Chris Turnbull, both consultants at the Churchill hospital. Their quiet authoritative contributions to Trustee meetings, and involvement with our conferences have been invaluable.

Finally, in this section, I wanted to comment about our present situation. In the last 18 months or so we learned that SATA was to be the beneficiary of a substantial financial legacy. That has translated into funds of about £250,000. The gentleman who left us the money was not known to us, but we are enormously grateful to him. It has enabled us, with confidence to recruit a new Managing Secretary, and use resources in more adventurous ways than was previously possible.

## TRAVELLING ABROAD THIS YEAR?

**IT IS ESSENTIAL TO KEEP YOUR CPAP MACHINE IN YOUR POSSESSION AT ALL TIMES. MAKE SURE YOU HAVE A MEDICAL EQUIPMENT BAGGAGE TAG FOR JUST £10 – ORDER FROM OUR WEBSITE**

# PRACTICAL PROBLEMS WITH CPAP – A USER'S PERSPECTIVE

**Geoff Stollard –** I am a chartered builder, living in the West Midlands and I have a wife, three children, and six grandchildren.10 years ago, my wife sent me to see our G.P. as I was snoring too much. He referred me to the hospital sleep clinic, and they sent me finger tests. I was then called in to see them and told I had been diagnosed with Sleep Apnoea, so I would need to wear a face mask and use a machine every night to pump air into my chest! They told me there is no known cure so you will need to use this machine for the rest of your life. I did not argue, what could I have said? I was shown the equipment, had a short demonstration and given a mask. Within about one hour I was on my way home, with the equipment packed in a grey shoulder strapped case, the one I still use. I checked online and found to my amazement that Sleep Apnoea is the highest risk of sudden unexpected death in the country, so, you become aware that it's a dangerous condition and therefore should be treated. I soon learnt, and over the years have learnt more, about the practical problems so, here is my summary: -

I have sleep apnoea so, like many of you, travelling and mobility is a major nuisance due to having to pack up the CPAP equipment to take with you, and then get it set up in an unfamiliar environment. Even if you're just going to stay with a friend, you have to make sure they have a bedside table big enough to rest the CPAP on, and ensure there's a three-pin socket somewhere close. It's always an absolute nightmare, and it takes time every day, to set it up. I often wonder if friends think, "*oh god he's like disabled, isn't he*" because I'm carrying a grey case full of equipment when I arrive. People are sympathetic, but often worried that the responsibility is on them to feed me air!

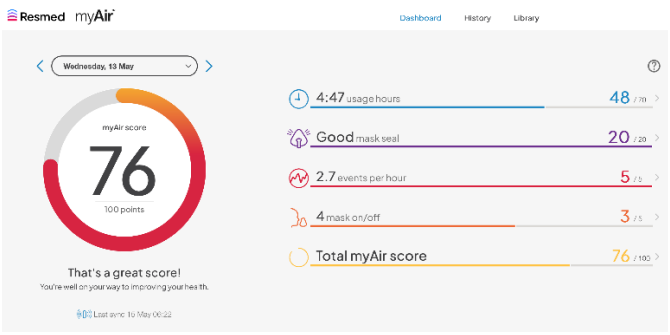
With hotels in the UK, you get to know the chains that will have the right type of socket connections and those where you may need a 30-metre extension cable to get to a three-pin socket. I keep a 30-metre extension cable in the boot of my car and the first thing I do when I arrive at a hotel is to make sure everything I need is close to the bed. This is, of course, the reality of sleep apnoea.

I've often asked myself whether I need to follow all the instructions that come with the CPAP. I mean do you really need to use bottled, or distilled water? I just use water straight out of the tap now and haven't had any problems - but I do live in a soft water area! Again, you're supposed to wash and clean the humidifier every day, emptying out water left from the previous night and then using a jug to fill it up. However, for me, that's difficult so I now carry the whole well to the sink, tip the water out and clean it, then fill it up under the tap. It rarely splashes out and if it does, well, it's only water. If your hose floods at night and there's a horrible noise, others don't realise initially that it's the hose that's flooded. It's just condensation in the tube that's the problem - I haven't caused it myself. And the answer is just to put the hose on the bedroom carpet and let it blow itself out and dry the tube by itself and in about one minute it's fine again. This can be frightening at first - and I'm sure a lot of people eventually give up.

I'm in my late 70's and my manual dexterity is way below the level it was 20 years ago. I have less feeling in my hands and less co-ordination, so I find it particularly difficult to open the water container. I wish the NHS had a special system for people of my age and that manufacturers could design a CPAP where you just lift a lid and fill with water rather than detaching the whole tank.

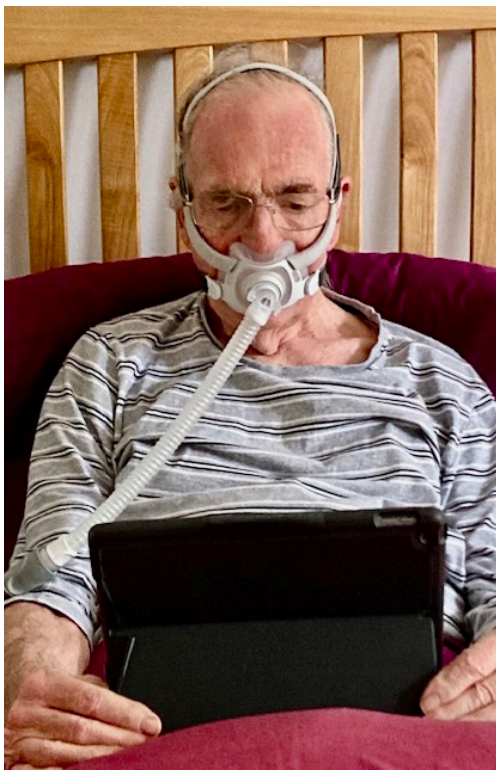
Talking to others about how they live with and cope with sleep apnoea is so valuable, particularly at the beginning, but also throughout – there is so much that patients simply aren't told – which is why I got involved with the Sleep Apnoea Trust. For instance, nobody tells you…that

- *you need a bedside table that is at least x width and x depth with the machine controls in line with your sight and easily reached whilst you are trying to sleep*
- *what the best way is to set up a machine*
- *how high above the floor this machine should be. What the ideal height is. All I know is that I need to switch the thing on*




In addition, there are so many pieces of information that still amaze me such as my machine telling me how many "events" I have had; however, nobody has explained what an "event" is! No-one has talked about the pressure the machine should operate at and whether it should be adjusted. I've no idea what the differences are. Mine was set up with the pressure at 10. And it's still at 10. I sometimes think I ought to change it and see if it reduces the number of "events" I have.

I go and see the clinic but now the only time I see someone is if something's broken. I must be on patient initiated follow up (PIFU) because I am rarely called in. In ten years, I've only ever seen one senior person, and struggled to find detailed answers to my questions.

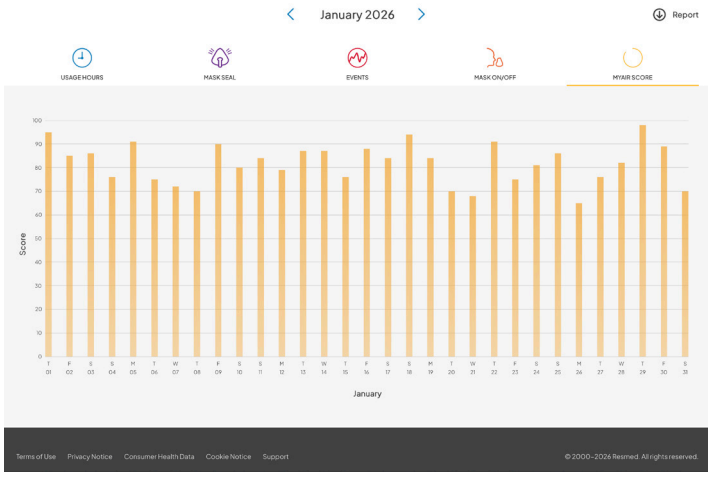


I wish 10 years ago, there had been someone to tell me how to work out the pressure, how tight the straps should be etc. I have no idea. I start the pressure nice and gently and it seemed fine, then within an hour or so I wake up because it's blowing too fast. And then the straps are far too tight. And you think, "*that's stupid*". We all have different faces, different abilities, and therefore different needs. I remember someone said to me, "*You should have the space to get a pencil between your face and the mask strap.*" But quite honestly it doesn't seem to work for me.

There never seems to be enough room to get the strap on, it always seems to overlap with the connections. And trying to get the Velcro straps in line with the straps on the mask is hard work and takes several attempts, particularly at night when I've just been asleep, it is extremely hard – magnetic clips have been a game changer for me.

It was years before I found out I had a microSD card in the CPAP sending information hourly to "the cloud" and that I could personally look up my own nightly results. I'm sure that half the people who have a CPAP don't even know about the card. I wonder why not? I often ponder what life would be like if we didn't have access to the internet with the support and information that comes from it?

I had to go to the sleep clinic at the hospital recently only because my CPAP machine had broken down. And the only thing broken was the tube coming into my mouth. It was starting to blow air at an absolutely ridiculous flow rate, so it woke me up. I initially thought it was the machine and I had to work out what on earth it was. I'm an engineer by background so I started looking at all the bits. I eventually realised that there is a little flap in the 90o bend, that twists and turns when you're blowing in as opposed to blowing out. That had become detached and so the hose was broken




After calling the clinic, I visited the drop-in clinic at my hospital. I can turn up anytime, without making an appointment. I've been before and there could be 100 people in a queue but when I got there, there was only about 10. There is a team of technicians, and I saw a one within about 5 minutes. They looked at my broken hose and gave one from what they classify as emergency supplies. After asking, they said the number of patients at the clinic is nearly 10 times as many as it was 10 years ago. I wondered if that was because sleep apnoea is on the rise, but they said it was a combination of that as well as raised awareness.

I think there are around 9 million people in the UK who have sleep apnoea. I have a ResMed machine and ResMed alone has over 27 million cloud-connectable devices in the market as of 2025. The company operates in more than 140 countries. The research potential is phenomenal from the information already collected, but my final question is "Will the NHS ever find the funds?".

# Join SATA

## The Trust has two levels of membership:

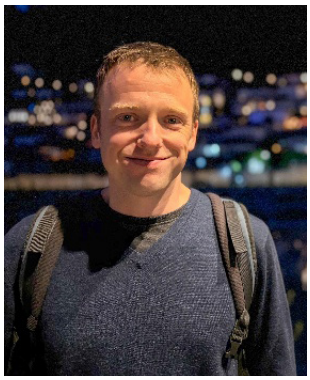
**Ordinary - £20 per annum** – Complimentary Medical Alert card, annual patient Conference, access to the Members Area of the website, pre-publication copy of Sleep Matters, and the opportunity to assist in research projects.

**Supported: - £10 per annum** – All the above benefits but a discounted fee for those facing financial hardship

**NB. Gift Aid** – If you are a UK income tax payer, the government supports charities by allowing us to reclaim the tax you paid on the income donated to the charity. This provides us with an extra 25 pence on every £1 you pay to us. Please register on the membership detail form below.

**https://sleep-apnoea-trust.org/join-sata/**

# SATA*day* 2026 ON SATURDAY 3RD OCTOBER – COMING ALONG NICELY!

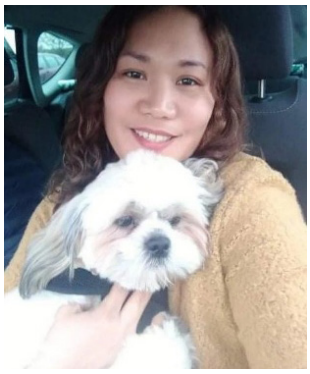


**Dr Chris Turnbull**, one of SATA's Clinical Trustees and the principal organiser of SATA's annual **SATA***day* online conference invites you to join us again this year on Saturday 3rd October 2026 from 10.00 a.m. He says:

"The sessions are coming together into our final format, and it's looking at being an interesting and informative set of sessions. **SATA***day* 2026 will be run from a professional studio based in Sobell House, on the Churchill site in Oxford, either with the presenters attending on the day or pre-recording professionally if they can't attend. This way, the conference will have a higher quality level, while losing nothing of the connectivity that members get from the 'Chat' function everyone enjoys."

Confirmed presenters so far are –

**Tom Chambers** (Co-founder & CMO of Theta Sleep; Anaesthetic & Sleep Medicine Doctor in the NHS), who will talk about consumer wearables for data and diagnosis



**Jennifer Troath** (Advanced Respiratory and Sleep Clinic Physiologist, George Eliot Hospital) who will talk about CPAP management, aerophagia, and sleep hygiene

**Dr Robert Koefman** and **Vicki Maylan** in conversation on raising awareness of sleep apnoea in primary care

**Dr Annabel Nickol** and **Sam Backway** (Sleep Specialist Nurse, Great Western Hospital), in conversation on what to do when you're not loving your CPAP

**SATA's Q&A Panel** As usual, questions can be put to the Q&A Panel in advance, and we will be better equipped to take additional questions from the "Chat function" during the conference and answer them 'in real time'

# SLEEP CLINIC LIAISON OFFICER REPORT

**Louise Mather** – It's been a busy time liaising with sleep clinics over the past few months. To give you a snapshot here's a brief update. As you read in the previous Sleep Matters we heard from the two volunteers who are now in place at the Oxford Sleep Clinic

There is a new volunteer, Peter, working at the Salisbury Sleep Clinic, we will be hearing about his experience in the next edition of Sleep Matters. A new volunteer will be starting shortly at the Great Western Hospital in Swindon, and for that clinic we're looking to facilitate more volunteers, so if you live near Swindon and would like to volunteer, please do get in touch.

A new volunteer has been trained to start at Fairfield Hospital in Bury, and one to start their training shortly at the Norfolk and Norwich Hospital. Papworth Hospital in Cambridge has an opportunity set up and are looking to identify someone to take on the role.

We're also in talks with sleep clinics in Trafford Hospital, Hereford, Weymouth, and Yeovil about volunteering opportunities. I visited Trafford Hospital with Claire on 15 March where we met with Maria, the Sleep Lead. We discussed volunteering, patient events/talks and the Trust's support for the clinic. Maria was keen to have a poster about the Trust and we're pleased to say that as of April, posters are being sent to clinics with patient information leaflets. A reminder – if you would like a poster or two to put up in community spaces, please don't hesitate to let us know on info@sleep-apnoea-trust.org

## Other outreach activities including presentations and media interviews


In January I met with ResMed to discuss ways that they can support SATA in local sleep apnoea awareness talks. As a result of this, I was invited to speak about sleep apnoea at the Vale Royal Rotary Club in Northwich. ResMed provided support to demonstrate equipment and assist in the Q&A session - our thanks to Jasleen Bijral and Miles Ndoro. The meeting was led by John and Wendy Watson; Wendy has since attended Board meetings with a view to becoming a Trustee. The Trust was very grateful for a donation of £250.00 from the Rotary Club

In February, alongside Chris Turnbull, I was interviewed by Hayley Bennett for the BBC Science Magazine (e-article). The resulting article appeared on Apple News first but Hayley has kindly provided a link for the article which appears on the SATA website. This will be published electronically in the BBC Science Magazine soon.


My media interviews continued in February with a piece in my local paper - the Knutsford and Northwich Guardian – this was about sleep apnoea awareness in general and the recent visit to the Vale Royal Rotary Club.

In March, I was given the opportunity to visit Ashfields Medical Centre in Cheshire. The team at the surgery were very interested in the SATA stand and display table and I also interacted with patients. I'd love to do more of this locally so if you're based in Cheshire, and think your surgery might be interested, please do let me know. This also ties in with the project Claire is supporting alongside Vicki Mayland about raising awareness of sleep apnoea in GPs (who, incidentally only get 2-3 hours of training about sleep apnoea in their long journey to become qualified). If you think you can help with the project, please do contact Claire. I'm also looking forward to hearing the talk at our online conference (**SATA***day)* on 3 October 2026 with Vicki Maylan and Robert Koefman discussing how to raise awareness of sleep apnoea in GPs and how we, as a community, can support this.

Many of you will have seen Claire's e-mail about the research that Iain Wheatley is carrying out about the impact of the Phillips CPAP recall. I was affected by this, myself, so took part in an online interview on 30 March. I'm very interested in seeing the outcome of his research, as I'm sure you are too. Hot off the press and linked to the sleepiness scale and questionnaire, Claire met with Sam Backway, the Specialist Sleep Nurse at the Great Western Hospital in Swindon on 20 April, and Sam shared a pre-sleep study questionnaire asking questions related to daytime and nighttime. I list them here in case any of them are relevant to your own friends and family. Each is 'scored' in terms of most days, weekly, rarely or never:

## How often do you experience the following?

**At night…**

Difficulty falling asleep

Difficulty staying asleep

Snoring

Choking or gasping for air

Others say you stop breathing

Overwhelming urge to move legs/arms

Twitching or jerking of the legs/arms

**During the day…**

Feel tired after a full night's sleep
Morning headaches
Difficulty concentrating
Trouble remembering
Dozing off (even if only for a second)
Daytime sleepiness
Feel sleepy whilst driving
Fall asleep at work
Stress, anxiety or sadness
Nasal problems (e.g. congestion, difficulty breathing through the nose)

Of course, we also now know of the co-morbidities (such as high blood pressure, nocturia, cardiac events, stroke, diabetes etc.) associated with untreated sleep apnoea, so GPs being aware of those too will help the cause.

In April I attended a Women's Health Day held in Cheshire, I was able to make some useful connections and offer talks to the following organisations, Her Place Charitable Trust, Smile Group (who support expectant mothers and new parents), Deafness Support Network, Stroke Survivors Support Group. In May I shared my sleep apnoea journey with sleep students from the University of the West of England (UWE) which is in Bristol. It's important that students keep in mind the impact of sleep apnoea on 'real people', and that they are aware of some of the symptoms that are associated with sleep apnoea but that are not included on the Epworth Sleepiness Scale or Stop Bang Questionnaire.

## All work and no play? A combination of both…


Lessons learnt from booking Eurostar Passenger Assist London, St Pancras - on my recent trip to Holland on Eurostar from London St Pancras, I booked in advance on their free of charge passenger assistance service (passenger assist on most UK trains is normally excellent). I have a couple of health conditions including Sleep Apnoea which make me eligible for this service to assist with baggage and hearing announcements so I find it invaluable. I booked assistance because, on the previous trip travelling through Eurostar Gare Du Nord, I found the automated gate controls distressing as I was being shouted instructions which I could not hear.

Following the initial check in at Gate 5 (which allowed me to skip the initial queuing on arrival at front of the main Eurostar terminal) the gate clerk was meant to allocate me a customer assistant to guide me through security and the two border controls. Instead, I was sent to join the right-hand side queue; and only later when I was struggling to hear directions, then an assistant approached me to offer help... she assured me that if I had booked I should have been allocated an assistant and sent down the left-hand channel of Gate 5.


The Assistant that approached me at St Pancras turned out to be very helpful and sent me to the designated seating area for Passenger Assist as the terminal was extremely crowded.

She checked whether I would need help boarding the train and where I would be seated on the train so that I could be met if required on arrival in Amsterdam. As it happens the travel company rep was meeting me on the station platform, so this was not needed.

Here's a photo of me to prove I made it to the Tulip displays at Keukenhof Gardens!

## Medical Alert Cards

IS YOUR SATA MEDICAL ALERT CARD READABLE ANYMORE?
IS THE INFORMATION CORRECT? HAVE YOU LOST IT?
**WE PROVIDE REPLACEMENTS FOR MEMBERS AT NO CHARGE!**
THE CARD PROVIDES HEALTH CARE PROVIDERS AND EMERGENCY PERSONNEL WITH VITAL INFORMATION ABOUT YOU AND YOUR SLEEP APNOEA.
**YOU SHOULD CARRY IT WITH YOU - ALWAYS**.

**Just contact us by email at:-**
**info@sleep-apnoea-trust.org**

# DIAGNOSING COPD AND OSA IN PAEDIATRICS: CHALLENGES AND STRATEGIES

Our Clinical Trustee Chris Turnbull comments on the following article - 'This month we are sharing a thought-provoking article about some of the challenges in paediatric sleep and breathing disorders. The article from Medscape discusses the difficulties in diagnosing OSAS, due to its different presentation in children, and key differences in treating childhood sleep apnoea. In addition, the article highlights a new concept that is not yet fully established. Chronic obstructive pulmonary disease has often been thought of as smoking related lung damage, occurring in adults. Whilst we have known that it can originate in childhood, the article goes further in speculating that COPD is common in children, discussing the similar challenges to children with OSAS in diagnosis and management.'

**Article Key Points**
**Paediatric OSAS and COPD diagnosis is challenging due to symptom overlap with ADHD and misconceptions about age-related prevalence. Accurate diagnosis requires awareness of behavioural symptoms and appropriate testing, while treatment strategies differ from adult approaches.**

**Joe Darrah, September 22, 2025**
Among adolescents, the presentation of obstructive sleep apnoea syndrome (OSAS) mirrors many typical signs of a much more common age-related diagnosis — hyperactivity, decreased attention span and appetite, excessive fidgeting or movements, irritability, and impulsivity.

"The same symptoms of attention-deficit/hyperactivity disorder (ADHD) could also be the symptoms of a child who has OSAS," said Allen J. Dozor, MD, associate physician-in-chief at Maria Fareri Children's Hospital, Valhalla, New York. "It can be very subtle, and it's a big problem because the symptoms are often different in children than in adults."

Treatment also tends to be different as does the treatment of chronic obstructive pulmonary disease (COPD), another difficult-to-diagnose condition among paediatrics, particularly because it has not been considered as a potential malady in this patient population enough over the years, according to Dozor. "Traditionally, COPD has been an expression limited to adults who smoked," he said. "It was strictly considered an adult disease. But it's a subject that's very hot right now and it's very important. And we really need to do better with diagnosing and treating because it can have major long-term consequences."

## Differences in OSAS Diagnosis

When it comes to OSAS, which, as Dozor explained is distinct from OSA in that OSAS refers to the clinical consequences that patients experience as a result of the obstructive events that define OSA, identifying daytime-related symptoms is crucial. "OSAS is the diagnosis where not only does the patient have OSA but it's actually affecting them in some way," said Dozor. "And those two tend to get blurred."

While reliable statistics on OSAS' incidence in paediatrics are not yet available, some of the commonly confusing elements in detecting the condition in children is that it is not necessarily linked to snoring and obesity like it tends to be in adult patients and does not always produce apparent daytime sleepiness in children. "You don't have to be obese, and the difference in symptoms is that most children with OSAS are not sleepy during the day like adults classically are," said Dozor. "It tends to manifest differently." Instead, Dozor suggests that clinicians be on alert for the behavioural-type concerns, which could be how the child expresses being sleep deprived. "It's important for all those who care for children to have suspicion of OSAS first," he said. "If they don't think about it, they won't make the diagnosis."

Another notable screening component is the potential for snoring during sleep, which is not a certain indicator but does need to be part of the overall observation. "Generally speaking, if the child does not snore it's unlikely they have OSAS," said Dozor. "And if they do have snoring, they still might not have OSAS. You don't have to work up a child who doesn't snore. And if they don't seem to have any symptoms other than snoring, you don't necessarily have to immediately order a sleep study."

However, in the event that a child does snore in addition to displaying the various types of troubling daytime behaviours, Dozor emphasized that a polysomnogram should occur imminently within a health-care facility as opposed to being conducted in the home. "With paediatrics, it's essential that if you suspect OSAS that the patient receive an in-laboratory sleep study," he said. "Adults often have home studies, which is a simplistic version. But home studies in paediatrics are known to be not as good. When paediatric OSAS is suspected, a sleep study should be ordered in a lab that also has experience with interpreting studies in children by paediatric sleep specialists."

According to Chelsie Rohrscheib, PhD, a neuroscientist and head sleep researcher at Wesper Inc, a digital health technology company based in New York City, bed wetting and abnormal sleep behaviours including sleep talking, sleepwalking, sleep paralysis, and nightmares can also be indicators of childhood OSAS. Additionally, Dozor suggests that any child who has been diagnosed with ADHD should receive at least one comprehensive in-house sleep study because the presence of OSAS will increase the severity of ADHD. "Solving the OSAS problem won't necessarily cure the child of everything, but it certainly could be a contributing factor in poor school performance and hyperactivity," he said. He also encourages that all babies born with down syndrome undergo a sleep study due to the high likelihood that OSA will develop in this population, which the National Down Syndrome Society has found could occur **in more than 50% of these children.**

## COPD Diagnosis Dilemmas

Similarly, diagnosing COPD in children is inconsistent when compared with adults — or perhaps too commonly non-existent. "There's no question about it; there are children who have COPD that often goes missed," said Dozor. "Paediatric COPD as a concept and the recognition that it can happen in children is so new. We have trouble with it because many clinicians, including pulmonologists, think that it is an 'adult disease' that they don't have to worry about." Beyond smoking and second-hand smoke, the triggers for COPD, which are typically environmental or based on one's anatomy, are generally consistent among both children and adults. "We all breathe in germs, allergens, dust, and pollution," said Dozor. "And that stuff bombards the walls of the bronchial tubes. And we now have learned that there are many children who have permanent narrowing, or obstruction, of the bronchial tubes. And the only way we've discovered this was to start doing pulmonary function tests (PFTs) that measure narrowing in children."

Despite increased awareness of this anatomical irregularity, the utilization of PFTs, particularly spirometry, the most common type of PFT used today, has not yet become a routine practice, said Dozor, who also serves as professor of paediatrics at New York Medical College and president of Boston Children's Health Physicians, both in Valhalla, New York. "Pulmonary function tests are frequently not used in children, or even young adults, nearly as much as they should be," he said. "Spirometry is a simple test and it's greatly underutilized. One of my missions is to try to convince primary care providers that they should be doing spirometry in their office. The equipment is not expensive. It's reimbursable by insurance. But it's still something that paediatricians generally have not figured out how to get into their workflow, and it does require staff training." Another complication is that spirometry typically cannot be relied on for children younger than 5 years, said Dozor. Instead, other PFT options for this cohort include lung volume testing, diffusion capacity testing, oxygen saturation, and other types of specialty PFTs. "In my practice, every patient age 5 and older, unless they're neurologically unable, has spirometry before I see them," said Dozor.

Permanent narrowing of the bronchi in paediatric COPD can also be brought on by environmental exposures, especially due to effects of second-hand smoke in utero or during early childhood. The issue is separate from OSAS, which overwhelmingly causes narrowing in the upper airway, and asthma, for which the narrowing can be reversable with medication. "COPD almost exclusively refers to narrowing of the lower airway, including the very small airways down deep that you cannot hear with a stethoscope," said Dozor, who is currently involved in a national study for the condition supported by the National Institutes of Health and the American Lung Association that is screening young adults for early signs of COPD and to follow those patients over many years to learn more about risk factors. "The goal in paediatrics is to send patients to adult specialists with the best possible lung function we can give them because after age

40 everybody's lung function starts to slowly go down no matter how much you exercise or that you don't smoke," said Dozor.

## Strategies for Treating OSAS and COPD

"Unlike adults, who are often placed on continuous positive airway pressure (CPAP), the primary and most successful method of treating OSAS in children is removal of the tonsils and adenoids," said Dozor. "But children can have large tonsils and adenoids that they may not be bothering them at all and might not be OSAS," he said. "Although sometimes it's appropriate to remove them because they can affect smell, weight gain, and appetite, I believe strongly that there are many false-positives to just observing that they look big."

In some cases, children can have temporary large tonsils and/or adenoids because of frequent age-related colds and infections that become smaller as the number of infections decrease and their airway opens more. At the same time, the muscles that keep the upper airway open can be affected from compensating for large tonsils and adenoids, causing OSA. "So there's unnecessary surgery and there's patients who should have surgery that goes missing," said Dozor, who suggests that patients who have any surgeries also have follow-up polysomnograms due to potential postoperative complications. "Many times today, surgeons will only shave the adenoids because complications are less likely with conservative treatment," he said.

Other treatment options include the correcting of oral cavity defects through surgery and orthodontics, such as adenotonsillectomy or maxillary expansion, said Rohrscheib. "Children are less likely to tolerate CPAP; however, CPAP and other strategies, such as weight loss, may still be used as a second-line treatment," she said.

For COPD, treatment focuses on supporting overall health, growth, and addressing any underlying cause of disease, such as scarring from a previous infection, premature birth, or genetic disorders that include cystic fibrosis (CF), said Rohrscheib. "Treatments often include inhaled medications, but these don't always work as well as in adults. Children are also typically placed on protocols that reduce risk of infections, help to clear mucus from the lungs, and are placed on high-nutrient diets to help with normal growth."

More novel treatments for OSAS include orthodontic rapid palatal expansion, myofunctional therapy, and hypoglossal nerve stimulation in select populations, said Rohrscheib. "And for COPD, especially those with CF, there are various molecular and gene-editing therapies, including utilization of technologies such as CRISPR (clustered regularly interspaced short palindromic repeats). Additionally, new antibiotic medications based on bacteriophage therapy are being explored."

*Rohrscheib reported being on staff at Wesper Inc., which offers devices used for testing sleep apnoea in adults. Dozor reported no relevant financial disclosures.*


*Cite this: Diagnosing COPD and OSA in Paediatrics: Challenges and Strategies – Medscape – September 22, 2025.*

**Sleep Apnoea Trust members – have your contact details changed?**

If you've changed any of your membership details (address, telephone or mobile number, or e-mail address), then please contact us on **info@sleep-apnoea-trust.org** so we can maintain our best level of service to you.

# VICKI MAYLAN – RAISING AWARENESS OF OSA AMONG GPS

## Lesser-known symptoms of sleep apnoea

I've never had a good relationship with sleep. From an early age I found that with any kind of life anxiety, my sleep would be the first thing to suffer. After having children, this became worse, because you're always listening out for them. I was diagnosed with fibromyalgia in my early 40's and my sleep was affected yet again. However, it was mostly manageable, and I learned to live with being a light sleeper, waking up a lot and being constantly tired. I had an oophorectomy (removal of one or both ovaries) in 2008, which plunged me into an instant menopause, and this, again, affected my sleep.

In 2022 I started to experience severe nocturia, getting up to pee 6 or 7 times per night and I once again visited my GP. Then followed 3 years of being treated for bladder problems I actually didn't have. I was prescribed several different types of medication, none of which helped and most of which had horrible side effects. In February 2023 I was referred to urology at the local hospital, but I had a very long wait for an appointment, during which time I continued to take bladder medication and had to tolerate the side effects.

When I was finally seen by a Urologist, he recommended various urinalysis tests, which I agreed to undertake. Some of the tests were quite invasive, but I felt that if they got to the root of the problem, it would be worth it. They didn't. All the tests were normal! Eventually I was 'discussed' in a Urology Multidisciplinary Team Meeting; the outcome changed my life. Someone in that meeting – and I really wish I knew who, knew about the correlation between fibromyalgia, nocturia and sleep apnoea. The Bladder Specialist Nurse rang me to tell me this and that I was being referred for a sleep test. I waited several months for the test but eventually received an appointment for the Sleep Clinic at my local hospital. I brought the sleep test equipment home and dressed myself in it that very night – there were a lot of wires, straps and accessories to manage! Fortunately, I managed to get some sleep, despite the invasive equipment. I was told that there would be quite a long wait for the results, as the clinic was short staffed and they were trying to recruit more Sleep Physiologists. More waiting for me!

As a Christmas present, the Urology Specialist Nurse told me I'd been diagnosed with severe OSA (69 apnoeas per hour). I was keen to start treatment before major foot surgery in January 2025. As it's considered dangerous to carry out surgery in a patient with untreated sleep apnoea, this was possible and I met the Physiologist, who introduced me to my new bed partner – Mr CPAP! I was given a full-face mask to begin with and information on how to use the machine, but not much else. I absolutely hated the full-face mask because I have an old scar on the bridge of my nose, which it irritated very badly and the straps made my headaches worse. I tried nose pads, mask liners and determination, but to no avail. After doing some research, I asked to try a nasal pillow mask, but unfortunately this made the inside of my nostrils very sore. I then requested to try a nasal cushion mask (which fits just under your nose) and what an amazing difference that made – I'm still using it. The effect of using CPAP on my nocturia was pretty miraculous. After just a few days of using it, I had gone from getting up 6 or 7 times a night to only a couple of times and after using the nasal mask for a while, that decreased to some nights NEVER getting up to pee. I can't tell you the difference that made to my life; when I told my GP, he was amazed.

## Educating the GP

This leads me on to the why I'm passionate about raising awareness of sleep apnoea amongst GPs. Most GPs will only think of sleep apnoea when presented with the traditional symptoms i.e. sleepiness, snoring and weight issues. Unfortunately, with female patients, it's all too easy to blame the menopause for symptoms such as fatigue and nocturia. Likewise, for Fibromyalgia patients, it's too easy to blame Fibro for everything! I understand that GPs need to know a little about many different conditions, but if they were made more aware of the more unusual symptoms of sleep apnoea, it could save our precious NHS a lot of money in the future.


**Sex differences in sleep-disordered breathing: how do they influence diagnostics and treatment recommendations?**

*Chair(s):* Manuel Sanchez De La Torre, Athanasia Pataka
*Presentation speaker(s):* Vicki Maylan, Sophia E. Schiza, Maria Rosaria Bonsignore, Jean-Louis Pépin
Session type: Mini symposium

I wasn't a typical sleep apnoea candidate, and I was treated for 3 years for a bladder problem I didn't have. I can't help thinking that if I had been referred, assessed, diagnosed and treated earlier, I wouldn't have ended up with weight gain, having to be medicated for high blood pressure, and now having a slightly dilated aorta. As a result, I made a video for the European Lung Foundation to use at the European Respiratory Society conference last year on the subject of 'Sex differences in sleep-disordered breathing: how do they influence diagnostics and treatment recommendations' which is now available here -

Sex differences in sleep-disordered breathing: how do they influence diagnostics and treatment recommendations? - Amsterdam 2025 - ERS Respiratory Channel

It's being used for training sessions for the ERS and for pharmacists in Greece. I'm delighted that this is being taken seriously, and professionals are finding my video helpful.

Having the diagnosis made me reconsider my husband Neil's symptoms; he snored heavily and stopped breathing when he was asleep. He was being investigated for a different respiratory issue, but I mentioned this to his consultant and as a result, he was referred to the Sleep Clinic and tested. Guess what… He had severe OSA and now we have his and hers CPAP machines!

## My recommendation

I would urge anyone who thinks that they, or a friend or relative, may have any of the many symptoms of sleep apnoea to go to their GP for a discussion. I believe we must take joint responsibility for own health, so before you visit your GP, it would be helpful to access all the relevant information on the SATA website – forewarned is forearmed! You may have to stand firm when requesting a sleep assessment and present your research to your GP. If your GP is still unreceptive, or waiting lists are long, you could organise your own self-financed sleep test. Untreated sleep apnoea can cause many health issues, so it is vital to get a diagnosis as soon as possible.

*Vicki and husband Neil*

# TAIL END – WHERE ARE WE NOW

Let me introduce you to a conundrum, if I may. Google defines a "conundrum" as being "a confusing or difficult problem that is hard to solve, or an intricate riddle that often relies on a pun or play on words". Our conundrum is – "the Sleep Apnoea Trust – The Independent Patient Voice". Whose voice precisely are we speaking in? There are currently significant differences in the quality of NHS service across the UK, based largely on the fact that each ICB (Integrated Care Board) sets up its own to meet its own needs, within the overall guidelines provided by NICE on the services that should be provided by law, the budgets they can extract from the Health Ministry, and their ability to attract the medical staff they need to achieve an appropriate service level.

Do we as the Trust represent happy patients, in areas where sleep clinics provide excellent and timely services, with easy contact for CPAP and supplies? Or unhappy patients, in areas where it might take months to get a diagnosis, followed by a delay of more months before a CPAP becomes available, during which the likelihood of more severe illness or death from any present co-morbidities becomes more likely.

SATA strives to represent both groups of patients – giving credit to the best areas as providing "best practice" service, and calling attention to those areas where service performance is far below an acceptable standard, and suggesting, as patients, how that service might well be best improved. There are areas we need to take action when services do not deliver the care that patients need. For example, in Scotland the wait for sleep apnoea treatment can be measured in years (https://www.sundaypost.com/fp/sleep-apnoea-deaths). In response, we have contacted all MSPs (Members of the Scottish Parliament) to express our concerns and advocate for change.

Our members are our focus – the Trust will do the best we can to advocate on your behalf by: raising awareness of Sleep Apnoea within the GP community to help them to recognise Sleep Apnoea more rapidly and accurately; helping Sleep Clinics to improve communications with their patients; promoting more timely diagnosis and treatment; and lobbying government to recognise that Sleep Apnoea, along with obesity and Type 2 diabetes, is one of the fastest-growing areas of poor health, but one that can save health service costs by timely treatment.

What are your thoughts? Send an e-mail to info@sleep-apnoea-trust.org to have your say – conundrums CAN be resolved!

**INFORMATION**

**Issue 82 of SLEEP MATTERS Summer 2026 is published by the Sleep Apnoea Trust – The Independent Patient 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.*



*Sleep Apnoea Trust, PO Box 60, Chinnor, Oxon OX39 4XE*
*Registered Charity no. 1186235*
*Email: info@sleep-apnoea-trust.org*
*Web: www.sleep-apnoea-trust.org*

**Affiliated Groups:**
*East Kent Sleep Apnoea Support Group (Ashford) 01303 269830*