ARTP SLEEP

S-News

Dreaming of a better night's sleep

Volume 3, Issue 2 Autumn 2012

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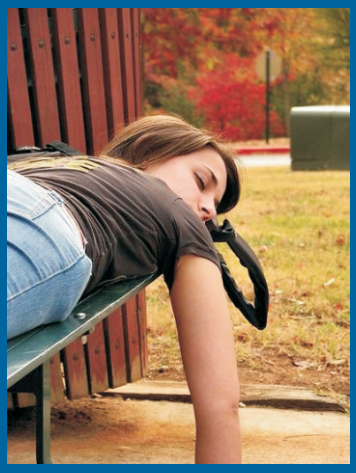


"If I can open others eyes to Narcolepsy and its symptoms, maybe someone will lead a better life."

ARTP SLEEP is a subsidiary of the Association for Respiratory Technology and Physiology

ARTP Sleep Foundation Group

ARTP Sleep Apnoea Consortium

Welcome

Welcome to the latest edition of S-news. I hope everyone has had an enjoyable summer and found some inspiration from the amazing achievements of our nation's athletes. Certainly, my local Parkrun seems to be busier than ever on a Saturday morning. In this edition we have the spotlight on Narcolepsy. We also have highlights from the recent ERS conference in Vienna, and update from the BLF OSA campaign and a travel supplement for OSA written by the fantastic folk at the Sleep Apnoea Trust. Enjoy!

Sleep People

Unfortunately no-one has come forward to be our sleep person for this edition. If you would like to fill this slot in the next edition please email your details to :

s-news@artp.org.uk

AHCS Academy for Healthcare Science

ACADEMY FOR HEALTHCARE SCIENCE HOLDS FORMAL LAUNCH AT HOUSE OF LORDS

The Academy for Healthcare Science, a new organisation working for the benefit of healthcare scientists across the four countries of the United Kingdom, held its formal launch yesterday (5th September) at a lunchtime reception in the House of Lords.

The event was kindly hosted by the Earl of Lindsay, who introduced proceedings, followed by speakers Sir Duncan Nichol CBE, former Chief Executive of the NHS in England and now the Academy's Chairman, Professor Sue Hill OBE, Chief Scientific Officer for England, Dr. Iain Chambers, the Chairman of the Association of Clinical Scientists, and Derek Bishop, President of the Institute of Biomedical Science.

The Academy was first initiated in April 2011, and has been operating in shadow form since then, whilst developing products and services primarily in the areas of equivalence, voluntary registration and representation of the sector's united voice. The House of Lords event marked the official launch of the Academy as a whole, although similar gatherings have been held in Edinburgh, Belfast and shortly Cardiff in recognition of the organisation's four-country remit.

The oversubscribed event was attended by a host of senior figures across healthcare, in particular the professional bodies making up healthcare science, all of whom are now members in some capacity of the Academy's central Council.

Sir Duncan Nichol, Chairman, said:

"Today's event was a wonderful opportunity to celebrate the formal launch of the Academy for Healthcare Science. I am very proud and excited to be at its helm as we move from shadow to fully-operational guise, and the Academy takes its place as a central player in the healthcare science landscape.

"We look forward to rolling out our products and services, which will prove essential to scientists working in UK healthcare, and to strengthening the representative voice of this crucial part of the NHS.

"I am very grateful to all the healthcare science professional bodies, as well as our colleagues at the Department of Health, and the myriad other groups and individuals who have worked tirelessly to support us through our formative days. With that commitment still behind us, I look forward to this new organisation going from strength to strength."

Dates for your Diary

ARTP NIV Course 26-27th November 2012, Novotel Birmingham

London Sleep Disorders Congress 3-5th December 2012, Institute of Physics, London

British Thoracic Society Winter Meeting 5-7th December 2012, QEII Conference Centre, Westminster, London

International Paediatric Sleep Association Congress 5-7th December 2012, Manchester Central Convention Complex

ARTP Annual Conference 7-9th February 2013, Barceló Hinckley Island Hotel, Hinckley

BSS 25th Anniversary Scientific Meeting 17-19th October 2013 John McIntyre Conference Centre, Edinburgh

Spotlight on Narcolepsy

The French physician Jean-Baptiste-Édouard Gélineau created the term *narcolepsie* by combining the Greek narkē (νάρκη) which means numbness or stupor with lepsis (λήψιζ) which means attack or seizure. Narcolepsy is a fairly rare, chronic, neurological sleep disorder which is estimated to affect at least 20-25,000 people in the UK, although it is believed that up to 85% of cases are undiagnosed. It affects males and females equally and most often begins between the ages of 15 and 30.

It can be said of narcolepsy that the brain doesn't progress through the normal stages of wakefulness, dozing and deep sleep, but rather goes directly in and out of REM

During normal sleep the first episode of REM is not seen until about 90 minutes after sleep onset. However, in narcolepsy REM sleep is seen within 5 minutes of sleep onset. There is a disruption of the normal sleep architecture with the order and length of REM and NREM being disturbed, sleep fragmentation and frequent arousals. Some of the normal aspects of REM sleep such as loss of muscle control, sleep paralysis and vivid dreams can occur during wakefulness. Thus patients with narcolepsy may also suffer from sleep paralysis (a temporary inability to talk or move when walking), hypnagogic /hypnopompic hallucinations (vivid and often frightening dream-like experiences when falling asleep or wakening), and automatic behaviours. 60-90% of patients with narcolepsy also have cataplexy, a temporary muscle weakness in response to emotional stimuli such as laughter or fright. Cataplexy ranges from slight, slackening of facial muscles, knee buckling to total collapse. There is often slurring of speech and blurring of vision, whilst hearing remains normal. Cataplexy may be said to be an intrusion of REM atonia into wakefulness. Thus a simple explanation of narcolepsy is that the brain doesn't go through the normal stages of wakefulness, dozing and deep sleep but instead goes directly in and out of REM sleep.

The disturbed sleep results in excessive daytime sleepiness, leading patients to nap often during the day. These naps may come with little warning and there may be an irresistible urge to sleep. Initially the naps may be refreshing but after a few hours the sleepiness returns.

The cause of narcolepsy is unclear. There is a genetic component and part of the diagnostic work-up is to look at HLA (Human Leucocyte Antigen) -typing. The HLA-DQB1*06:02 allele is strongly associated with narcolepsy, but, by itself, is not causative. Greater than 99 percent of affected Caucasians with cataplexy have the HLA-DQB1*06:02 allele. (ARUPS lab test directory). A possible cause of narcolepsy is the abnormal functioning of certain neurotransmitters, such as a shortage of the sleep-regulating hormone hypocreptin (Hungs & Mignot). Some research suggests this may be due to an auto-immune process, whereby antibodies attack the lateral part of the hypothalamus which is the area of the brain which produces hypocretin. However, other research has shown patients with narcolepsy with near-normal levels of hypocreptin. Initial triggers may include infections such as measles or mumps. Since many sufferers first exhibit signs of narcolepsy in adolescence, the change in hormones at this time are also thought to act as a trigger. Other more recent associations include the pandemrix influenza immunization (WHO).

Narcolepsy is usually diagnosed by a combination of polysomnography (PSG), multiple sleep latency test (MSLT) and Epworth Sleepiness Scale (ESS). During a PSG patients with narcolepsy will have a very short sleep latency and will quickly go into REM sleep. They will have frequent arousals. The PSG can also help eliminate other sleep disorders from the diagnosis. Similarly, during the MSLT

patients with narcolepsy will have a short sleep onset latency and will enter REM sleep early, often at sleep onset. All patients with untreated narcolepsy exhibit excessive daytime sleepiness and thus score highly on the ESS.

Although medications can help to control the symptoms of narcolepsy the condition itself cannot be cured. Since it is thought that narcolepsy may be due to an auto-immune response then the possibility of immunosupression has been investigated. However, by the time someone exhibits the symptoms of narcolepsy it is probably too late. The possibility of hypocretin replacement is still being investigated but is currently a way off reality in humans. The "gold standard" treatment for the associated daytime sleepiness is Modafinil. However, it may have a number of side effects and in 2007 the FDA issued a warning about severe skin reactions to Modafinil. The non-specific pyschostimulant Dexamphetamine, may be used as an adjunct to Modafinil. Other stimulants include methylphenidate (Ritalin), mazindol and caffeine. Cataplexy is often treated with tricyclic antidepressants such as venlafaxine, clomipramine and SSRIs such as fluoxetine. These have the action of inhibiting REM sleep. Sodium oxybate (Xyrem) is also another treatment available for treating both cataplexy and excessive daytime sleepiness. Lifestyle changes may also be helpful in managing symptoms.

"You're not healthy unless your sleep is healthy" -Dr William Dement

Take Action on OSA

Can you help us to draw attention to **obstructive sleep apnoea** (OSA)?

At the British Lung Foundation we are working hard to **raise awareness of OSA among the public and GPs**. The next important step is to make sure that policy-makers know all about it too.

Please **email your local representative** and ask others to do the same.

OSA can be a dangerous condition, and if untreated can leave people extremely sleepy, which can have a big impact on the affected people's social and professional lives. OSA is also associated with serious conditions such as heart disease, diabetes and stroke.

OSA is however simple to treat, so we believe that no one with OSA should have to suffer. Our OSA charter calls on governments across the UK to take action, so that people with OSA and their families get the support and treatment they deserve.

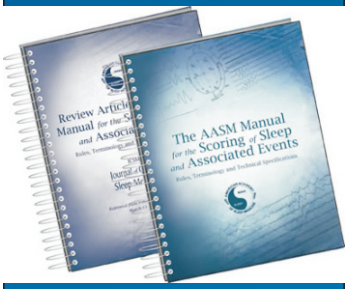
To make sure that OSA is on the political agenda, **we've made it easy to contact your local representative (whether it is a MP, MSP, AM or MLA)** to tell them about the condition and what they can do to help. Just go to www.blf.org.uk/osa-action

The more people who write to their local representatives, the better: please ask your friends, family and people you know who have been affected by OSA to help. You could also tell people about it on Twitter, Facebook and other social media sites.

Remember, these are the ways you can help:

- Write to your local representative by visiting www.blf.org.uk/osa-action
- Ask others to do the same by forwarding this email and sharing link on social media
- Take the Epworth sleepiness test
- Read the OSA Charter
- Download our button and include it on your website and email footers.

Thank you for your support in raising awareness of OSA.



New AASM Scoring Manual Ver 2.0 is now available

Only 1% of patients fitting the criteria for bariatric surgery were able to have it due to lack of funding.

ERS Highlights

Vienna September 2012

Link between sleep apnoea and cancer mortality?
https://www.ersnetsecure.org/public/prg_congres.abstract?ww_i_presentation=57345
Some previous studies have suggested a strong link between sleep apnoea and obesity hypoventilation and the risk of dying from cancer. This was particularly seen in those that spend more than 14% or the night with an oxygen saturation of less than 90%. However, the study presented by Campos-Rodríguez *et al.* found that there although there was a significantly increased incidence in cancer in patients who also have sleep apnoea, when the results were adjusted for age, sex, BMI and other confounders there was no association.
Another study from the same institution found that mimicking the intermittent hypoxia seen in sleep apnoea significantly increased lung metastases in mice.
https://www.ersnetsecure.org/public/prg_congres.abstract?ww_i_presentation=57346

Polygraphy or polysomnography for diagnosing OSA?
https://www.ersnetsecure.org/public/prg_congres.abstract?ww_i_presentation=57340
Escourrou and Jilwan presented on behalf of the European Sleep Apnoea Database study group the results from data from 8228 patients. AHI and ODI were significantly higher when the results of polysomnography were compared to those obtained by polygraphy. The authors concluded that this was most likely due to the scoring of hypopnoeas by arousal in polysomnography.

Severity of OSA independently increase glycated haemoglobin in adults without known diabetes
https://www.ersnetsecure.org/public/prg_congres.abstract?ww_i_presentation=57343
Priou *et al.* presented their findings which concluded that among adults without known diabetes, increasing OSA severity is independently associated with impaired glucose metabolism that may expose to higher risks of diabetes and cardiovascular disease.

CPAP therapy reduces healthcare costs
https://www.ersnetsecure.org/public/prg_congres.abstract?ww_i_presentation=57349
A Hungarian study showed that hospital admissions, treatment days and hospital care costs were 22%, 25% and 34%, respectively, less in the 3 year period following initiation of CPAP therapy, compared to the 3 year period prior to CPAP treatment in patients with OSA.

Sleep in the News

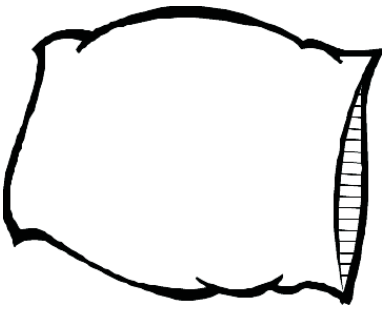
Scientists warn that sleep disruption may be one of the earliest signs of Alzheimer's Disease.
http://www.bbc.co.uk/news/health-19487092
A study published in Science Translational Medicine showed that in mice, there was a significant disruption in sleep-wake cycles at the first signs of beta amyloid brain plaques forming. Author Dr David Holtzman, from Washington University said: “If sleep abnormalities begin this early in the course of human Alzheimer's disease, those changes could provide us with an easily detectable sign of pathology. As we start to treat Alzheimer's patients before the onset of dementia, the presence or absence of sleep problems may be a rapid indicator of whether the new treatments are succeeding.”

In a related story it has been suggested that the sleep hormone Melatonin may be used to treat Alzheimer's Disease.
http://www.bbc.co.uk/news/uk-scotland-glasgow-west-12879959

Obesity in Wales is only just behind that in the USA.
http://www.bbc.co.uk/news/uk-wales-19366302
Yet despite this, there is only one NHS funded obesity clinic in Wales. Only 50 out of 5000 who fit the criteria for bariatric surgery were able to have it due to lack of funding.

Pillow Talk

Manufacturer's news, new equipment and a bit of gossip!



At ERS in Vienna ResMed launched their AutoSet CS-A for complex CPAP patients and those suffering from central and mixed apnoeas. The world renowned PaceWave algorithm is now offers an AutoASV mode which is able to personalize therapy by continuously learning and rapidly responding to the patient's changing needs. so that stabilizing breathing has never been easier.

Internally, ResMed have announced that Donna Mayers (South West) and Elly Baxter (North Thames & East England) have joined as Account Managers, completing the team across the country. Laura Jennings has now moved across to the Business Development Team for Respiratory Care whilst Tamara Lewin has recently moved across as RealSleep Service Development Manager.

SERVE-HF, the largest study to investigate if treatment of predominant central sleep apnea (CSA) improves survival and outcomes of patients with stable heart failure, has enrolled its 1,100th participant. The study, sponsored by ResMed Ltd., is the largest of its kind. This milestone brings the SERVE-HF study, which began in 2008, one step closer to its target of 1,250 participants. The primary goal of the study is to determine whether managing CSR-CSA with ResMed's proprietary adaptive servo-ventilation technology (found in its AutoSet CS™) increases survival rates and decreases the burden of hospitalizations in this patient population. Adaptive servo-ventilation is an intelligent method of non-invasive ventilation that continuously monitors and stabilizes the breathing patterns of individuals with SDB throughout the night. "We've designed the study not only to assess survival rates but also to see if adaptive servo-ventilation improves quality of life, sleep, and physiologic changes associated with heart failure, such as enlarged hearts," stated Prof. Cowie, Royal Brompton Hospital in London.

Fisher & Paykel expand its nasal mask offering with the introduction of the F&P Eson™ nasal mask for use in the treatment of OSA. "Every feature on the Eson has been designed to address the common complexities homecare providers and patients face when fitting, wearing and maintaining masks" commented Michael Daniell, Fisher & Paykel Healthcare's Chief Executive Officer. "Our design team's focus has been on simplicity and performance; the things that matter most to those that use the mask." The Eson's three simple components: the RollFit™ Seal, ErgoFit Headgear and Easy Frame, work in harmony to deliver the comfort, seal and easy use for which Fisher & Paykel Healthcare masks are renowned. As the name suggests, the RollFit seal rolls back and forth on the bridge of the nose. In doing so, RollFit minimises pressure on the nasal bridge without the need for complicated T-piece adjustments. The Eson is currently available in New Zealand, Australia and Canada and will soon be introduced to Europe. The Eson nasal mask complements the F&P Pilairo nasal pillows mask which has recently been introduced into New Zealand, Australia, Canada and the USA with a very positive reception from customers and patients. In addition, the company's Lady Zest™ Q nasal mask, which is designed specifically for women, is now available . "We have enjoyed a very encouraging initial response to these new premium masks and we expect that they will contribute significantly to our OSA product group revenue growth" concluded Mr Daniell.

Philips Respironics has announced the release of the new System One 60 series with smarter technology, advanced intelligence and comfort for exceptional care and easier patient management.

- Auto-Trial and CPAP-Check modes provide the patient with efficient therapy while reducing care intervention
- Opti-Start feature in the REMstar Auto is intended to improve patient comfort and reduce the likelihood of residual events at the beginning of therapy.
- Enhanced design will make the device look less like a medical device and better fit in the patient's bedroom.

Man should forget his anger before he lies down to sleep.

Mahatma Gandhi

A well-spent day brings happy sleep.

Leonardo da Vinci

The amount of sleep required by the average person is five minutes more.

Wilson Mizener

It is a common experience that a problem difficult at night is resolved in the morning after the committee of sleep has worked on it.

John Steinbeck

Obstructive Sleep Apnoea and Travel Supplement

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Preparing for your trip – what might you need?

The amount of preparation you need to make for your trip and any additional equipment you might require will vary depending on whether you are:

1. Travelling in the UK or abroad
2. Staying with friends or in a hotel
3. Camping/caravanning
4. Travelling by car, train, by air or by ship (or on foot)
5. Able to access a dependable power source

Initial questions to ask include:

1. Is suitable power available to run my CPAP machine in the place where I am going?
2. Is there any additional equipment I might need?
3. Can I keep my machine with me when I travel?
4. Will there be any problems with Customs or Security?
5. Will there be any problems at check in?
6. Can I use my machine whilst in transit (e.g. on an aeroplane)?
7. Do I need special insurance cover for myself and for my CPAP equipment?
8. Are there any health problems that I may encounter?

Getting there

1. By car. This should be no problem as you can carry all you need quite easily.
2. By train or bus. Your machine and any additional equipment will add to the weight and bulk of your luggage but apart from that there should be no problems (You probably won't be able to use your machine whilst you are actually travelling).
3. By sea. You should contact the shipping company to ask about use of CPAP on the ship especially if you are going on a cruise. (Is a suitable power source available? What type of plug is needed?).
4. By air (see attached chart):

- Take the machine with you on the aircraft because hold baggage can go missing!
- Get a letter from your clinic to cover you with the check-in staff, security and customs.
- The CPAP machine and any additional equipment will add to the weight and volume of your hand baggage.
- Many airlines restrict the number of items of hand baggage that you can take on board. You can avoid this by putting your machine in your normal hand-baggage (beware of weight considerations). But if you need to take it separately, you may need to contact the airline to make special arrangements.
- In theory you can use a CPAP machine on an aircraft. However, the willingness of airlines to allow this seems to vary widely. Contact the airline you are flying with well in advance to see if you can arrange this. Don't take no for an answer as the first instinctive reaction of the airline may be to refuse your request. Try contacting the technical department of the airline if the “front of house” people are not much help – at least you may get some ammunition to help you in your fight! Some airlines have already 'passed' certain machines for use, for example *ResMed* machines on *Quantas*. They require a simple medical form to be completed in advance – so leave plenty of time.
- Some people with OSA can use a dental device (also known as an oral appliance, or mandibular advancement device) for short periods instead of CPAP. Such an appliance can be useful on aircraft. Your sleep clinic, or failing that a good dentist, can advise. You would need to get this organized and have a trial run as long before your trip as possible as some people find it difficult to use these devices.

Some things that you may find useful anywhere.

1. Extension lead. There may be no plug socket within reach of the bed.
2. Surge protector. Electrical surges can occur anywhere and can damage your machine. (The routine use of a surge protector is recommended even at home).
3. Mat for the machine. Bedside furniture is not always well made and can amplify the noise of the machine if it is not padded. (NB. Some machines get warm in use – check to ensure that any mat you use is not going to be affected by heat).
4. Travel adapter(s) for the country(s) you are going to so that you can plug into the mains.
5. Padded bag for the machine. (You may end up travelling over rough roads – which can reduce a CPAP machine to a box full of spare parts if it is not protected).
6. Spare fuses (and a screwdriver so that you can open a plug to change a fuse!).
7. Insulating (electrical) tape. (Great for dealing with holes in air hoses – which can (and do) occur at the least opportune moments).

Where are you staying?

With friends/family or in a hotel or boarding house

These locations are considered together as the problems can be surprisingly similar (in the UK at least!). Consider the items in the list above – especially the first two! If in doubt check that power supplies are no problem before you travel.

Camping/Caravanning
Camp sites may have mains power outlets available – check before you go. If you are using a tent and there is no nearby power source you may need a battery. Caravans often have a source of 12 volt power (see below) – either via the car battery or through a separate battery (and motor caravans have ready access to the car battery). If you are using the battery of your car to power external equipment, take care not to run the battery down so far that you cannot start the engine!

Motor boats and sailing yachts
Marinas usually have sources of mains power available but check before you go. Motor boats and yachts usually have reasonable power supplies available to run items of electrical equipment. If you are going sailing on a friend's boat check availability of power before you go. If buying a boat youshould check this out as part of the pre-purchase examination of the craft.

Cruise ships
Cruises are usually planned well in advance. As part of your planning, contact the cruise line to ensure that you can access a power source suitable for your machine in the cabin on the ship.

Power supplies
(If in doubt, always seek advice from the manufacturer of your machine, or from the technical staff at your clinic before you go).
The main thing to check before you travel with your CPAP is the type of power supply available to you where you are going and in particular the voltage (in some parts of the world the power is 110 volts not 220 - 240 - e.g. parts of the USA). Then check what voltage(s) your machine will run off. Some will only take 220 – 240 volts, others can work off other voltages (e.g. 110 volts or 12 volts). (NB They may need to be reset before they can work off other voltages – usually by a simple switch. Make sure your machine is set correctly before you try to run it in a new location). If you have a 220 - 240 volt only machine and you are going somewhere where the voltage is different then you may need to borrow a machine which will work off whatever power source is available (some clinics have loan machines) or else ensure that you can supply your machine with the voltage it needs. You can get small transformers that will allow you to run (for example) a 220 - 240 volt machine off 110 volts but check that the transformer will take the power demand you are making.

Mains power
The power supply in the more populated areas of developed countries should be reliable. In less-developed parts of the world (and in more remote areas of the developed world), power sources may be unreliable or even nonexistent. There are a few things that it is worth doing before you go:
- Try and get information about the reliability of the power supply in the country or area where you are going.
- In many parts of the world the advertised mains voltage is more nominal than real and you may need to look into an alternative power source such as a battery.
- Hotels may advertise that they have their own generator – but does it run all night? What if it breaks down?

Off the beaten track
You may wish really to get away from it all and find yourself away from a source of mains electricity.
Equally you may find that the power supply in some countries is unreliable. This does not mean that you have to do without your CPAP machine and there are several ways of producing the power that you need. The suitability of each will depend on how you plan to get where you are going. Heavy equipment and a walking holiday are probably not compatible! For short periods a dental device
(oral appliance or mandibular advancement device) may be suitable for short periods instead of CPAP (see above).

Generators.
Even the quietest makes some noise and may not be suitable for use where others can be disturbed (e.g. on a camp site). Small generators also have small fuel tanks - not enough for a night's run.

Batteries
Lead-acid batteries (the sort of battery that is found in all cars) are suitable to run a CPAP machine when you are away from the mains supply. There are other types of re-chargeable battery and several (particularly Lithium batteries) are more compact than the lead-acid type and often much lighter BUT they are very (very) expensive. Modern battery packs are now available to rent from a number of suppliers, so this can be a more cost-effective solution for short duration trips. You need to get a normal 12 volt battery of at least 30 Amp Hours (Ah) capacity. For short periods of time (two or three weeks) an ordinary car battery is fine. For longer periods get a deep drain (leisure) battery. Some batteries will take 10 hours to recharge! If you need such a battery when you are abroad you will need to get it when you arrive (and should budget accordingly). Airlines will not carry lead acid batteries – and even if they did, such batteries are so heavy that they would use up your baggage allowance.

Charging your battery
There are several options:
1. *Arrange for regular charging with a local garage.*
   Could be expensive and it does tie you to the garage – you have to get your battery back before the garage closes!
2. *Take a mains charger with you.*
   Some very light and compact electronic chargers are available which will not dent your baggage allowance.

3. Alternative energy sources
You can get highly portable solar panels but they are very expensive and really only worthwhile if you are going to use them regularly (or to allow you to go on that 'once in a lifetime' holiday). Some additional equipment is needed including a device called a *charge controller* (small and light) which prevents overcharging which can damage a battery. (Normal battery chargers have these built in). Wind generators are really only a possible power source on a boat.

Inverters
If your machine cannot be connected directly to a 12 volt power supply, do not despair! You can still use a battery to run it by use of a device called an inverter, which converts the 12 volt direct current (DC) output of your battery to the 220 - 240 volt alternating current (AC) that your CPAP machine requires. Check that the inverter you get is suitable for your machine. The cheap, basic inverters that can be bought at car parts suppliers, camping shops etc. may not be suitable for your machine or your humidifier. Check with the manufacturer of your machine as to what type of inverter is suitable before buying.

Other matters

Airport Security and Customs
Most airport and customs officials are helpful and a covering letter from your clinic will help you overcome any problems that you may encounter from officialdom. You may occasionally get stopped and asked to show your machine to airport security but as more and more people are traveling with these machines, the more the security people recognize them when they see them on X-ray. [*Tip for the regular traveller*: Most clinic letters come on A4 paper. Take a copy reduced to A5 (half size – more convenient) and get it laminated to protect it from wear and tear. Keep it in the bag with your machine].

Health and Hygiene
If you have any particular health problems (e.g. heart disease, breathing difficulties) or are worried about the health implications of travelling with OSA, you should always check with your GP or your clinic as to any special precautions you need to take in the areas where you are going. *Hygiene*: keep your mask, hose etc. clean - your clinic should have advised you how to do this. In hot climates, especially in hot humid climates, bacteria and fungi grow well. This should not be a problem provided you maintain good hygiene standards for all your equipment but you need to take particular care if you are using a humidifier. Soap and water are fine for regular cleaning, but do dry things carefully after washing to ensure that your equipment does not deteriorate and to prevent the growth of fungi in (for example) hoses (also the water in most parts of the world is far from pure). Disinfectant wipes are useful for cleaning the equipment when you are travelling. Some disinfectants also have a detergent action, so are good for cleaning as well as disinfection, but regular use can damage plastic items such as masks and hoses. Chlorine-based disinfectants (e.g. Milton) are very effective but can also damage plastics (and are corrosive so take care how you use them). Always follow the instructions on bottles of disinfectants to ensure safe and effective use. Keep any head straps etc. scrupulously clean. Microorganisms can grow quickly on sweat-soaked straps and can cause skin problems. If you need any gel or other item to prevent pressure sores take plenty with you – especially if travelling in hot climates.

Humidifiers
If you use a humidifier your clinic should have advised you as to how to keep it clean.

Insurance
Do inform the company providing your travel insurance of the fact that you have OSA otherwise you may find that your policy is not valid. Be prepared to deal with the questions that may arise as the condition is still not well known amongst the staff of insurance companies. Once again, plan well in advance as this may take time to sort out.

Disclaimer: The editors and publishers of SLEEP MATTERS and S-NEWS cannot accept any responsibility for problems that may arise due to following the advice given, or to the failure, unsuitability or non-availability of equipment.

BLF OSA Awareness Campaign Update- September 2012

The British Lung Foundation welcomes its new Chief Executive, Penny Woods and new Director of Services and Projects, Steven Wibberley.

In this newsletter, you'll find updates about the OSA project, but first, we are asking for your help…

Over the coming months we are conducting the first UK-wide OSA patient survey of its kind. If you would be interested in taking part by handing out the survey to diagnosed patients in your sleep clinic during the Autumn, then please contact Judy Harris, BLF OSA project manager, for more information.

Now for the project's progress:

1. Promoting OSA as a strategic priority to improve services

Our Policy and Parliamentary campaign has included:

- Liaising with Meg Munn MP about her OSA campaign – Meg has highlighted the BLF's OSA Charter recommendation to include an OSA indicator in the Quality Outcomes Framework (QOF), and has cited our role in 'leading a major campaign to raise awareness of OSA, and to improve diagnosis and treatment';
- Writing an evidence submission to a joint all-party parliamentary group inquiry examining what the key priorities will be for the **cardiovascular disease outcomes strategy**;
- Working with the Department of Health (DH) and the new DH OSA working group which is making recommendations about future OSA service needs in England;

Key meetings were held on various aspects of project development, including:

- Reviewing the Welsh strategy for sleep disordered breathing;
- Sharing information and priorities with Majella Tuohy, the OSA lead for Northern; Ireland, and with Cathy Regan, the new OSA project manager with the DH;
- Reviewing the new NHS guidance for respiratory and sleep physiology.

The BLF has teamed up with St Thomas' Hospital to produce an abstract to submit for the British Thoracic Society (BTS) Winter conference 2012 – this abstract has been accepted and a poster will be presented about the findings from the BLF's online Epworth Sleepiness Scale, which has now been completed by over 26,000 people.

Mapping - we are in the process of producing a map of the known sleep services across the UK, and of also highlighting potential OSA "hotspots" – areas across the UK where there could potentially be more people at risk of OSA.

2. Raising awareness of OSA

National BLF OSA media coverage included:

- **All about you,** online health information, with BLF website address – the same week nearly 1,000 people took the BLF online Epworth.
- **Pick me up,** women's journal with a circulation of 385,000, featuring a woman with OSA. In the following week, the number of women taking the BLF online Epworth increased dramatically, and for the first time more women than men took the test in the month.

3. Finding undiagnosed people

- **Online Epworths -** the BLF online Epworth was transferred over to the new BLF website OSA pages and two additional questions were added – about how easy it was to fill in the form and what the person will do next. Of the 984 people who took the Epworth in July 2012, ***over half were women*** (following the Pick me up article mentioned above). 8% of men and 5% of women had scores indicating they were severely sleepy (over 19), with 50% of men and women scoring 11 or over, indicating a level of sleepiness warranting further investigation.

4. Planned activities for the coming months

Over the next few months we will be focusing on:

- **OSA Patient survey;**
- **OSA Health economics;**
- Launching an extended version of the BLF OSA Charter and beginning our lobbying campaigns for better awareness of OSA and improved equality of access to specified service provision, including diagnosis and treatment;
- **Awareness campaigns** - planning our first pilot campaign of events and activities in a targeted geographical area, based on findings from the mapping exercise aimed at raising awareness of OSA amongst the at risk population;

British Lung Foundation

BLF Helpline - 08458 50 50 20
Confidential advice and support for anyone affected by lung disease.
Helpline open Monday to Friday, 10am to 6pm. Calls charged at local rate.

New OSA leaflet available

Would you like to feature as next month's sleep person, or would you like to publish a short article?

Please submit all articles to s-news@artp.org.uk

- **OSA patient pack** - the first draft has been written- it includes lots of information all along the patient pathway, from recognising signs and symptoms to managing their condition, and also has handy sections to complete about their own condition, treatment and management. This will be available to sleep clinics in the New Year.

Become a member of the British Lung Foundation

If you are new to working in partnership with the BLF, we would like to encourage you to become a member. Visit the membership page of our website for more information.

Pass it on

Please forward this to any colleagues who might be interested and encourage them to join this contact list. If each of you forwards to five colleagues, this bulletin will reach nearly 1,000 people.

Thank you

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