



DEALING WITH CPAP CLAUSTROPHOBIA & PANIC ATTACKS IMPROVES CPAP COMPLIANCE

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

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

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

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

Therefore, SATA has started to look at other reasons for non-adherence and to address issues we have not dealt with before. Poor mask tolerance is frequently the perceived problem by patients struggling to settle with CPAP. Sleep Clinics should always remember that, according to the National Institute for Care and Health Excellence (NICE) Technology Appraisal (TA) 139, CPAP therapy be legally-mandated and free-to-patients, since the cost of non-treatment of sleep apnoea is almost twice the cost of treatment (Guest 2008). A theoretical saving by restricting mask choice for a patient can lead to non-adherence and will cost the Hospital Trust and Clinical Commissioning Group many thousands of pounds more in dealing with the other illnesses that may develop as a result of untreated sleep apnoea. It is an economic no-brainer!

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

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

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

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

This was enough to prompt SATA to do some research and come up with some ideas on how to deal with this threat to CPAP therapy adherence.

THINGS TO REMEMBER IF YOU HAVE CPAP CLAUSTROPHOBIA

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

- ***CPAP masks will not suffocate you***

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

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

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

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

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

- ***Wear the CPAP mask while awake.***

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

- ***Develop a Positive attitude to CPAP.***

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

- ***Be patient with CPAP therapy.***

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

- ***Mask type is vital to help your CPAP claustrophobia.***

Research studies show that a poor fitting mask is the main cause for CPAP claustrophobia. Getting the best possible mask fit is vital in overcoming mask claustrophobia. All good sleep clinics will offer a good

range of mask types and sizes, and the specialist sleep team have expertise in helping find the right one for you, depending upon the shape of your face and whether you breathe through your nose or mouth. Patients may prefer a nasal mask, that just covers the nose, or nasal pillows that sit below the nose, because they know they can always breathe by opening their mouth. But this only treats the sleep apnoea if they can prevent mouth breathing when they are asleep. For some this comes naturally and for others an adjustable soft chin strap to hold the mouth closed can assist.

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

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

- ***CPAP Ramp Facility***

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

- ***EPR***

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

CPAP MASK PANIC ATTACK

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

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

- ***Slow and very gradual conditioning process***

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

1. For panic attacks, perhaps the most usefully suggestion is for the patient to increase the time spent with their mask on a very gradual basis. To be precise, wearing the mask for a few minutes during the day, until the feeling of panic starts and then remove it. This will gradually condition the patient to get used to the mask. Then try again later in the day.
2. Start to increase the amount of time the mask is worn, say up to an hour. Avoiding panic attacks is a step by step and sometimes a very slow progress and cannot be rushed.
3. The next stage is to turn the CPAP on to experience how the body reacts to the feeling of the pressure. This will allow the patient and their brain to develop an understanding of how the machine will work and feel when in use.
4. The next step is to plan a sleep during the day for one hour with the CPAP machine switched on as getting used to the pressure for a longer period can be as challenging as wearing the mask.

5. The next step is to schedule a 3 to 4 hour night sleep with the CPAP therapy and see how it goes.
6. Gradually increasing the time until the patient feels they are getting really refreshing sleep and their energy levels feel restored. The number of hours needed on CPAP is entirely personal and varies hugely from patient to patient as everyone is uniquely different.

- **Breathing Exercises**

Another way to become more comfortable with mask choice is by doing breathing exercises.

1. Slowly inhale for four seconds, and then exhale for four seconds. Count to ten and focus on breathing if the feeling of panic occurs with the mask on.
2. When the body realises it can breathe through the mask, it won't instinctively tense up and seize when it's supposed to be relaxing and sleeping.
3. Additionally, turning the CPAP on to feel the experience of air pressure, will allow the brain to understand how the machine works and feels while in use.
4. Generally speaking, CPAP panic will go away as soon as the patient gets used to the mask and the air flow. It just takes some time and patience.

- **Repetition is the key to Success**

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

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

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

Information gleaned from the following sources

Alaskan Sleep Clinic

American Sleep Apnea Association

Claustrophobic Tendencies and Continuous Positive Airway Pressure Therapy Non-adherence in Adults with Obstructive Sleep Apnea . Edmonds, Young, King, Sawyer x 2, Rizzo – Heart-Lung 2015 Mar-Apr 44(2) 100-106

<https://cpapvictoria.com.au/>

NHS England

NICE UK

Trends in CPAP adherence over twenty years of data collection: a flattened curve. Rotenberg, Murariu and Pang Jnl. of Otolaryngology - Head & Neck Surgery 2016.

& other sources that have briefly written about these issues

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