

The Oxford Sleep Unit
Oxford Centre for Respiratory Medicine
Osler Chest Unit, Churchill Hospital

Information for CPAP users



Now that you have your CPAP equipment, this booklet gives you more information about CPAP treatment. Please keep it in a safe place as you may need to refer to it in the future.

How to contact us

For help and advice about CPAP

Please telephone one of the Sleep Unit Nurses (Debbie Smith, Joy Crosby, Beverley Langford-Wiley, Tara Harris, Gill Nellis or Annesha Ruiz) on: Oxford (01865) 225959. We are usually available between 9.00 am and 5.00 pm Monday to Friday. If we are unable to come to the telephone immediately, please leave a message and we will call you back.

For replacement parts, machine faults and enquiries about holiday loan machines

Please telephone Korrie Jackson, Matt Cothier or Val Denney, Clinical Support Officers on Oxford (01865) 225969 (leave a message on the answerphone if necessary).

To change an outpatient appointment

Please telephone one of our Appointment Clerks on Oxford (01865) 225229 or 225228.

Please note that we are unable to offer a drop-in service due to the very large number of people using CPAP.

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Osler Chest Unit, Churchill Hospital
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What is CPAP?

Nasal continuous positive airway pressure (CPAP, pronounced "seepap") is used to treat the daytime sleepiness which can be caused by snoring and obstructive sleep apnoea.

Obstructive sleep apnoea

In this condition the upper part of the air passage, behind the tongue, narrows and collapses during sleep, causing an interruption to breathing (apnoea). When the air passage is closed, no air can pass into the lungs. As the oxygen in the blood is used up by the body, the levels of oxygen in the blood fall.

Eventually, the body detects these problems and you will wake up slightly - not usually enough to remember it, but just enough to open the air passage so that breathing can start again. In severe cases, only a few breaths are taken before the sufferer drifts back into deeper sleep and the air passage collapses once again.

This cycle of events can repeat itself many times during the night. Although the apnoeas are not dangerous in themselves, each brief awakening required to re-open the air passage destroys the normal deep sleep. The result is that sleep is severely disrupted, leading to considerable sleepiness during the day.

Other symptoms that may occur in obstructive sleep apnoea are the need to pass urine frequently during the night, and impotence. Both of these usually resolve once treatment is established.

Snoring

Snoring occurs when the air passage is narrowed and the air flowing through the narrowed air passage causes it to vibrate. Sucking air in through the narrowed air passage requires more effort and it is believed that this extra effort to breathe causes repeated disturbances to sleep, which can lead to daytime sleepiness. Snoring is a milder form of airway narrowing than obstructive sleep apnoea.

You may have a problem with severe snoring and no obstructive sleep apnoea, or you may have a combination of both, with periods of obstructive sleep apnoea (for instance when you sleep on your back)

and periods of snoring. Alternatively, you may have obstructive sleep apnoea throughout the whole of the night.

The severity of the problem will affect the amount of sleep disturbance there is and this in turn will affect the amount of daytime sleepiness that you may experience.

Nasal continuous positive airway pressure

CPAP treatment is designed to stop the air passage from narrowing during sleep. The treatment increases the pressure in the air passage and holds it open. This prevents the air passage from narrowing or collapsing. Once the air passage is held open, breathing is completely normal and there are no interruptions to sleep. This treatment is therefore not a cure but will control the condition as long it is used.

How CPAP works

Obstructive sleep apnoea

- Upper air passage collapses during sleep
- Sufferer struggles to breathe
- Brain woken briefly and breathing restarts
- Cycle of events can happen as many as 400 times a night
- Sleep is disturbed leading to daytime sleepiness

Snoring

- Throat narrows and vibrates causing noise of snoring
- Sleep is disturbed because of the considerable effort required to breathe through the partially blocked throat
- Disturbed sleep leads to daytime sleepiness

CPAP

- Stops airway narrowing/collapsing by increasing pressure of air being breathed
- This holds throat open when the CPAP is being used
- Breathing becomes normal and sleep is undisturbed

The CPAP system consists of:

- A pump to produce the pressurised air
- A flexible length of tubing to carry the air to you
- A close fitting mask worn over the nose with ports or a device to allow the exhaled air to escape
- Head straps or a stretchy cap to hold the mask on

The CPAP machine

The CPAP machine consists of a pump which sucks air in from the room, through a dust filter, and blows it out at a pre-set pressure.

A number of different manufacturers make CPAP machines, and although they vary in size, shape, weight, and the number of additional features that they contain, their main feature is to produce a constant air pressure.

The Sleep Unit will provide all NHS patients with a standard CPAP machine, but if you wish to purchase your own machine we can advise you on some of the alternative machines which are available.

The CPAP mask

The standard CPAP mask fits over the nose, leaving the mouth free. The top of the mask should rest against the bridge of the nose, just below the eyebrow level, and the bottom of the mask should rest against the upper lip.

Mask designs vary between manufacturers but they share a number of common features. These are:

- a flexible cushion which rests against the face (some masks have a second, very thin membrane in addition to this)
- a hard plastic shell with attachment points for the head straps
- an inlet tube which the CPAP tubing (bringing the air from the machine) attaches to
- an outlet port (or ports) which allows the air which you breathe out to escape. (The outlet ports may be in the mask itself, or in the inlet tube, or may consist of a separate tube or valve connected between the mask and tubing).

A small amount of tenderness on the bridge of the nose is not uncommon in the early days but you should contact us if it persists or is severe.

Fitting the CPAP system

The easiest way of getting the mask on is to hold it in place over the nose with one hand and slide the straps over the head with the other hand. You will get used to feeling for and adjusting the straps at the front and sides. Adjust the head straps so that the mask fits snugly against the face. In general, it is best to get the head straps well

down at the back of the neck so that the lower strap passes below the ears and then adjust evenly on both sides.

Once the blower is switched on, increase the tension on the straps gently if necessary to ensure that the mask fits without air leaking around it. You will probably need to readjust the straps again once you are lying down. If the mask is leaking, adjust by holding it firmly and pulling it well clear of the nose to let the cushion spring back into shape then let the mask re-settle on the face again.

It is best to experiment to find the best position for the blower and tubing to suit your preferred sleeping position and the restrictions of your bedroom. Many CPAP users find it best to place the blower towards the top of the bed so that the tubing can run from above and behind the head as this makes turning to either side easier.

Using the CPAP system

- Fit mask with blower turned off
- Adjust head straps for a snug fit
- Check and readjust head straps when lying down
- Position CPAP machine towards head of bed so that tubing comes from behind
- Switch CPAP machine on and **breathe only through your nose**
- Continue to use nasal sprays if prescribed

What to expect when using CPAP at home

Don't forget to keep your mouth closed and breathe in and out through your nose when using CPAP. It is normal to feel some resistance to breathing out; this is because you have to breathe out against the incoming air. Your body will have no difficulty in doing this when you are asleep, but it can take a while to get used to this feeling. If you do open your mouth, the air will escape (i.e. it will travel up your nose and then come out of your mouth), and this can make you feel as though you cannot get your breath. This, of course, will make it difficult to talk while using a CPAP mask.

If you have been prescribed some nasal sprays, continue to use these regularly for at least the first two weeks on CPAP. If you are not having any nasal problems after this period then you can stop taking the sprays.

If you wake in the night and feel uncomfortable with the pressure of the machine, switch it off and take the mask off for a few minutes. Make sure that your nose has not become congested, clear the nose and use some more of the nasal spray if necessary. Then put the mask back on and adjust it until it's comfortable before switching the machine on again. Remember to keep your mouth closed and breathe slowly in and out through your nose. It may help to take a really deep breath in and then out through your nose.

Some machines have a ramp feature so that they start off at a lower pressure and gradually increase the pressure over a period of about 5 – 30 minutes, so when you switch on the machine again, it will start at a lower pressure.

Some people who have been deprived of sleep for a long time find that they sleep really deeply on the first night as the body catches up with lost sleep. Occasionally the body catches up with its lost dreaming sleep as well and people experience vivid dreams for a few nights when using the system. This does not continue once the body has adjusted to having a normal night's sleep once more.

Don't worry if you are not able to use the CPAP all night, especially at first. Even 3-4 hours with the CPAP is likely to improve the quality of your sleep. Our usual advice is to use the CPAP as much as you feel you need to in order to control your daytime sleepiness.

When you wake in the morning, you may well feel much more refreshed than normal but some people take a few nights to really begin to feel the effects of the CPAP treatment.

The trial period

We will give you CPAP for a trial period so that you can decide whether you feel that the treatment is helping your symptoms.

We understand that this can be a difficult time for you as you are adjusting to new CPAP equipment yourself and you may also have to cope with the reactions of your partner or other family members to the equipment. You are encouraged to telephone one of the Sleep Unit Nurses if you are experiencing any problems (see also the section below on common problems and solutions) and this may also be a good time for you (and/or your partner) to talk to a member of the support group, the Sleep Apnoea Trust Association (helpline numbers at the back of this booklet).

You will be sent an appointment to return to the outpatient department about 2 - 6 weeks after beginning the treatment. **Please remember to bring your machine and equipment with you on this occasion.** At this appointment we will ask you whether you feel that using the system has been beneficial.

If you wish to continue using CPAP then you will be able to keep the equipment. If you feel it has not helped you, you will be able to return the equipment to us. You are under no obligation to continue to use the treatment if you do not feel it is helping you. If you have had any difficulties using the CPAP, you will be able to discuss these with the doctor or nurse. If necessary the trial period can be extended.

Driving regulations

If you have been diagnosed as having obstructive sleep apnoea syndrome, the DVLA has regulations about this. This is because driving accidents are much more likely to occur due to drivers feeling sleepy and falling asleep at the wheel.

Private car (group 1 entitlement)

You must inform the DVLA. They will not prevent you from driving, but they will contact the Sleep Unit for further information - by which

time hopefully you will have been treated and thus be quite safe to drive.

However, you must **stop driving** if the condition causes excessive awake-time sleepiness which is likely to interfere with your driving ability. You will be permitted to drive when your symptoms are adequately controlled.

If you are in any doubt about how sleepy you are then it would be our advice not to drive.

PSV / HGV (group 2 entitlement)

Once a diagnosis of sleep apnoea has been made, you must inform the DVLA. You must **stop driving** if the condition causes excessive awake-time sleepiness. When it is confirmed by specialist assessment that your condition is adequately controlled (hopefully soon after starting CPAP), you may resume driving, subject to annual review.

It is important to remember that if you have a motor vehicle accident then your insurers can request details of any medical condition for which you are currently being treated. In the case of obstructive sleep apnoea causing daytime sleepiness your insurers could refuse to support any insurance claim. Please check your motor insurance policy to see whether they require you to notify new medical disorders.

Although these regulations appear harsh, they are there to protect you and others. Obstructive sleep apnoea is highly treatable with CPAP and, once controlled, you should be able to start driving again. The DVLA will accept the recommendation of your consultant.

DVLA

Drivers Medical Unit

Swansea SA99 1TU

Tel: 01792 782341

www.dvla.gov.uk – Drivers Information/Medical rules

Some common problems and solutions

Claustrophobia

It is not uncommon to take a while to get used to wearing the mask at night. Some people find that they are unable to keep the mask on all night and some people take it off in their sleep without being aware of it. If you are having problems wearing the mask, check first that you have adjusted it correctly with no leaks and remember to **breathe through your nose all the time, keeping your mouth closed**. Often a feeling of panic is due to air rushing out of the mouth, so remember to keep it closed all the time and try taking a few deep breaths in and out through your nose.

Do not worry if you are not able to keep the mask on for the whole night. Even a few hours of good sleep with the mask on may be adequate to control your sleepiness and as you adapt to the system you will probably be able to wear it for longer periods.

Soreness on the bridge of your nose

If you find that the bridge of your nose is becoming red, try wearing the mask with the straps a little looser. It is not uncommon for this to happen in the early days but you should contact us if the skin becomes very inflamed and sore, or if loosening the straps causes too much air to leak from the mask.

Unable to get mask to seal

Remember to adjust the mask with the blower turned off. First lift it clear of your face and then let it settle again to ensure that the mask cushion has not become distorted. Try adjusting the head straps – they may need to be slightly tighter. A small leak from the mask will not affect the pressure. However, if the leak is going into the eyes, causing them to become red and to water, then you should contact us.

Sneezing

Occasionally the CPAP treatment causes irritation to the nasal lining, which results in sneezing and nasal streaming (rather like hay-fever). This may settle down on its own. If it does not then nasal sprays, which reduce the inflammation of the nasal lining and dry up the nose, are the best treatment. You may already have been given these

sprays (Beconase Aqueous and Rinattec). Continue to use these night and morning and the problem should ease. There are no problems with using Beconase and Rinattec regularly if you need to and you can buy these from a chemist or get a repeat prescription from your GP.

Nasal congestion

If your nose becomes blocked and congested during the night then it will be difficult to use the system. Once again, use the nasal sprays regularly to try and keep the nose really clear. If you have a cold, you may not be able to use the system for a night or two. This will not do you any harm, although you will not sleep as well. A few doses of a nasal decongestant that you can buy from the chemist (such as Otrivine) may help to clear your nose so that you can use the CPAP, but such decongestants must not be used on a long term basis (i.e. more than 5 nights) since they will make the problem worse if you use them for too long.

Machine noise

If either you or your partner finds the CPAP machine too noisy then it can be safely put in a cupboard or box as long as there is a small amount of room around it for the air to circulate. Insulating the cupboard with polystyrene tiles or carpet tiles, or placing the machine on a thick piece of carpet instead of a hard surface, also helps. If you wish to move the machine further away from you then we can provide a second length of tubing and a connector. Ear plugs may be helpful and you can buy these from most chemists.

Mouth leak

Once you are asleep, and as long as your nose remains clear, you will keep your mouth closed naturally. Very occasionally people have problems with their mouth falling open during sleep and the air escape can cause the mouth to become very dry. You may be able to resolve this yourself by altering your sleeping position or the number and position of your pillows. If this does not solve the problem, it may be necessary to use an extra strap under the chin to hold the lower jaw up. The Sleep Unit will be able to advise you and provide a chin support. A simple method is to use a towelling headband (available at most sports shops) around the head and under the chin. A large size

Tubigrip bandage under the chin and over the top of the head will also work.

Coldness and drying of the nose and throat

If this occurs, it may be helpful to keep the bedroom a little warmer and try and increase the humidity in the room with a tray of water above a radiator. It may also help to run the CPAP tubing under the bedclothes (a second length can be provided if necessary) so that it stays warm.

If any of these measures do not help, or you would like more advice, then please contact one of the Sleep Nurses at the Sleep Unit.

Routine care and maintenance

Equipment cleaning

It is best to wipe the mask every day if possible. A non-alcoholic antiseptic wipe is ideal. Alternatively, all the plastic parts (i.e. mask and tubing) can be washed in water and washing up liquid. (Avoid using soap as it will not remove the 'grease' which can cause the mask to slip during the night.) This is best done in the morning so that they will be dry for the next night. The headgear can be put in the washing machine on a gentle wash. The CPAP equipment should be cleaned at least once a week.

Most CPAP machines have a dust filter which can be removed and washed or replaced. Your filter will be replaced as necessary at the routine yearly maintenance check at the Sleep Unit.

Follow up care

If you decide to keep the CPAP machine, then after your first follow-up appointment we will send you an appointment to attend our CPAP clinic in approximately 12 months. This clinic is run jointly by one of the hospital engineers and one of the Sleep Unit nurses. **You should bring your machine, the mains lead and all the equipment with you to this appointment. Please make sure it has been thoroughly cleaned.**

The engineer will check the machine, perform an electrical safety

test and replace the filter if necessary. The nurse will check all your other equipment and replace any worn items such as the mask and headgear. If you have been experiencing any difficulties with CPAP then please tell the nurse, who will be able to advise you.

If you wish to see one of the doctors then it would be helpful if you could telephone us in advance to arrange this, though there is usually a doctor available if needed. If your problem is more urgent, please telephone the Unit as it may be necessary to make you a separate outpatient appointment.

In between your appointments, please telephone one of the Sleep Nurses (see page 3) if you need help or advice. We keep a record of the equipment that you have so replacements can be sent by post if necessary.

Maintenance and servicing

- Wipe mask daily
- Wash mask in water + washing up liquid (not antibacterial) at least once a week
- Headgear can be machine washed on a gentle cycle
- Clean or change air filter on CPAP machine as recommended in manufacturers handbook
- Worn out equipment will be replaced as required, please telephone the Sleep Unit on 01865 225969

Travelling

If you are travelling abroad, we can give you a letter to show the customs or security officials in case they ask you about your machine. You will also need to buy a travel adapter suitable for the country you are to visit.

The CPAP machine should always be carried as hand luggage in an aircraft and must not be stowed in the hold.

If you require a machine which will run off a 12 volt DC supply (i.e. for a caravan or boating holiday) you may be able to borrow one of our loan machines for a short period.

Private patients

All private fees that the Sleep Unit receives go towards running the sleep service and not to any individual. Although you will be seen by a doctor to review your trial of CPAP, the yearly follow-up clinic is run by one of the Sleep Unit nurses and our engineer. If you wish to see a consultant at this appointment then please telephone us to arrange this. There is usually a doctor available during the clinic appointment to deal with any medical queries. Some health insurance companies cover both the inpatient and outpatient treatments for sleep related problems but unfortunately most of them do not cover the cost of replacement equipment such as the CPAP mask and headgear or repairs to the CPAP machine.

If you feel that future charges are going to become a significant problem, then it may be possible to revert to treatment under the NHS. To do this please ask your own General Practitioner to write to us.

Machine Faults

If your machine stops working, or you think that it is faulty in any way, please telephone our Clinical Support Workers on **(01865) 225969**. We will ask you to bring the machine to the Churchill Hospital and we will give you a replacement. We cannot guarantee that the replacement machine will be the same model but it will treat your sleep apnoea just as well.

Replacement items (mask, headgear, etc)

If any parts of the breathing circuit need to be replaced, please call our Clinical Support Workers (01865) 225969. Replacement items are sent out by second class post which leaves the hospital by 4.00 p.m., so please telephone early in the day if possible.

If you would like to collect the items yourself or see one of the Sleep Unit Nurses, **please telephone to arrange an appointment.**

Unfortunately we cannot operate a 'drop-in' service due to the very large numbers of people using CPAP.

The CPAP equipment is expensive to replace (£100 for a mask + headgear) so please take care of all your equipment and store it safely during the day.

Please note that we can only deal with machine faults or requests for replacement items between 9 a.m. and 5 p.m. Monday to Friday. If you have problems with your machine or equipment over a weekend or Bank Holiday, please wait until the Sleep Unit is open again on the next working day. A night or two without your CPAP will not do you any harm although you should be aware that your sleepiness may begin to return.

Further information and support

The Sleep Apnoea Trust Association (SATA)

Tel & Fax: 0845 6060685

email: sata.admin@tiscali.co.uk

www.sleep-apnoea-trust.org

SATA is a registered charity. It was formed in 1993 by patients of the Oxford Sleep Unit. SATA has members nationwide. You should receive the SATA information leaflet with this booklet.

The aims of the Association include the following:

- Helpline for patients and partners
- Regular newsletters (Sleep Matters)
- Increase awareness within medical and allied professions
- Greater recognition/funding by the NHS and private health insurance
- Liaise with CPAP manufacturers, and other support groups

SATA needs your support and we certainly encourage all our patients to join.

If you need an interpreter or need a document in another language, large print, Braille or audio version, please call **01865 221473**. When we receive your call we may transfer you to an interpreter. This can take some time, so please be patient.

Joy Crosby, Staff Nurse
Debbie smith, Sister
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