

Modafinil for the treatment of narcolepsy

The purpose of this leaflet is to provide you with some information about modafinil which has been prescribed to treat your narcolepsy. If you have any questions or concerns, please speak to your doctor, pharmacist or nurse caring for you.

What is narcolepsy?

Narcolepsy is a long-term condition which causes excessive sleepiness during the day and may disrupt your sleep at night. You can also have sleep attacks where you fall asleep at inappropriate times during the day without any warning.

What is modafinil?

Modafinil belongs to a group of medicines called stimulants. It can be used to treat some of the symptoms of narcolepsy. Although there is no cure for narcolepsy, modafinil can help to control your symptoms.

Modafinil promotes wakefulness by stimulating your brain to increase alertness and reduce excessive sleepiness during the day.

How do I take the medicine?

Modafinil should be swallowed whole with a drink of water, and can be taken with or after food. Do not break or crush the tablet.

Take modafinil exactly as your consultant or pharmacist tells you to. There are two strengths of tablet available – 100mg and 200mg. When you first start modafinil it is common to be prescribed a dose of 50mg to 100mg daily, usually increased to 200mg daily. You may be asked to take this as a single dose of 200mg in the morning, or divided into 100mg in the morning and 100mg at midday. Your consultant or pharmacist will tell you which is right for you. Your dose may be increased after a little while, depending upon your symptoms.

What should I do if I forget to take the medicine?

Don't worry. Just remember to take the next dose when it is due. **Do not take two doses together to make up for the forgotten dose.**

Are there any side effects?

In addition to their desired effects, most medicines can cause unwanted side effects although not everyone experiences them. The following are examples of some of the common side effects reported by patients taking modafinil (up to one in one hundred patients). The unwanted effects often fade as your body adjusts to the new medicine, but speak with your doctor or pharmacist if any of the following continue or become troublesome.

Side effect	What should I do if it happens?
Headache Note: if you are prone to migraines, taking modafinil may increase how often you get them and their severity	This usually passes within a day or so, but in the meantime, drink plenty of water and take your usual painkiller, for example, paracetamol. If the headache continues, speak with your consultant or GP.
Dry mouth	Try chewing sugar-free gum or sugar-free sweets.
Feeling or being sick Indigestion Stomach ache	Stick to simple meals – avoid rich or spicy foods.
Diarrhoea	Drink plenty of water to replace lost fluids.
Constipation	Try to eat a well-balanced diet and drink several glasses of water each day.
Feeling dizzy or tired Blurred vision	Do not drive or use tools or machinery until you feel better. Sleepiness associated with your condition can add to this.
Flushing Loss of appetite Nervousness Difficulty sleeping Anxiety Depression, confusion or confused thinking Numbness or tingling feelings	Speak to your GP if any of these continue or become troublesome.

Important: if you experience any of the following symptoms, contact your GP for advice **as soon as possible**:

- Any changes to your mood, behaviour, or thinking
- Chest pain, fast heartbeat, or unexplained breathlessness
- Any suicidal thoughts, or thoughts about harming yourself

For further information on side effects, please see the manufacturer's leaflet that comes with the medicine.

If any of the side effects persist or become a problem, contact your GP, consultant or pharmacist.

Can I take modafinil with other medicines?

Modafinil may interact with some medicines. It is therefore important to let us know about any medicines that you are currently taking so that we can check modafinil is suitable for you. If you are buying any medicines over the counter from a pharmacy, always mention that you have been prescribed modafinil. It is safe to take paracetamol and ibuprofen with this medicine. Advice should be sought when purchasing herbal or homeopathic remedies.

Is there anything else I need to know?

Hormonal contraceptives, including oral contraceptive pills, implants, intrauterine contraceptive devices (IUCDs) and contraceptive patches, are less effective when used with modafinil and are therefore not recommended. Speak to your GP or consultant about which contraceptive methods are suitable for you while you are taking modafinil.

Narcolepsy and Driving: In the UK, you are required by law to let the Driver and Vehicle Licensing Authority (DVLA) know if you are diagnosed with narcolepsy. You may be allowed to drive again when your symptoms are well controlled with medication, but you will need to have regular reviews. Your consultant will advise you about this.

If you are a driver, please be aware that modafinil may affect your reactions and ability to drive. It is an offence to drive while your reactions are impaired. Even if your driving ability is not impaired, if you drive, you are advised to carry with you some evidence that the medicine has been prescribed for you – a repeat prescription form or a patient information leaflet from the pack is generally considered suitable.

Pregnancy and Breast Feeding: Modafinil is not recommended for use during pregnancy, and women of childbearing age should use effective contraception during treatment and for two months after it is stopped. If you are considering becoming pregnant or you discover that you are pregnant, you should discuss with your consultant so that a management plan can be agreed.

Sleep hygiene: Taking modafinil is not a replacement for a good sleep routine. It is still important to aim to get around seven to eight hours of sleep at night if possible. Patients should be advised to go to bed when tired and get up at about the same time each day.

If you are having an operation or dental treatment, tell your consultant or GP who will be able to advise you further.

Do not drink alcohol while taking modafinil as they can enhance each other's side effects such as increased dehydration.

Modafinil should be kept out of reach of children. The expiry date is printed on the container. Do not use the medicine after this date. The remainder should be returned to your local pharmacy to be thrown away.

How will my treatment be reviewed?

Your treatment will be reviewed on an ongoing basis at the Sleep Centre and the dose adjusted in response to your symptoms. This will be a long-term treatment if it is of benefit. Your consultant will want to check to ensure that the treatment is helping. You may need to have your blood pressure and heart rate checked regularly.

How do I get a repeat prescription?

Your GP will give you a repeat prescription for modafinil. Please ensure you request your repeat prescription early so that you don't run out or risk missing any doses of your medication.

If your GP won't supply your modafinil, the Sleep Centre will continue to provide you with a prescription which you can take to the outpatient pharmacy on site for supply. Unfortunately this prescription will not be accepted in your local pharmacy.

Useful sources of information

Narcolepsy UK – Supporting people with narcolepsy. You might find this charity's website – www.narcolepsy.org.uk – useful for connecting with patients who suffer from the same condition as you but any new information found should not alter your current treatment regimen and you should discuss any new advice with the doctor caring for your condition.

Contact us

If you have any questions or concerns about your sleep disorder please contact the Sleep Disorder Centre on 020 7188 3430 (9am to 5pm).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline. **t:** 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch: **t:** 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day. **t:** 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health. **w:** www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 **e:** members@gstt.nhs.uk
w: www.guysandstthomas.nhs.uk/membership

Leaflet number: 4489/VER1

Date published: September 2017

Review date: September 2020

© 2017 Guy's and St Thomas' NHS Foundation Trust
A list of sources is available on request