

Venlafaxine XL for the treatment of cataplexy in narcolepsy

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

What is cataplexy in 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. Cataplexy is a condition associated with narcolepsy that results in sudden muscle weakness triggered by strong emotions such as laughter, anger, fright or surprise. Muscle weakness can vary in severity and cataplexy attacks can differ in both nature and duration.

What is venlafaxine XL?

Venlafaxine XL belongs to a group of medicines called anti-depressants. It can be used to treat cataplexy in narcolepsy and is thought to work by interfering with certain chemicals in the brain which may be involved in causing the symptoms of cataplexy.

Venlafaxine XL is used as an extended-release (XL) preparation. Extended-release tablets and capsules release venlafaxine XL slowly over 24 hours to give a longer-lasting action. This will prevent severe cataplexy attack(s) which is when you have cataplexy attacks repeatedly for hours or days without a rest period and in the absence of emotional triggers.

Severe cataplexy attack(s) can develop if venlafaxine XL is stopped suddenly or if switched to the immediate-release version.

Taking an unlicensed medicine

The use of venlafaxine XL for cataplexy is unlicensed, which means that although the manufacturer of the medicine has not specified it can be used in this way, there is evidence that it works to treat this particular condition. The leaflet, **Unlicensed medicines – a guide for patients**, has more information about unlicensed medicines. If you would like a copy, please ask your doctor, nurse or pharmacist. Alternatively, you can call the Pharmacy Medicines Helpline – contact details are at the end of this leaflet.

How do I take the medicine?

For the treatment of cataplexy, venlafaxine XL should be taken once a day in the morning. Venlafaxine XL may be taken with or without food. Swallow the tablet(s) whole with a drink of

water. Do not chew or crush them. Keep taking the medicine until your consultant tells you otherwise. Stopping suddenly can cause side effects such as recurrent cataplexy, feeling and being sick, anxiety, headaches and sleep disturbances. Your consultant will want you to reduce your dose gradually if you need to stop treatment.

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

If you forget to take the dose in the morning, don't worry. However you should take the dose as soon as you remember as missing a dose of venlafaxine XL can result in severe cataplexy attack(s).

Try not to take Venlafaxine XL within a couple of hours before your bedtime as your sleep may be disrupted. Take the next dose when it is due the following morning. **Do not take an extra dose the following morning to make up for a missed 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 side effects reported by patients taking venlafaxine XL. The unwanted effects often fade as your body adjusts to the new medicine, but speak with your GP or pharmacist if any of the following continue or become troublesome.

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

Side effect	What should I do if it happens?
Very common (up to one in 10)	
Headache	Drink plenty of water and take your usual painkiller, for example, paracetamol. If the headache continues, speak with your GP.
Dry mouth	Try chewing sugar-free gum or sucking sugar-free sweets.
Feeling and being sick	Stick to simple foods. Try taking your doses after meals if you are not already doing so.
Sweating	Take care not to become overheated during exercise or hot weather.
Common (up to one in 100)	
Feeling dizzy, tired or sleepy	Do not drive or use tools or machinery until you feel better. Do not drink alcohol.
Constipation	Try to eat a well-balanced diet containing plenty of fibre and drink plenty of water each day.
Uncommon (up to one in 1,000)	
Loss of weight or appetite Sleeping problems, yawning Tingling feelings Feeling nervous or confused Eyesight problems Chills, hot flushes Difficulties having sex Raised cholesterol Menstrual problems	If any of these become troublesome, speak with your GP or consultant.

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.
- Any suicidal thoughts, or thoughts about harming yourself.

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

Can I take venlafaxine XL with other medicines?

Venlafaxine XL 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 venlafaxine XL is suitable for you. If you are buying any medicines over the counter from a pharmacy always mention that you have been prescribed venlafaxine XL. It is safe to take paracetamol with this medicine but always ask your pharmacist for advice before buying any anti-inflammatory painkillers, such as ibuprofen or aspirin. Advice should be sought when purchasing herbal or homeopathic remedies.

Is there anything else I need to know?

It can take a week or two after starting this treatment before the effect builds up, and up to four weeks before you feel the full benefit. It is therefore important that you continue taking the medicine, even if you feel that it is not helping you.

Venlafaxine XL can make your skin more sensitive to sunlight. Try to avoid strong sunlight, use a sun cream with a high protection factor. Do not use sunbeds.

Venlafaxine XL can alter the levels of sugar in your blood. If you have diabetes you may need to check your blood sugar more regularly. Your GP can advise you about this.

Do not drink alcohol whilst you are taking venlafaxine XL. Mixing alcohol with venlafaxine XL may increase the risk of other side effects such feeling or being sick, and may worsen any dizziness or drowsiness.

Venlafaxine XL 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.

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 doctor will advise you about this.

If you are a driver, please be aware that venlafaxine XL 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: If you are considering becoming pregnant or have discovered you are pregnant, you should discuss this with your consultant so that a management plan can be agreed.

Sleep hygiene: Taking venlafaxine XL 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.

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 venlafaxine XL. Please ensure you request your repeat prescription early so that you don't run out or risk missing any doses of your medication.

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

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