

Fluoxetine for the treatment of cataplexy in narcolepsy

The purpose of this leaflet is to provide you with some information about fluoxetine, 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 fluoxetine?

Fluoxetine belongs to a group of medicines called anti-depressants. It can be used to treat cataplexy in narcolepsy. Fluoxetine works by interfering with certain chemicals in the brain which may be involved in causing the symptoms of cataplexy.

Taking an unlicensed medicine

The use of fluoxetine 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, fluoxetine should be taken once a day in the morning. Fluoxetine may be taken with or without food. Keep taking the medicine until your doctor tells you otherwise. Stopping suddenly can cause problems and your doctor 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, do not worry. However you should take the dose as soon as you remember, as you may experience severe cataplexy attack(s). Try not to take fluoxetine within a couple of hours of 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 the 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 common side effects reported by patients taking fluoxetine (up to one in one hundred patients). 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?
Feeling or being sick Indigestion Diarrhoea	Stick to simple foods – avoid rich or spicy foods.
Dry mouth	Try chewing sugar-free gum or sucking sugar-free sweets.
Headache	Drink plenty of water and take your usual painkiller, for example, paracetamol.
Feeling restless or shaky	These usually settle within a few days. If any becomes troublesome or severe, speak with your GP or consultant.
Feeling dizzy, tired or weak Blurred vision	If this happens, do not drive or use tools or machinery until you feel better. Do not drink alcohol.
Flushing or sweating	Take care not to become overheated during exercise or hot weather
Difficulty sleeping or yawning Loss of appetite, or weight Aches and pains Reduced sexual drive or ability Palpitations Itching Changes in taste Difficulty in passing urine	If any of these become troublesome, speak with your GP.

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

- A rash or blisters on the skin, swelling of your face, or difficulty breathing.
- Any changes to your mood (such as feeling anxious, nervous or agitated), behaviour, or thinking (forgetful).
- 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.

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. Do not stop taking it after a week or so, thinking it is not helping.

You may have distressing thoughts while taking fluoxetine (especially if you are depressed), and think about harming yourself or ending your life. **Important:** If this happens, it is very important that you tell your doctor about it **as soon as possible**.

Fluoxetine 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.

Fluoxetine 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 while taking fluoxetine as it may increase symptoms of depression or anxiety, cause increased dizziness, drowsiness or co-ordination issues.

Fluoxetine 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.

Can I take fluoxetine with other medicines?

Fluoxetine 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 fluoxetine is suitable for you. If you are buying any medicines over the counter from a pharmacy always mention that you have been prescribed fluoxetine. Advice should be sought when purchasing herbal or homeopathic remedies. In particular, do not take the herbal remedy St John's wort. It is safe to take paracetamol with this medicine but ask for advice before buying any anti-inflammatory painkillers such as ibuprofen or aspirin.

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 fluoxetine. Please ensure you request your repeat prescription early enough to prevent your supply running 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

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

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