Melatonin for the treatment of REM behaviour disorder

This leaflet provides you with some information about melatonin, which has been prescribed to treat your sleep disorder. If you have any questions or concerns, please speak to the doctor, pharmacist or nurse caring for you.

What is REM behaviour disorder (RBD)?
RBD happens during rapid eye movement (REM) sleep. This is usually the phase of sleep when we dream, and our muscles are temporarily paralysed so we cannot move.

People who have RBD are able to move their muscles while they dream, which means they can act out the content of their dreams.

This can lead to episodes of intense shouting or speaking, and violent movement or behaviour which can result in injury to you or your bed partner.

What is melatonin?
Melatonin is a natural chemical which is released by the body during the hours of darkness. It makes you sleepy and regulates your body clock. Because of this, melatonin has been used as a medicine to treat sleep disorders that involve disruption of the body clock and those which cause abnormal events during sleep.

Taking an unlicensed medicine
The use of melatonin for the treatment of RBD is unlicensed, which means that the manufacturer of the medicine has not specified it can be used in this way. However, 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 RBD, the usual dose of melatonin is between 0.5mg to 16mg every night.

The person prescribing this medicine for you will let you know what dose you should take. Melatonin is supplied as modified-release 2mg tablets (Circadin®), and these can be cut into halves or quarters, to make up the dose you need. Your consultant will tell you when it is okay to split the tablet when a lower dose or a more immediate effect is required. You will be given a tablet cutter if this is necessary, and we will explain how to do this.
Melatonin should be taken orally (by mouth) once a day at night, three hours before you go to bed. It should be swallowed whole (unless taking doses lower than 2mg), with a glass of water after food.

**What should I do if I forget to take the medicine?**
If you forget to take a dose of melatonin, don’t worry. Take the next dose when it is due. **Do not take an extra dose the following night 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 gets them. The following are examples of some of the side effects reported by patients taking melatonin. 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.

<table>
<thead>
<tr>
<th>Side effect</th>
<th>What should I do if it happens?</th>
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<tbody>
<tr>
<td><strong>Uncommon (between one in 1,000 and one in 100)</strong></td>
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<tr>
<td>Headache</td>
<td>Take your usual painkiller (for example, paracetamol)</td>
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<tr>
<td>Feeling tired or sleepy</td>
<td>Take the dose three hours before bedtime. Do not drive and do not use tools or machines until these effects have worn off.</td>
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<tr>
<td>Indigestion, feeling sick (nausea), stomach ache</td>
<td>Stick to simple foods. Avoid rich or spicy meals</td>
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<tr>
<td>Reduced body temperature or night sweats</td>
<td>Contact your GP before taking the next dose.</td>
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<tr>
<td>Dry or itchy skin</td>
<td>Try applying an anti-itch cream or a cooling moisturiser</td>
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<tr>
<td><strong>Rare (between one in 10,000 and one in 1,000)</strong></td>
<td></td>
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<tr>
<td>Fast heart beat (palpitations)</td>
<td>Contact your GP before taking the next dose.</td>
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<tr>
<td>Feeling irritable or restless</td>
<td>If any of these become troublesome, speak with your doctor</td>
</tr>
<tr>
<td>Abnormal dreams</td>
<td>If any of these become troublesome, speak with your doctor</td>
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For further information on side effects, please see the manufacturer’s leaflet that comes with the medicine.

**Is there anything else I need to know?**
Do not drink alcohol while you are taking melatonin because it will reduce the medicine’s effectiveness in helping you to sleep. Alcohol can also make your RBD worse.

If you are a driver, please be aware that melatonin 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 some evidence with you which shows that the medicine has been prescribed for you – a repeat prescription form or the patient information leaflet from the packet is generally considered suitable.
Melatonin should be kept out of reach of children. If anyone other than you takes this medicine, you, they, or their parent/carer should contact NHS 111 for advice. If they are unwell, they should call for an ambulance.

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.

**Pregnancy and breastfeeding:**
We do not recommend the use of this medicine if you are pregnant or breastfeeding. You should let your consultant know if you are planning a pregnancy so that a management plan can be agreed. If you discover that you are pregnant, please contact your consultant for advice as soon as possible.

**Sleep hygiene:** Taking melatonin 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. It is advisable to go to bed when tired, and get up at about the same time each day. Maintain a normal total sleep time. Sleep deprivation will increase RBD. Monitor for any sleepiness.

**Bedroom safety precautions for RBD**
- Move objects away from your bedside. This includes night stands, lamps, or other objects that could cause injury.
- Move your bed away from the window.
- Encourage your bed partner to report any worsening or changes in your night-time behaviour.

**Can I take melatonin with other medicines?**
Melatonin may interact with some medicines. It is important to let us know about any medicines that you are currently taking, so that we can check it is suitable for you. If you are buying any medicines over the counter from a pharmacy, always mention that you have been prescribed melatonin. Seek advice from a pharmacist when buying herbal or homeopathic remedies. It is safe to take paracetamol or ibuprofen with this medicine.

**How will my treatment be reviewed?**
Your treatment will be reviewed on an ongoing basis at the Sleep Disorder Centre and the dose adjusted depending on your symptoms. This will be a long-term treatment if it is of benefit. Your consultant will want to check to make sure that the treatment is helping.

**How do I get a repeat prescription?**
Your GP will give you a repeat prescription for melatonin which you can take to your local pharmacy for supply. Should your GP not prescribe melatonin for you, please contact the Sleep Disorder Centre for advice. Please make sure you request your repeat prescription early to prevent you running out, or missing any doses of your medication.
Contact us
If you have any questions or concerns about your sleep disorder, please contact the Sleep Disorder Centre, **t:** 020 7188 3430, Monday to Friday, 9am to 5pm.

Out of hours, please leave a message and a member of staff will call you back in working hours, or contact your GP or NHS 111.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.guysandstthomas.nhs.uk/leaflets](http://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 website
Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.
**w:** [www.nhs.uk](http://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](http://www.guysandstthomas.nhs.uk/membership)