

# Your child's medication: Modafinil for narcolepsy

## Information for children, families and carers

We have given you this factsheet because your child has been diagnosed with a condition called narcolepsy and has been prescribed a medication called modafinil as part of their treatment programme. This factsheet explains how your child should take modafinil. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

Please note that our information may differ from that provided by the medication manufacturer. This is because their information usually relates to adults.

### **Modafinil (also known as Provigil)**

Modafinil is in a class of medications called central nervous system (CNS) stimulants. It is used to treat excessive daytime sleepiness due to narcolepsy and other sleep disorders.

### **How does modafinil help to treat narcolepsy?**

Narcolepsy is a long-term condition which disrupts the normal sleep/wake cycle.

Common symptoms of narcolepsy include:

- falling asleep at inappropriate times during the day
- fragmented night-time sleep
- excessive daytime sleepiness

There is no known cure for narcolepsy. However, we can help to manage your child's symptoms with a combination of:

- scheduled daytime naps
- lifestyle changes
- modafinil medication and/or other medications

Modafinil works by stimulating your child's brain, making it more alert and increasing wakefulness.

## Is modafinil suitable for everyone?

Your child should not take modafinil if they:

- have a history of cardiac arrhythmias
- have high blood pressure
- are pregnant

Modafinil should be used with caution if your child has:

- a history of mental health problems
- a history of drug and alcohol misuse
- a history of liver disease

## How to take modafinil

Modafinil comes as a tablet. Your child should swallow the tablet whole with water, soon after they wake up in the morning. If your child is unable to swallow tablets, please discuss this with us.

Modafinil should be taken with or just after having food.

The medication should start to work 30 to 60 minutes after your child takes it. The effects will slowly increase over a couple of hours.

If your child's sleepiness is unmanageable in the afternoon and evening, we may recommend that they take modafinil in two doses during the day. **You must discuss this with us before starting this.**

**Your child should not stop taking modafinil suddenly or without the support of our sleep clinic.**

## Dose

Modafinil comes in 100mg or 200mg tablets. We will prescribe your child a low dose to start with. We will increase the dose gradually to avoid side effects and to control your child's symptoms. We will discuss your child's dose regime with you.

It is important that you follow the instructions about how much your child should take. The dose will be shown on the medication label.

## Storage

Keep your child's medication in a locked cupboard.

## Other medications

Check with us before your child takes any new medication while they are taking modafinil. Check with your pharmacist before your child takes any over-the-counter medication.

## Alcohol

Your child must not have any alcohol while they are taking modafinil.

## Contraception

It is important that females of childbearing age use contraception while they are taking modafinil, as it can cause birth defects in an unborn child.

Modafinil can reduce the effectiveness of some hormonal contraceptives. It is therefore important that you tell the doctor advising on contraception that your child is taking modafinil.

## Pregnancy

Modafinil should not be used during pregnancy due to the risk of birth defects.

## Travel

If you need a letter in order to travel abroad with your child's medication, please contact us as soon as possible so we can arrange this.

## Monitoring

Before your child starts taking modafinil, we will check their height, weight, and blood pressure. We will then need to see your child in our sleep clinic regularly while they are taking modafinil.

If we increase your child's dose, they will need to have their blood pressure checked within 48 hours of starting the new dose. If this is the case, please contact us with your child's blood pressure reading.

## What if my child takes too much modafinil?

It can be dangerous to take too much modafinil.

If your child takes too much modafinil, call NHS **111** for advice and have the medication or packaging to hand. In an emergency, take your child to your nearest emergency department. Make sure to take your child's medication container and packaging in with you, even if it is empty. This will help the healthcare professional caring for your child.

## What if my child misses a dose of modafinil?

Do not give your child the missed dose. Give your child their next dose at the usual time. **Never give a double dose of modafinil.**

## What if my child is sick (vomits) after taking a dose of modafinil?

Do not repeat the first dose. This is because it can be difficult to know how much was absorbed.

## Side effects

As with all medications, there may be side effects with taking modafinil. We will prescribe your child a low dose to start with, to reduce the chance of side effects.

## Common side effects

- Anxiety or mood changes - Monitor your child for any changes.
- A change in appetite, a dry mouth, stomach ache, nausea (feeling sick), constipation or diarrhoea - To help with this, your child should eat a balanced diet and drink plenty of water.
- If your child is prone to migraines, modafinil may make them more intense - Encourage your child to drink plenty of water.
- Heart palpitations (when your heartbeat becomes more noticeable), dizziness or chest pain - Your child should not ride a bike or drive a car if the medication makes them feel dizzy or light-headed, clumsy or unable to concentrate or make decisions.

Stop the medication and seek urgent medical advice from your GP or NHS **111** if your child:

- develops blisters
- develops a rash
- starts to have suicidal or self-harm thoughts

It is important to tell the healthcare professional that your child has taken modafinil.

**In an emergency**, take your child to your nearest emergency department. Please also inform our sleep clinic.

For a full list of possible side effects, please see the manufacturer's leaflet that comes with your child's medication.

If your child experiences any of the side effects listed above, or you have concerns about your child, please contact us for advice. Outside of our working hours, contact NHS **111** for advice.

## General advice for medication

- Try to give your child their medication at the same time(s) each day to help you remember.
- Never give your child's medication to anyone else, even if their condition appears to be the same, as this could be dangerous.
- **If you think that someone else has taken your child's medication by accident, contact the person's general practitioner (GP) or NHS 111 immediately, or take them to the nearest emergency department if they are unwell.**
- If you think the medication is not working, contact us but continue to give the medication as usual. Do not give any extra doses as this may be dangerous.
- Make sure that your child always has enough medication. Order a new prescription at least two weeks before it runs out.
- Make sure that the medication your child has at home has not reached the 'best before' or 'use by' date on the packaging. Give old medication to your local pharmacy to dispose of.

## Contact us

If you have any questions or concerns, please contact us.

Sleep clinic

Telephone: **023 8120 5922** (Monday to Friday, 9am to 5pm)

Email: [paedssleepadmin@uhs.nhs.uk](mailto:paedssleepadmin@uhs.nhs.uk)

## Useful links

[www.nhs.uk/conditions/narcolepsy](http://www.nhs.uk/conditions/narcolepsy)

[www.medicinesforchildren.org.uk/advice-guides/general-information-about-medicines/unlicensed-medicines](http://www.medicinesforchildren.org.uk/advice-guides/general-information-about-medicines/unlicensed-medicines)

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