

Your child's medication: Methylphenidate 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 methylphenidate as part of their treatment programme. This factsheet explains how your child should take methylphenidate. 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.

Methylphenidate

Methylphenidate is in a class of medications called central nervous system (CNS) stimulants. It is used to control symptoms of attention deficit hyperactivity disorder (ADHD), but it can also be used to treat excessive daytime sleepiness due to narcolepsy and other sleep disorders.

How does methylphenidate 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
- methylphenidate medication and/or other medications

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

Is methylphenidate suitable for everyone?

Your child should not take methylphenidate if they have:

- a history of heart disease (any problem affecting the heart, including arrhythmias)
- high blood pressure
- psychosis (when people lose some contact with reality) and/or other psychiatric disorders
- severe depression
- anorexia nervosa (an eating disorder and serious mental health condition)
- hyperthyroidism (where the thyroid gland produces too much of the thyroid hormones)
- vasculitis (a group of conditions that cause inflammation of the blood vessels)

Methylphenidate should be used with caution if your child has:

- anxiety
- a family history of Tourette's syndrome (a condition that causes a person to make involuntary sounds and movements called tics)
- epilepsy (a condition that affects the brain and causes frequent seizures)

How to take methylphenidate

Methylphenidate comes as:

- slow-release tablets
- slow-release capsules
- immediate-release tablets
- an immediate-release oral solution (a liquid)

It is important that you are aware which type your child is taking. We also recommend that you stick to the same brand of methylphenidate unless we advise otherwise.

If your child is prescribed slow-release tablets or slow-release capsules

Your child must swallow slow-release tablets and capsules whole with water. They must not chew or crush them.

If your child is prescribed immediate-release tablets

Your child can swallow the immediate-release tablets whole or halved with water. If your child is unable to swallow tablets, you can crush the tablets and your child can take them with a spoonful of soft food, such as yoghurt or mashed potato.

If your child is prescribed an immediate-release oral solution (a liquid)

Shake the bottle for at least 10 seconds and follow the instructions in the patient information leaflet that comes with the medication. Your child should swallow the dose with a drink of water. The oral solution may only be suitable for use for a stated period after opening it. Please check the patient information leaflet to see when this is.

Methylphenidate can be taken with or without food. The medication should start to work 5 to 20 minutes after your child takes it.

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

Dose

Methylphenidate comes in different strengths. We will prescribe your child a low dose to start with. We will increase the dose gradually to minimise the risk of 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 methylphenidate. 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 methylphenidate.

Contraception

Methylphenidate is not known to interact with hormonal contraception.

Pregnancy and breastfeeding

Methylphenidate should only be taken during pregnancy if the benefits outweigh the risks.

Contact us for advice if your child:

- is pregnant
- thinks they may be pregnant
- is planning to have a baby
- is breastfeeding

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 methylphenidate, 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 methylphenidate.

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 methylphenidate?

It can be dangerous to take too much methylphenidate.

If your child takes too much methylphenidate, 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 methylphenidate?

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

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

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 methylphenidate. We will prescribe your child a low dose to start with, to reduce the chance of side effects.

Common side effects

- Nausea (feeling sick) and loss of appetite – When your child first starts taking methylphenidate, they may feel slightly sick in the morning and lose their appetite. To help with this, your child should try to have a small plain breakfast.
- Diarrhoea - To help with this, your child should drink plenty of water.
- Headaches - To help with this, your child should drink plenty of water, and if needed, they can take a mild pain relief medication, such as paracetamol. Always read the label or instructions that come with the medication before giving it to your child.

These side effects will usually disappear with time as your child's body adjusts to the new medication. If the side effects do not improve within a few weeks or you have any concerns about your child, please contact us for advice.

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

General advice for medication

- Try to give your child their medication at about 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 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

Useful links

www.nhs.uk/conditions/narcolepsy

www.nhs.uk/medicines/methylphenidate-children

www.narcolepsy.org.uk/resources/methylphenidate

www.medicinesforchildren.org.uk/advice-guides/general-information-about-medicines/unlicensed-medicines

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit www.uhs.nhs.uk/additionalsupport

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