

Trihexyphenidyl hydrochloride for dystonia



This leaflet is for parents and carers about how to use this medicine in children. Our information sometimes differs from that provided by the manufacturers, because their information is usually aimed at adults. Please read this leaflet carefully. Keep it somewhere safe so that you can read it again.

Do not stop giving trihexyphenidyl suddenly as your child may get withdrawal effects.

Name of medicine

Trihexyphenidyl hydrochloride (also known as benzhexol hydrochloride); we refer to it as trihexyphenidyl in this leaflet.

Why is it important for my child to take this medicine?

Children with dystonia can get painful and distressing movements and muscle spasms and may have difficulty with sitting, standing and moving. Trihexyphenidyl acts in the brain to slow down messages to the muscles and nerves. This reduces muscle stiffness and improves comfort.

What is trihexyphenidyl available as?

- **Tablets:** 2 mg, 5 mg
- **Liquid medicine:** 5 mg in 5 mL

When should I give trihexyphenidyl?

Trihexyphenidyl may be given **once, twice or three times** each day, depending on what suits your child.

- **Once a day:** this can be morning or evening, depending on what works best for your child.
- **Twice a day:** this should be once in the morning and once in the evening. Ideally, these times are 10–12 hours apart, for example some time between 7 and 8 am, and between 7 and 8 pm.
- **Three times a day:** this should be once in the morning, once in the early afternoon and once in the evening. Ideally, these times are at least 6 hours apart, for example at 8 am, 2 pm and 8 pm.

Give the medicine at about the same time(s) each day so that this becomes part of your child's daily routine, which will help you to remember.

How much should I give?

- Your doctor will work out the amount of medicine (the dose) that is right for your child. The dose will be shown on the medicine label.
- Your doctor may recommend that you give a low dose of trihexyphenidyl to start with, and then increase the dose bit by bit. This helps your child to get used to the medicine. Your doctor will explain what to do.



It is important to follow your doctor's instructions about how much to give. Do not change the dose without talking to your doctor.

How should I give it?

Trihexyphenidyl should be given with some food or straight afterwards.



Liquid medicine: Shake the bottle well and measure out the right amount using an oral syringe or medicine spoon. You can get these from your pharmacist. Do not use a kitchen teaspoon as it will not give the right amount.



Tablets: These should be swallowed with a glass of water, juice or similar. Your child should not chew the tablets.

You can crush the tablet and mix it with a small amount of soft food such as yogurt, jam or mashed potato. Make sure your child swallows it all straight away, without chewing.

When should the medicine start to work?

Trihexyphenidyl starts to work straight away but you may not see immediate changes – it may take a few weeks for the full effect to be seen as you gradually increase the dose. Continue to give the medicine as instructed by your doctor.

What if my child is sick (vomits)?

- If your child is sick less than 30 minutes after having a dose of trihexyphenidyl, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of trihexyphenidyl, you do not need to give them another dose. Wait until the next normal dose.
- If your child is sick again, seek advice from your doctor, pharmacist or hospital. They will decide what to do based on your child's condition and the medicine involved.

What if I forget to give it?

If you usually give it once a day

Give the missed dose when you remember during the day, as long as this is at least 12 hours before the next dose is due. You do not need to wake a sleeping child to give a missed dose.

If you usually give it twice a day

If you remember up to 4 hours after you should have given a dose, give your child the missed dose. For example, if you usually give a dose at about 7 am, you can give the missed dose at any time up to 11 am. If you remember after that time, do not give the missed dose. Give the next dose as usual.

If you usually give it three times a day

Do not give the missed dose. Give the next dose as usual.



Never give a double dose of trihexyphenidyl.


What if I think I have given too much?

If you think you may have given your child too much trihexyphenidyl, contact your doctor or local NHS services (details at end of leaflet), or take your child to hospital. Take the medicine container or packaging with you, even if it is empty. This will be useful to the doctor. Have the medicine or packaging with you if you telephone for advice.

Are there any possible side-effects?

We use medicines to make our children better, but sometimes they cause effects that we don't want (side-effects).

Side-effects you need to do something about

 If your child struggles to do a wee when they feel they need to, take them to your doctor or hospital straight away.

- Your child's eyesight may become blurred (fuzzy). If this happens, contact your doctor for advice.

Other side-effects you need to know about

Your child may get these side-effects when they first start taking trihexyphenidyl hydrochloride. They will usually get better within a week or so as your child's body gets used to the medicine. Continue to give trihexyphenidyl as your doctor has told you to during this time. If any of these side-effects continue for longer than a week or so, or if you are worried, contact your doctor.

- Your child may get constipation (have difficulty doing a poo). Laxatives may help – ask your pharmacist for advice.
- Your child may feel sick or be sick (vomit).
- They may have a dry mouth. Taking sips of water or sucking on citrus fruits (e.g. oranges) may help.
- They may seem agitated, show changes in mood, have difficulty remembering things, may seem confused and may have hallucinations (seeing things that are not there).

There may sometimes be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor. You can report any suspected side-effects to a UK safety scheme at mhra.gov.uk/yellowcard.

More information on side-effects can be found in a leaflet on our website.

Can other medicines be given at the same time as trihexyphenidyl?

- Trihexyphenidyl should not be taken with some medicines that you get on prescription. Tell your doctor and pharmacist about any other medicines your child is taking before giving trihexyphenidyl.


- You can give your child medicines that contain ibuprofen or paracetamol, unless your doctor has told you not to.
- Check with your doctor or pharmacist before giving any other medicines to your child. This includes herbal and complementary medicines.

Is there anything else I need to know about this medicine?

- Do not suddenly stop giving trihexyphenidyl to your child, as they may get withdrawal symptoms.
- If your doctor decides to stop this medicine, they will discuss this with you. You will usually reduce the dose bit by bit. If you or your child want to stop this medicine, discuss this with your doctor. Do not change the dose without talking to your doctor first.

General advice about medicines

- Try to give medicines at about the same times each day, to help you remember.
- If you are not sure a medicine is working, contact your doctor but continue to give the medicine as usual in the meantime. Do not give extra doses, as you may do harm.
- Only give this medicine to your child. Never give it to anyone else, even if their condition appears to be the same, as this could do harm.

 If you think someone else may have taken the medicine by accident, contact a doctor straight away.

- Make sure that you always have enough medicine. Order a new prescription at least 2 weeks before you will run out.
- Make sure that the medicine you have at home has not reached the 'use by' date on the packaging. Give old medicines to your pharmacist to dispose of.

Where should I keep this medicine?

- Keep the medicine in a cupboard, away from heat and direct sunlight. It does not need to be kept in the fridge.
- Make sure that children cannot see or reach the medicine.
- Keep the medicine in the container it came in.

Who to contact for more information

Your doctor, pharmacist or nurse will be able to give you more information about trihexyphenidyl and about other medicines used to treat dystonia.

You can also get useful information from:

England: NHS 111 Tel 111 nhs.uk

Scotland: NHS 24 Tel 111 nhs24.scot

Wales: NHS 111 Wales Tel 111 111.wales.nhs.uk

Northern Ireland: NI Direct nidirect.gov.uk

Dystonia UK: dystonia.org.uk

www.medicinesforchildren.org.uk