

Baclofen 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 baclofen suddenly as your child may get withdrawal effects.

Name of medicine


Baclofen

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

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

What is baclofen available as?

- **Tablets:** 5 mg and 10 mg
- **Liquid medicine:** 5 mg or 10 mg in 5 mL


 When you get a new bottle of liquid medicine, check what strength it is and how much to give (the dose).

When should I give baclofen?

Baclofen can be given three or **four times** each day.

- **Three times each day:** These times should be 4–6 hours apart. For example, this could be between 7 and 8 am, at about midday, and between 7 and 8 pm.
- **Four times each day:** This should be first thing in the morning, around lunchtime, early afternoon and at bedtime. Ideally, these times are at least 4 hours apart.

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.

 It is important that you follow your doctor's instructions about how much to give.

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.
- When you first start giving baclofen to your child, you may give them a low dose to start with and then increase the dose bit by bit over a few days or weeks. This helps your child to get used to the medicine. Your doctor will explain what to do.

How should I give it?

Baclofen should be taken with some food or straight afterwards.



Your doctor may tell you to give a quarter, half or whole tablet.

Tablets (or part tablets) should be swallowed with a glass of water, juice or squash. Your child should not chew the tablet or part tablet.



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.

When should the medicine start to work?


Baclofen starts to work straight away and your child's muscles should begin to feel less stiff after taking baclofen regularly for 3–4 days. However, it may take up to 2 weeks or longer for the full effect to be felt, because the amount of medicine has to be increased slowly.

What if my child is sick (vomits)?


- If your child is sick less than 30 minutes after having a dose of baclofen, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of baclofen, 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 forget to give a dose, your child's muscles may become a little stiffer. Give the dose as soon as you remember. Wait at least 4 hours before giving the next dose.

 Never give a double dose of baclofen.

What if I think I have given too much?


 It can be dangerous to give your child too much baclofen.

If your child has a seizure (fit or convulsion), is very sleepy or difficult to wake up, or has difficulty sleeping, they may have had too much baclofen. Take them to hospital straight away. 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 has a seizure (fit or convulsion) or is very sleepy or difficult to wake up, they may have

had too much baclofen. Take them to hospital straight away.



If your child has difficulty breathing, take them to hospital straight away.

- If your child is confused, can't sleep or has nightmares, or seems anxious or shaky, contact your doctor.
- If your child's muscles become floppy (hypotonic), contact your doctor, as you may need to give less baclofen.
- Your child may have difficulty passing urine (having a wee). If they cannot pass urine, contact your doctor for advice.

Other side-effects you need to know about

- Your child may be more sleepy than usual.
- They may feel sick.
- Your child may feel light-headed when they sit up. Tell your doctor if this happens, as your child's blood pressure may low.

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 baclofen?

- You can give your child medicines that contain ibuprofen or paracetamol, unless your doctor has told you not to.
- Baclofen 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 baclofen.
- 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?



Liquid medicine comes in different strengths. When you get a new prescription, check what strength you have and how much you should give your child, as this may be different from the previous supply. If you are not sure how much to give, contact your pharmacist, nurse or doctor.



Do not suddenly stop giving baclofen 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. Do not change the dose without talking to your doctor first. 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.
- You may need to order baclofen tablets or liquid medicine specially from your pharmacy. Make sure you do this in plenty of time so that you don't run out.

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 the medicine you have at home has not reached the 'best before' or '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 baclofen 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