



Propranolol for tetralogy of Fallot



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 propranolol suddenly, as your child may have a harmful increase in blood pressure or heart rate or their heart may not beat properly.

Name of medicine

Propranolol

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

Children with tetralogy of Fallot sometimes have "spells" when the heart does not pump blood as it should, so blood flow to the lungs is reduced and there is less oxygen in the blood. Children may become irritable, cry uncontrollably, have rapid and deep breathing, their skin may turn blue or pale grey, and they may go floppy. This is called a cyanotic episode. Propranolol makes the heart muscle beats more slowly. This allows it to pump more blood to the lungs and more oxygen around the body.

What is propranolol available as?

• Liquid medicine: 5 mg in 5 mL, 10 mg in 5 mL, 40 mg in 5 mL, 50 mg in 5 mL

When should I give propranolol?

Propranolol should be given three or four times each day. Your health professional will tell you how often to give it.

Three times each day: These should be 6-7 hours apart, depending on what time your child wakes up and goes to bed. For example, this could be between 7 and 8 am, between 1 and 2 pm, and between 7 and 8 pm.

Four times each day: These should be 4–6 hours apart, depending on what time your child wakes up and goes to bed. For example, this could be between 7 and 8 am, between 11 am and 12 am, between 3 and 4 pm, and between 7 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 health professional may suggest that your child has a low dose of propranolol to start with. They may then increase the dose as your child gets used to the medicine and depending on how your child responds to it.

Your health professional will work out the amount of medicine (the dose) that is right for your child. The dose will be shown on the medicine label.



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

How should I give it?



Liquid medicine: Shake the medicine well. Measure out the right amount using an oral syringe. You can get these from your pharmacist. Do not use a kitchen teaspoon.

Make sure your child takes it all straight away.



Liquid medicine comes in several different strengths. Make a note of which one you usually have, and check that you have been given the right one each time.

When should the medicine start to work?

• The medicine starts working straight away, although you will not see any difference in your child.

What if my child is sick (vomits)?

- If your child is sick less than 30 minutes after having a dose of propranolol, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of propranolol, 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 health professional. 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, give the dose as soon as you remember. However, you must wait at least 6 hours before giving the next dose. If you are unsure, contact your healthcare professional for advice.

What if I think I have given too much?



It may be harmful to give too much propranolol.

If your child has any of the following symptoms, they may have had too much propranolol:

- they feel faint, dizzy, or cold and sweaty
- they have a seizure or fit
- slow or rapid heart rate (they may feel as though their heart is racing or fluttering)
- they begin to breathe quickly or have trouble breathing.

Contact your health professional or take your child to hospital. Take the medicine packaging or container with you, even if it is empty. This will be useful to the health professional

Are there any possible side-effects?

We use medicines to make our children better, but sometimes they cause unwanted effects (side-effects).

(Continued on the next page)



Side-effects you must do something about



🚮 If your child is short of breath or wheezy after having propranolol, take them to hospital or call an ambulance, as the medicine may have triggered an asthma attack.



🚮 If your child's face, lips or tongue start to swell, or they develop a rash, they may be allergic to propranolol. Take them to hospital or call an ambulance.



If your child has an irregular or fast heart beat (they may say their heart feels fluttery or is racing), contact your health professional straight away.



If your child gets a yellowish tinge to their skin or whites of their eyes, or they have severe stomach pain, pale poo, dark wee or a high temperature (over 38°C), contact your health professional straight away, as there may be a problem with their liver.



If your child gets nosebleeds that last over 10 mins unexplained bruising, or they bruise more easily than usual, contact your health professional, as there may be a problem with your child's blood.

Other side-effects you need to know about

- Your child may feel dizzy or light-headed when they stand up, or they may faint. Encourage them to stand up slowly, and to sit or lie down if they feel dizzy or lightheaded. If this happens frequently, contact your health professional to check your child's blood pressure, as it may be too low.
- Your child may feel physically tired (lethargy) and they may have difficulty getting to sleep.
- · Your child may say that their heart is beating slowly.
- · Your child may get headaches.
- Your child's hands and feet may feel cold. This is nothing to worry about but if their hands or feet hurt, contact your health professional for advice.
- Your child may feel sick or be sick (vomit) when they first start taking propranolol. Giving the medicine with some food may help. If this is still a problem after a week, contact your health professional for advice.

There may sometimes be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your health professional.

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

- You can give your child medicines that contain paracetamol or ibuprofen, unless your health professional has told you not to.
- Propranolol should not be taken with some medicines that you get on prescription. Tell your health professional about any other medicines your child is taking before giving propranolol.

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



Tell your health professional if your child has ever had asthma or wheeziness, as propranolol may trigger asthma in a small number of children.



Do not stop giving propranolol suddenly as your child may get a harmful increase in blood pressure or heart



When you get a new prescription of liquid medicine, check what strength you have and how much to give your child, as it may be different from the previous bottle.

- Your child's blood pressure and pulse rate will need to be measured regularly to check how propranolol is working. It is important that your child goes to these appointments.
- Propranolol is used to treat several different conditions in children. If you look for information on propranolol, make sure it relates to the condition that your child has.

General advice about medicines

- If you are not sure a medicine is working, contact your health professional but continue to give the medicine as usual in the meantime. Do not give extra doses, as you may do harm.
- 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.
- The liquid medicine does not keep for long once it has been opened. Write the date that you start it on the bottle and make sure you follow the instructions on the bottle about how long you can keep it.

Who to contact for more information

Your healthcare team will be able to tell you more about propranolol and about other medicines used for children with tetralogy of Fallot. You can also get 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

Children's Heart Federation

Tel 0300 5610065 chfed.org.uk

www.medicinesforchildren.org







