

Succinic acid for mitochondrial disease

This leaflet is about the use of succinic acid for complex I deficiency mitochondrial disease.



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.

Name of drug

Succinic acid

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

In complex I deficiency, cells do not have enough succinic acid, which the mitochondria in cells need to work properly to make energy.

Giving your child succinic acid does not cure the mitochondrial disease but may help to reduce the symptoms.

What is succinic acid available as?

- **Capsules:** 500 mg


When should I give succinic acid?

Succinic acid is usually given **twice each day**, 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.

Give the medicine at about the same times 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 succinic acid (the dose) that is right for *your* child. The dose will be shown on the medicine label.

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

How should I give it?



Capsules should be swallowed whole with a glass of water, milk or juice. Your child should not chew the capsules.

You can open the capsules and mix the contents with a teaspoon of jam, yogurt or honey. Your child should swallow it all straight away.

If you need to give less than a 500 mg dose, open the capsule and dissolve the powder in 10 mL of water (measured using an oral syringe or medicine spoon). Give your child the right amount using an oral syringe or medicine spoon. Your nurse or pharmacist will explain how to do this. Throw any unused mixture down the sink. Do not keep it for later.

When should the medicine start working?

The medicine may take some time to show any real effects. Your child may need to take it for up to 6 months to see if it helps.

What if my child is sick (vomits)?

- If your child is sick less than 30 minutes after having a dose of succinic acid, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of succinic acid, you **do not** need to give them another dose. Wait until the next normal dose.

What if I forget to give it?

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. Wait until the next normal dose.

What if I give too much?

If you think you may have given your child too much succinic acid, contact your doctor or local NHS services (details at end of leaflet). Have the medicine packet with you if you telephone for advice.

Are there any possible side-effects?

We use medicines to make our children better, but sometimes they have other effects that we don't want (side-effects). Your child may feel sick or be sick (vomit) when they first start taking succinic acid. Giving each dose with some food may help. This effect usually wears off after a few days. If it is still a problem after a week, contact your doctor.

Can other medicines be given at the same time as succinic acid?

- You can give your child medicines that contain paracetamol or ibuprofen, 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 or complementary medicines.

Is there anything else I need to know about succinic acid?

- Mitochondrial diseases vary widely between children and it may take some time to find a medicine that helps with the symptoms. It is important that you continue to give the medicine regularly.

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 your 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 'best before' or 'use by' date on the packaging. Give old medicines to your pharmacist to dispose of.

Where I should 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 child's doctor, pharmacist or nurse will be able to give you more information about succinic acid and about other medicines used to treat mitochondrial diseases.

You can also get useful information from:

England: NHS 111

Tel 111

www.nhs.uk

Scotland: NHS 24

Tel 111

www.nhs24.scot

Wales: NHS Direct

Tel 111

www.111.wales.nhs.uk

Northern Ireland: NI Direct

www.nidirect.gov.uk

The Children's Mitochondrial Disease Network

Help and information line: 01606 43946

www.emdn-mitonet.co.uk

www.medicinesforchildren.org.uk



Version 1.2, February 2010 (November 2011). © NPPG, RCPCH and WellChild 2010, all rights reserved.

The primary source for the information in this leaflet is the British National Formulary for Children. For details on any other sources used for this leaflet, please contact us through our website, www.medicinesforchildren.org.uk

We take great care to make sure that the information in this leaflet is correct and up-to-date. However, medicines can be used in different ways for different patients. It is important that you ask the advice of your doctor or pharmacist if you are not sure about something. This leaflet is about the use of these medicines in the UK, and may not apply to other countries. The Royal College of Paediatrics and Child Health (RCPCH), the Neonatal and Paediatric Pharmacists Group (NPPG), WellChild and the contributors and editors cannot be held responsible for the accuracy of information, omissions of information, or any actions that may be taken as a consequence of reading this leaflet.