Medicines for Children

information for parents and carers

Ubidecarenone for mitochondrial disease

This leaflet is about the use of ubidecarenone (also widely known as ubiquinone) for mitochondrial disease.

This leaflet has been written specifically about the use of this medicine in children. The information may differ from that provided by the manufacturer. Please read this leaflet carefully. Keep it somewhere safe so that you can read it again.

Name of drug

Ubidecarenone

Also known as ubiquinone, co-enzyme Q10 and co-Q10

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

In some mitochondrial diseases, the cells do not have enough co-enzyme Q10 (also known as ubiquinone), which the mitochondria in cells need to work properly to make energy. Giving your child ubidecarenone does not cure the mitochondrial disease but it may help reduce the symptoms.

It is important that your child takes this medicine regularly to replace the ubiquinone that your child's body does not produce naturally.

What is ubidecarenone available as?

- **Capsules:** 10 mg, 30 mg or 120 mg (other strengths are also available)
- **Tablets:** 10 mg
- **Liquid medicine:** 50 mg in 10 mL (other strengths are also available)

When should I give ubidecarenone?

Ubidecarenone can be given **once or twice each day**. Try to give it at about the same time(s) each day.

- If it is to be given once each day, this can be in the morning or the evening.
- If it is to be given twice each 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.

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

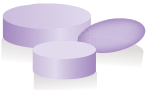
How much should I give?

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

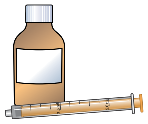
⚠ **It is important that you follow your doctor's instructions about how much to give.**

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 dissolve the contents of a capsule in water or fruit juice. Your doctor will have told you how much liquid to use, and how much of it to give your child. Give the right amount of mixture to your child straight away, using a medicine spoon or oral syringe.



Tablets should be swallowed with a glass of water, milk or juice. 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, honey or jam. Make sure your child swallows it straight away, without chewing.



Liquid medicine: Shake the medicine well. Measure out the right amount using an oral syringe or a 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 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 is helps.

What if my child is sick (vomits)?

- If your child is sick less than 30 minutes after having a dose of ubidecarenone, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of ubidecarenone, 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 GP, pharmacist or hospital. They will decide what to do based on your child's condition and the specific medicine involved.

What if I forget to give it?

If you are giving it once a day

If you remember before bedtime, give the missed dose. You do not need to wake up a sleeping child to give a missed dose. You can give the missed dose in the morning, as long as this is at least 12 hours before the next dose is due.

If you normally give it twice each 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. Just give the next dose as usual.

What if I give too much?

If you think you may have given your child too much ubidecarenone, contact your doctor or local NHS services (111 in England and Scotland; 0845 4647 in Wales) 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 have other effects that we don't want (side-effects).

Your child may get the following side-effects when they first start taking ubidecarenone. These should wear off as your child's body gets used to the medicine. If they are still a problem after a week or so, contact your doctor.

- Your child may have stomach ache or cramps, feel sick or be sick (vomit). It may help to give each dose of ubidecarenone with some food.
- They may have diarrhoea. Encourage them to drink plenty of fluid so that they do not get dehydrated.
- They may not feel hungry. Encourage your child to eat lots of small meals.
- Rarely, your child may get headaches, feel dizzy or have changes in mood (for example, be irritable or agitated).

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 http://www.mhra.gov.uk/yellowcard.

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

- 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 ubidecarenone?

- The metabolic 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 ubidecarenone 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 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 child's doctor, pharmacist or nurse will be able to give you more information about ubidecarenone and about other medicines used to treat mitochondrial disease.

You can also get useful information from:

England
NHS 111: 111 - www.nhs.uk

Scotland – NHS 24
NHS 24: 111 - www.nhs24.com

Wales/Galw Lechyd Cymru
NHS Direct: 0845 4647 - www.nhsdirect.wales.nhs.uk

Northern Ireland
NI Direct: www.nidirect.gov.uk

The Children's Mitochondrial Disease Network
www.emdn-mitonet.co.uk
Help and information line: 01606 43946

www.medicinesforchildren.org.uk

RCPCH Royal College of Paediatrics and Child Health Leading the way in Children's Health

WellChild the national charity for sick children

NPPG Neonatal & Paediatric Pharmacists Group

Health & care information you can trust The Information Standard Certified Member

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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