



# Carnitine for metabolic disorders

This leaflet is about the use of carnitine for metabolic disorders that cause carnitine deficiency.



This leaflet has been written 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 adult patients. Please read this leaflet carefully. Keep it somewhere safe so that you can read it again.

## Name of drug

**Carnitine (also known as L-carnitine)**

**Brand name:** Carnitor®

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

When your child's body digests fat in their food, it is broken down into fatty acids. The fatty acids are moved into cells and turned into energy. The body needs carnitine to move the fatty acids into the cells.

Your child does not have enough carnitine and therefore cannot use fat properly to give them energy. They may feel tired or weak or be confused, have stomach pain or diarrhoea or be sick (vomit). Taking carnitine regularly should improve your child's symptoms and make sure they have enough energy.

## What is carnitine available as?

- **Tablets:** 330 mg
- **Chewable tablets:** 1 gram
- **Liquid medicine:** 300 mg/ml (30%), 100 mg/ml (10%)

## When should I give carnitine?

Carnitine 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 carnitine (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?



**Tablets** should be swallowed with a glass of water, milk or juice. Your child should not chew the tablet.



**Chewable tablets** should be chewed and then swallowed.



**Liquid medicine:** 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 working?

It will take a few weeks for carnitine to work properly, so you may not see much difference in your child's symptoms to start with. It is important that you continue to give carnitine as you have been told to by your doctor.

## What if my child is sick (vomits)?

- If your child is sick less than 30 minutes after having a dose of carnitine, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of carnitine, 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. Just give the next dose as usual.

## What if I give too much?

You are unlikely to do harm if you give an extra dose of carnitine by mistake. If you think you may have given your child too much carnitine, contact your doctor or local NHS services (111 in parts of England; 0845 4647 in parts of England and Wales; 0845 24 24 24 in Scotland).

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 have stomach pain, feel sick (nausea) or be sick (vomit). Giving the medicine with some food or milk may help. They might also have diarrhoea.
- You may notice your child has a fishy body odour. Using a deodorant may help to hide this. If it is still a problem after 2 weeks, contact your doctor.

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://yellowcard.mhra.gov.uk>.

## Can other medicines be given at the same time as carnitine?

- 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.

## 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 carnitine and about other medicines used to treat carnitine deficiency.

You can also get useful information from:

### England - NHS 111

111

[www.nhs.uk](http://www.nhs.uk)

### England - NHS Direct

0845 4647

[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

### Scotland - NHS 24

08454 24 24 24

[www.nhs24.com](http://www.nhs24.com)

### Wales/Galw Iechyd Cymru - NHS Direct

0845 4647

[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

### Northern Ireland - NI Direct

[www.nidirect.gov.uk](http://www.nidirect.gov.uk)

### Climb (Children Living with Inherited Metabolic Diseases)

0800 652 3181

[www.climb.org.uk](http://www.climb.org.uk)

[www.medicinesforchildren.org.uk](http://www.medicinesforchildren.org.uk)