

CPT 1 Deficiency



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What is CPT 1 Deficiency?

CPT1 is an enzyme in the body that helps change fat to energy. CPT1 deficiency happens when this enzyme is missing or not working well. Your child was born with this condition.

The classic CPT1 is a rare serious disease. Babies with classic CPT1 are missing the CPT1 enzyme.

A milder form of CPT1 is common in First Nation people. Babies with mild CPT1 are as healthy and normal as other babies. Your child has a mild form of CPT1.

How does CPT 1 affect my child?

It is important to feed your child often and get medical help when your child is sick.

When your child is sick, you will need:

- an alarm to remind you to feed your child regularly, and;
- a thermometer to check if your child has a fever.

If your baby gets ill and does not eat for several hours, he/she can get very sick very quickly. If your baby is not treated quickly, he/she can have seizures, coma and even die.

You have been given an emergency letter that describes your child's condition. This will save time when you get medical help. Always carry your emergency letter with you at all times. Give it to the doctor, nurse or other health professional that is looking after your child.

What about medications, medical care, surgeries and procedures?

Your baby or child with CPT1 can have medications, medical care, or surgery as needed to stay healthy. If your baby or child needs surgery

or a procedure, he/she will not be able to eat or drink through the mouth for several hours. Your child will be given sugar/ glucose through an intravenous (a needle that is put into your child's vein). The intravenous will be started before surgery and continue until surgery is over and your baby or child is able to eat again. It is your responsibility to tell your doctor, dentist or other health professional that your child has CPT1 deficiency and needs an intravenous glucose fluid for the time your child cannot eat or drink.

What about immunizations?

Your baby should have his/her regular immunizations on schedule. Feed your baby every 2 hours for 24 hours after he/she gets the immunization shot. Sometimes babies can get a fever with immunizations. If your baby gets a fever, treat with medications like infant or child Tylenol™, Tempra™ or Advil™ as directed by your health professional. If the medication does not bring the fever down, you need to go to the nearest hospital or medical clinic. Take your emergency letter with you.

How do I feed my Baby with mild CPT1?

Newborn to 3 months old

Your baby's need for food such as breastmilk or formula is the same as other babies. Feed smaller amounts more often.

When your baby is well

It is important to feed your baby regularly every 3-5 hours **both day and night**.

When your baby is unwell

Feed your baby more often, every 2 hours, both day and night.

Take your baby to the nearest hospital or medical clinic with your emergency letter:

- if your baby won't eat.
- if your baby has a fever or is vomiting.

3 to 6 months old

Your baby's need for food such as breastmilk or formula is the same as other babies. Feed smaller amounts more often.

When your baby is well

It is important to feed your baby regularly every 4-6 hours both day and night.

When your baby is unwell

Feed your baby more often, every 2 hours, both day and night.

Take your baby to the nearest hospital or medical clinic with your emergency letter:

- if your baby won't eat.
- if your baby has a fever or is vomiting.

6 to 12 months old

As he/she grows, your baby will change how often and how much he/she wants to eat. During the day, offer food or drink every 3-4 hours. You can start to offer your baby cereal, fruits, and vegetables. Begin to use a cup.

Let your baby sleep for 6 to 8 hours at night.

When your baby is well

Be sure that your baby eats or drinks before he/she goes to bed at night and when he/she gets up each morning.

When your baby is unwell

Offer your baby fluids more often, every 2 hours, both day and night.

Take your baby to the nearest hospital or medical clinic with your emergency letter:

- if your baby won't eat.
- if your baby has a fever, or vomits.

Meanwhile, try to have your child drink something with sugar in it such as breast milk, formula, regular juice, or tea with sugar. Do not use diet or sugar free drinks.

Over 1 year old

When your child is well

Offer your child meals and snacks each day at regular times. Breakfast and bedtime snack are of special importance. *Your child does not need more food than other children his/her age.*

When your child is unwell

Give your child small amounts of food or drink every 2-4 hours both day and night.

Take your child to the nearest hospital or medical clinic with your emergency letter:

- if your child won't eat.
- if your child has a fever, or vomits.

Meanwhile, try to have your child drink something with sugar in it such as juice, regular kool-aid, tea with sugar, regular pop. Do not use diet or sugar free drinks.

Quick Reference

Age	0-3 months	3-6 months
Daytime feeding when well	3-5 hrs	4-6 hrs
Nighttime feeding when well	3-5 hrs	4-6 hrs
Feeding when ill day and night	2 hrs	2 hrs

Age	6-12 months	Over 1 year
Daytime feeding when well	3 meals and 3 snacks	
Nighttime feeding when well	6-8 hrs	10-12 hrs
Feeding when ill day and night	2 hrs	2 – 4 hrs