



# Vitamin and mineral deficiencies in people with neuroendocrine tumours

Nutrient deficiencies may occur in people with neuroendocrine tumours due to increased needs, reduced or altered dietary intake, and poor absorption from the gut due to surgery or treatment. There are a number of vitamin and mineral deficiencies that may occur, however the ones discussed in this fact sheet are the most common. Other deficiencies may be diagnosed based on an individual's diagnosis, treatment and symptoms.

## Do I need to take a multivitamin?

If you are eating well and consuming a good variety of foods through your diet, it is unlikely that taking additional vitamins and minerals will have any benefit. For those that are eating less than usual or have changed the types of food that they eat, a general multivitamin/mineral supplement may be worth taking. If you have been diagnosed with a vitamin deficiency it is usually better to take that particular vitamin as a supplement, as directed by your doctor.

## Niacin (Vitamin B3)

People with carcinoid syndrome or serotonin-producing tumours are at risk of niacin deficiency. Niacin and serotonin are made by the body using an essential protein from our diet called tryptophan. When tryptophan is used to make serotonin in excess, there may not be enough left to make niacin in the body too, leading to risk of niacin deficiency.

### How are niacin levels tested?

This is done through a 24-hour collection of urine.

### What are the symptoms of niacin deficiency?

- *Mild deficiency:* Indigestion, fatigue, canker sores\*, vomiting, depression.
- *Severe deficiency (Pellagra):* Rash, dark pigmentation on skin, swollen mouth and bright red tongue, vomiting and diarrhoea, headache, fatigue, depression, disorientation or confusion, memory loss.

## Taking a niacin supplement

For prevention of deficiency a dose of 20-40mg nicotinamide should be taken daily. Some doctors may recommend a vitamin B complex that contains other B vitamins as well. If you are unsure if you should take a niacin supplement or how much to take, ask your doctor.

If deficiency already exists then a much higher dose is recommended (usually above 100mg per day) but ask your doctor for advice specific to you.

*\*Canker sores: Painful oval shaped sores on the mouth which are white or yellow coloured, please note these are not cold sores.*

## Vitamin B12

There are several factors that can affect the absorption of vitamin B12 in your gut. Vitamin B12 is absorbed in the ileum (small bowel) so you may be at risk of B12 deficiency if you have had bowel surgery. Surgery to your stomach will also put you at risk of vitamin B12 deficiency because a substance produced by your stomach, called intrinsic factor, aids in absorption of B12. The absorption of B12 can be affected by small intestinal bacterial overgrowth, which can occur in some people after bowel surgery or in cases where a NET in the small bowel is affecting bowel function (leading to diarrhoea). Meat is a good source of B12 in our diet so if you are vegetarian or vegan, you may also be at risk of vitamin B12 deficiency.

### How are vitamin B12 levels tested?

This is easily tested through a blood test.



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## What are the symptoms of vitamin B12 deficiency?

Vitamin B12 plays an important part in the production of red blood cells. A deficiency may cause anaemia (fatigue, weakness, light-headedness), heart palpitations, shortness of breath, pale skin, smooth tongue and nerve problems (numbness, tingling, weak muscles). However, you can have a deficiency of B12 and not have these symptoms so it is best to check this through a blood test.

## Taking a B12 supplement

If you are at risk of vitamin B12 deficiency taking a B12 tablet (1000ug or 1mg per day) may be helpful.

If you have been diagnosed with vitamin B12 deficiency, B12 injections (1000ug) are the best treatment to ensure adequate absorption. Check with your doctor about the best method of vitamin B12 supplementation for you.

## Fat-soluble Vitamins (A, D, E and K)

Deficiency of fat-soluble vitamins may occur when there is reduced absorption of fat in the gut. Reduced fat absorption can occur after small bowel surgery, use of somatostatin analogues (e.g. lanreotide, octreotide), and in cases of severe diarrhoea and poor dietary intake. Vitamin D deficiency is quite common in people with NETs in the gut and pancreas. Deficiency of other fat-soluble vitamins – A, E and K, may also exist in people with NETs.

## How do I know if I am not absorbing fat appropriately?

If you have diarrhoea and/or your stools appear pale, oily, float or are hard to flush, then this might indicate that you are not absorbing fat as you should. Talk to your doctor, nurse or dietitian if your stools appear different or if you have diarrhoea. If your doctor or dietitian thinks you may have problems absorbing fat, they may recommend you take pancreatic enzyme tablets to help with this. Creon is a common brand of pancreatic enzymes and is taken at the beginning of meal times.

## How much Creon do I need?

If you have been told you need to take Creon, it is ideal to start taking 20,000 -25,000 units of Creon (2 x 10,000 unit capsule, or 1 x 25,000 unit capsule) at each meal. Additional capsules (10,000 – 25,000 units) may also need to be taken when eating snacks, particularly if they contain fat.

## How are fat-soluble vitamins levels tested?

Vitamin D can easily be tested through a blood sample. Vitamins A, E and K can also be tested through a blood sample but are not as easily accessible so it is best to check with your local doctor. If you are worried that you may be deficient in any of the fat-soluble vitamins talk to your doctor.

## What are the symptoms of fat-soluble vitamin deficiency?

- *Vitamin A:* night blindness
- *Vitamin D:* poor bone health and osteoporosis
- *Vitamin E:* dry skin, neurological symptoms (loss of coordination, unsteady)
- *Vitamin K1:* increased risk of bleeding

Even if you don't have any of these symptoms, you may still be at risk of deficiency, so speak to your doctor if you are concerned.

## Taking a fat-soluble vitamin supplement

You should not supplement fat-soluble vitamins unless you have a deficiency and are instructed to do so by your doctor. Because they are fat-soluble they are not easily removed by the body when in excess and can therefore lead to overdose and toxicity if too much is consumed.

*Please note:* This fact sheet is designed as a general guide for people diagnosed with a NET. For advice specific to you and your situation, talk with your doctor or nurse.