

Nutrition and neuroendocrine tumours (NETs): carcinoid syndrome and somatostatin analogues (SSAs)

Nutrition and dietetics [Patient information](#)

Carcinoid syndrome

NOTE: this section is only appropriate for those with high serotonin levels. This is tested by a urine or blood test for 5h1aa. Ask your NET nurse or doctor if you are not sure about this.

Carcinoid syndrome is a group of symptoms that can happen when a neuroendocrine tumour (NET) makes too much of a chemical called serotonin. This can cause:

- skin flushing (going red or hot)
- diarrhoea
- tummy pain
- wheezing or trouble breathing

When your body makes too much serotonin, it can use up a lot of tryptophan (a building block of protein) and niacin (vitamin B3). This means you may need more protein and more niacin in your diet. It is recommended to:

- have at least four sources of high protein in meals or snacks per day. For example, fish, poultry, lean meat, eggs, dairy foods, beans, lentils, tofu, Quorn®, nuts.
- take a daily niacin supplement (nicotinamide) of at least 40 milligrams. This can be nicotinamide on its own or a vitamin B complex which contains nicotinamide. You can get this from your GP or buy it yourself. Ask your NET team if you need help with this.

There is no strong evidence around avoiding certain foods. Some patients do notice that certain foods make their symptoms worse. You can make changes to your diet you want to. You don't have to. If you cut out lots of foods, ask a dietitian to help make sure you are getting all the nutrients you need.

Things that may make symptoms worse:

- A large meal
- Fatty foods
- Spicy food
- Alcohol

- Foods or drinks high in 'amines'. These are aged cheeses, alcohol, aged or processed fish and meat, offal, yeast extract, fermented tofu or dairy, soy sauce, miso, sauerkraut, dark chocolate, cocoa, and coffee.

Carcinoid syndrome diarrhoea

Diarrhoea is a common symptom of carcinoid syndrome; it may help to:

- eat little and often
- drink plenty of fluids
- avoid foods that you feel make your diarrhoea worse (see information above)

You may need to take anti-diarrhoeal tablets e.g. loperamide. These tablets are best taken around 30 minutes before a meal. Always speak to your dietitian, nurse, or doctor before starting these. Speak to your NET dietitian, nurse or doctor if you are still struggling with diarrhoea after trying the above,

Somatostatin analogues

Change in bowels caused by somatostatin analogue injections

If you are being treated with somatostatin analogue injections (octreotide/lanreotide) a common side effect is reduced pancreatic enzymes. This can cause several symptoms including:

- steatorrhoea - poo may be pale (cream/yellow/grey), oily or greasy, floating and difficult to flush away, frothy, very smelly
- lots of wind
- tummy cramps
- bloating

If you experience these symptoms, it is important to tell your NET dietitian, nurse, or doctor. You will often be prescribed pancreatic enzymes to help your body break down your food properly. These may be called Creon® or Nutrizym®.

- Suggested starting dose: One capsule with each snack or milky drink. Two capsules with each meal.
- The dose may need to be increased until your symptoms have gone or improved.
- Take your first capsule with your first mouthful of food, sip of milky drink, or prescribed supplement drink. Then spread them over the period of eating or drinking.
- Do not take with hot liquids.
- Store capsules under 25 degrees C.
- They do not usually need to be taken with fruit juice, fruit, vegetables, fizzy drinks, or squash.
- If you eat slowly or have multiple courses, you should take some at the start and some part way through the meal, or with each course.
- The enzymes are produced from pigs and there are no effective vegan alternatives.
If this is a concern, please speak to your dietitian or nurse.

Fat soluble vitamins

If you need to take enzymes, you may be more at risk of low levels of vitamins A, D, E, and K. Taking enzymes will help your body to absorb these vitamins better.

You may need blood tests to check your vitamin levels. You may need supplements if they are low. Everyone in the UK is advised to take a 10 microgram (400IU) vitamin D supplement in winter (October to March). Taking your vitamin supplements with food and enzymes will help your body to absorb them.

Alternative diets

There are a lot of diets and/or foods in the newspapers or online that can claim to cure or improve cancer. Most of these diets are not proven to work. They can even be unsafe. The safest approach is to follow a varied and balanced diet. This helps you to get all the energy, protein, vitamins, and minerals you need.

Speak to a dietitian if you would like to try a certain diet or supplements. They can check that your diet will still provide everything your body needs.

Useful contact details and resources

Ruth Lee

Neuroendocrine oncology dietitian

Wessex NET group

Tel: **07887 832343**

Email: **ruth.lee4@nhs.net**

Macmillan Cancer Support

www.macmillan.org.uk

or **0808 8080000**

National cancer charity

Neuroendocrine Cancer UK:

www.neuroendocrinecancer.org.uk

National charity for NET patients

PLANETS cancer charity

www.planetscharity.org

Local Wessex charity for NET patients

Creon booklet

- for more information on enzyme tablets

www.creon.co.uk/-/media/creoncouk/assets/pdf/2024/uk_non_2024_00104_pert-booklet-printed-version.pdf



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