



Royal Berkshire
NHS Foundation Trust

Neuroendocrine tumours (NETs) and diet

Information for patients

Name: _____

Your CNS: _____

Your Dietitian: _____

Dietitian contact number: _____

Diet is something that you can take control of to help you get the best possible results from your treatment and improve your quality of day-to-day living. This leaflet gives you advice and information about managing your diet to help with symptoms of your neuroendocrine tumour (NET) and NET treatment(s).

Contents

Common symptoms	3
• Carcinoid syndrome	4
• Diarrhoea	5
• Fat malabsorption (steatorrhoea)	6
• Weight loss	7
• Nausea and vomiting	8
• Wind and bloating	8
• Constipation	9
• Bowel obstruction	9
• Feeling full	9
• Indigestion and reflux	10
• Taste changes	10
• Sore mouth	11
Dietary changes for specific tumours	11
• Insulinoma	11
• VIPoma	13
• Glucagonoma/Somatostatinoma	13
Dietary changes for specific treatments	14
Alternative diets	14
Complementary therapies	15
Useful resources	15
Contact details	15

Benefits of eating well for your type of NET:

- It helps your body cope better with treatment.
- It helps wounds and damaged tissues heal better after treatments: including surgery, chemotherapy and radiotherapy.
- It improves your body's immune system which protects you from infections.
- It will also help you stay at a healthy weight. This is always important, even if you are not having treatment.
- It helps to maintain your fitness level so you can continue to carry out everyday tasks.

Healthy eating

A healthy, well-balanced diet should be followed if you are not underweight and your symptoms are well controlled, unless you are told otherwise. This includes:

- Fruit and vegetables – at least 5 portions a day.
- Starchy carbohydrates e.g. wholegrain bread, rice, pasta and potatoes.
- Protein e.g. meat, fish, eggs, beans, lentils, nuts.
- Milk and dairy (or alternatives) e.g. milk, yoghurt, cheese.
- Oils and spreads in small amounts, preferably unsaturated, eg vegetable/sunflower/rapeseed/olive oils and spreads.
- Minimal amounts of foods high in fat and sugar e.g. chocolate, cakes, biscuits, soft drinks, crisps, sweets, deep-fried foods.
- Fluid – 8-10 glasses or cups a day.

Common symptoms

There are a range of symptoms that people with NETs may experience which can be improved with diet. These symptoms can be caused by the NET itself, medications you are taking or treatments that you are having.

Carcinoid syndrome

In some patients the NET makes hormones (chemicals) that can cause symptoms such as flushing, diarrhoea and wheezing. The process of making these hormones uses tryptophan, which in turn is needed to make niacin (vitamin B3); levels of both of these can become low.

As a result, diets should aim to provide increased amounts of dietary protein and niacin, therefore it is recommended to:

- Have at least four sources of high protein in meals or snacks per day, e.g. fish, poultry, lean meat, eggs, dairy foods, beans, lentils, tofu, Quorn, nuts and seeds.
- Consider taking a daily niacin containing tablet such as Vitamin B Strong compound.

There are some foods that people report are more likely to trigger abdominal pain, diarrhoea and flushing symptoms, but these can be different for each individual. You can keep a food and symptom diary – a simple list of everything you eat and drink daily and any symptoms you may have – to try to identify which foods trigger your symptoms.

A dietitian can help you to ensure that vital food groups are not removed from the diet to prevent any nutrient deficiencies.

Common triggers:

- A large meal.
- High fat content (fats higher in medium chain triglycerides (MCTs) e.g. coconut oil may help prevent symptoms as they are digested differently).
- Alcohol.
- Spice.
- Meals moderate to high in amines.
 - Foods high in amines: aged cheese, alcohol, smoked/salted fish and meat, yeast, fermented tofu, miso, sauerkraut.

- Foods moderate in amines: large dose of caffeine, chocolate, peanuts, brazil nuts, coconut, avocado, banana, raspberries, most soybean products (soy sauce, tempeh), broad beans.

Diarrhoea

Diarrhoea may be a result of hormones, treatment or intolerance to foods. If it is worse than normal and you have not just started a new treatment see your doctor as you may have an infection. Some suggestions of things you can try are:

- Try reducing insoluble fibre in your diet e.g. cook, peel and remove seeds from fruit and vegetables and reduce bran, whole-wheat, nuts, seeds, beans, peas and lentils.
- Try reducing your intake of alcohol and caffeine from tea, coffee and fizzy drinks.
- Avoid spicy and fatty foods.
- Avoid sugar-free sweets, gum, mints and drinks containing sorbitol, xylitol and mannitol.
- A non-dairy multi-strain probiotic containing Bifidobacterium and Lactobacillus (such as Bio-kult advanced multistrain) may help. The recommended dose is greater than 2 billion parts. These are available to buy without a prescription from larger pharmacies or online. If you wish to take probiotics during chemotherapy, please discuss this with your medical team.
- If suffering from diarrhoea and you have tried all of the above, you could ask to see a dietitian for a trial of the low FODMAP diet (diet low in fermentable carbohydrates).
- If your terminal ileum (end of small bowel) or gall bladder have been removed this can cause diarrhoea. You may need to have a SeHCAT scan (a test to find out how well your gut is able to absorb bile acids) and then follow a low-fat diet with the guidance of your dietitian and/or doctor who may prescribe a bile acid binding drug, e.g. cholestyramine (Questran) or colesevelam.
- If you have had some types of gastro-intestinal surgery or been on long term antibiotics your diarrhoea may be due to small

intestinal bacterial overgrowth (SIBO) – too many bacteria, which can be harmful. There is not a reliable test to diagnose SIBO but your doctor may prescribe antibiotics to help treat it.

Fat malabsorption (steatorrhea)

Steatorrhea is caused by fat not being properly digested by the body and therefore it passes out in your stool which can become pale, oily, floating, frothy and/or smelly. It is due to the enzymes which normally break down our food not being available. In NET patients this can be due to the tumour itself, a side effect of taking somatostatin analogues (octreotide/lanreotide) or surgery where some or your entire pancreas has been removed.

You will often be prescribed pancreatic enzymes to help break down your food normally. Types of pancreatic enzyme replacement therapy (PERT) include: Creon®, Nutrizym®, Pancrease HL® or Pancrex®.

- Suggested starting dose: One capsule containing 22,000 or 25,000 units of lipase with a snack/small meal. Two capsules containing 22,000 or 25,000 units of lipase with a meal.
- The dose can then be increased based on patient weight and symptoms.
- Take with a drink before your first mouthful of food or a sip of milky drink or a nutritional supplement drink.
- They do not usually need to be taken with fruit juice, fruit, vegetables, fizzy drinks or squash.
- They are most effective after 30-40 minutes so if you are having a long meal you may need to take some at the start and some part way through the meal.
- You may need to take proton pump inhibitors e.g. omeprazole, before taking the enzymes as they help improve their effectiveness.
- Avoid alcohol one hour before and after PERT and meals.

Fat malabsorption and fat-soluble vitamin deficiency

If you are not absorbing fat, it can lead to deficiencies of vitamins A, D, E, K and B12. Taking PERT will help your body to absorb these; any ongoing deficiencies will be treated with vitamin supplements.

Weight loss

Sometimes when you have a NET you may lose weight which could be due to the tumour itself or the treatments you are having.

You can try to increase your intake with these tips:

- Eat little and often – 3 small meals and 3 snacks a day.
- Use convenience foods e.g. ready meals, tinned food, breakfast cereals.
- Use a side plate or saucer for your meals if it seems less daunting.
- Have protein (meat, fish, egg, dairy, beans, lentils, nuts, Quorn or tofu) at least three times a day.
- Fry or add oil/butter/margarine to foods e.g. potatoes, vegetables, eggs, fish, meat.
- Have full fat and full sugar foods.
- Add cream/cheese/butter/margarine to vegetables, potatoes, soups.
- Try to have a pudding once or twice a day with cream/ice cream/custard.
- Use fortified milk – add 3-4 tablespoons of skimmed milk powder to one pint of whole milk.
- Have regular milky drinks e.g. hot chocolate, Horlicks®, Ovaltine®, Nesquik®, milkshake, Complan®.

If you continue to lose weight ask to see a dietitian for a personalised dietary plan and for a trial of nutritional supplement drinks e.g. Ensure®, Fortisip®, Fresubin®.

Nausea and vomiting

How to manage nausea:

- Eat small, frequent meals throughout the day to avoid feeling full.
- Take small sips of nutritious drinks e.g. milk, milkshakes, nutritional supplement.
- Drink between meals rather than with them to avoid feeling full.
- Avoid cooking smells if possible, eg by eating cold foods and drinks, which have less smell than hot, cooked foods.

To reduce nausea, try:

- Tart flavours, e.g. Citrus juices, sorbets and lemon curd.
- Peppermints or peppermint tea.
- Plain biscuits, crackers or dry toast.
- Avoiding greasy or fatty foods.
- Ginger in food or drinks.

Wind and bloating

This can be caused by the NET itself or treatments and can accompany diarrhoea and constipation.

To help prevent symptoms:

- Try avoiding gas-producing foods e.g. onions, garlic, cabbage, sprouts, beans, lentils, cauliflower, broccoli, nuts and spicy foods. You can try these one at a time to see which cause symptoms.
- Try a low insoluble fibre diet: cook, peel and remove seeds from fruit and vegetables and reduce bran, whole-wheat, nuts, seeds, beans, peas and lentils.
- Avoid fizzy drinks and chewing/bubble gum.
- Chew your food well.
- Try eating oats, e.g. porridge.
- Try including up to one tablespoon of linseeds per day in your diet. Sprinkle it on your cereal/porridge/yoghurt but stop if you find it makes your diarrhoea worse.

Constipation

The cause of this should be investigated by the healthcare team and medication can be prescribed to help regulate bowel motions.

How to help prevent constipation:

- Drink plenty of fluids, at least 10 glasses a day.
- Increase the fibre in your diet (oats, bran, wholegrains, whole-wheat, brown rice/pasta, fruit, vegetables, nuts, seeds, beans, lentils).
- Try drinking prune juice.
- Try having one tablespoon per day of brown or golden linseeds (whole or ground) per day. Sprinkle them on your cereal or yoghurt.
- Take regular, gentle exercise.

Bowel obstruction or narrowed bowel

Sometimes a small intestine NET or previous bowel surgery can lead to a blockage in the bowel due to a build-up of fibrous tissue. These blockages cannot always be prevented with diet but your risk may be lowered with these tips:

- Follow a low insoluble fibre diet: cook and peel fruit and vegetables and reduce bran, wholewheat, nuts, seeds, beans and lentils.
- Chew your food well.
- Drink plenty of fluids.
- Some people may need to progress to a puree or liquid diet but this will be done with your dietitian.

NOTE: if you have a small bowel NET and severe abdominal pain you should go to your nearest Emergency Department (A&E).

Feeling full

There are many reasons that you may feel full after eating only a small amount of food. It may be due the NET itself, an enlarged liver or previous surgery. To help increase your dietary intake you could:

- Eat little and often, e.g. 3 small meals plus 3 snacks.
- Drink fluids separately to eating so they don't fill you up.
- Choose nutritious drinks e.g. milk, milky drinks, Complan®, nutritional supplement drink.
- Avoid fatty or rich foods.

Indigestion and reflux

This is a common symptom with gastrinomas; you may experience heartburn or an unpleasant taste in your mouth. To help improve this you could:

- Eat smaller and more frequent meals.
- Not lie down after eating and don't eat within 3-4 hours of bedtime.
- Avoid acidic foods e.g. citrus fruits and juices and tomato-based products.
- Avoid or cut down on alcohol, coffee, fatty or spicy foods.

Taste changes

Sometimes medications, treatments or infection can make foods taste unpleasant or have no taste at all. These suggestions may help:

- Try different foods including those previously disliked.
- Try foods at different temperatures.
- Try sharp or sour tasting foods e.g. citrus fruit, fruit juice, lemonade.
- Use plastic utensils.
- Rinse mouth with lemon flavoured water if foods taste metallic.
- Try different types of protein if meat tastes unpleasant, e.g. eggs, dairy products, beans, lentils.
- Use plenty of herbs, spices, dressings and marinades.
- Try foods with an appealing smell.
- Try palate cleansing foods before eating, e.g. non-citrus sorbet, celery, mint, parsley.

Sore mouth

This can be due to infection or a side effect of treatment, the following ideas may help:

- Eat little and often.
- Try drinking through a straw.
- Suck on crushed ice or ice lollies.
- Eat soft, moist foods – add gravy or sauce.
- Add sugar and cream to fruit to make it less acidic.
- Drink plenty of fluids.
- Chew sugar-free gum.
- Avoid crunchy, rough or sharp foods.
- Avoid hot, spicy or salty foods.
- Avoid acidic foods, e.g. tomatoes, citrus fruits, vinegar.
- Avoid hot drinks, fizzy drinks and alcohol.
- Ask your doctor about medicines or mouthwashes which may help.

Dietary changes for specific tumours

Insulinoma

This is a rare type of NET that releases insulin, which can then lead to low blood sugar levels (less than 4mmol/l) – hypoglycaemia. The symptoms of this are feeling sweaty, shaky, faint, feeling anxious and/or confused.

If you feel any of the above symptoms, you should immediately eat/drink one of the following:

- Three glucose or dextrose tablets.
- Five jelly babies.
- Small glass of a sugary (non-diet) drink e.g. Lucozade, cola.
- Small carton of pure fruit juice.

If after 15-20 minutes your blood sugar levels are still low, repeat the above. When your blood sugar levels are more than 4mmol/l eat or drink one of the following:

- Your next meal if due.
- Small sandwich.
- Piece of fruit.
- Small bowl of cereal.
- Glass of milk.

You can make changes to your diet to help prevent low blood sugars, but it will not change the insulin produced by the tumour. To prevent a low blood sugar level you could:

- Eat little and often.
- Have a bedtime snack to prevent overnight low blood sugar.
- Consider eating in the night to prevent overnight low blood sugar.
- Try a low glycaemic index diet – see table below.

Low glycaemic index (GI) diet:

- The GI measures how quickly a carbohydrate food raises blood sugar levels.
- Low GI carbohydrates are better for patients with an insulinoma as they slowly raise blood sugar levels for a longer amount of time to keep blood sugar levels stable.

Carbohydrate	Low GI choice
Bread	Multigrain, granary, rye, seeded, wholegrain, pitta, chapatti.
Potatoes	New potatoes including skin, sweet potato, yam.
Pasta	Al dente pasta, noodles.
Rice	Basmati, long grain or brown rice.
Breakfast cereal	Porridge, muesli, oat and bran based cereal.
Other grains	Bulgur wheat, barley, couscous and quinoa.
Other foods	Most vegetables, beans, lentils, nuts, seeds, wholegrain crackers.

VIPoma

This is a rare type of NET which produces vasoactive intestinal polypeptide (VIP) which can cause large amounts of watery diarrhoea. This can cause dehydration, numbness, muscle aches and weakness due to loss of fluid, potassium and bicarbonate in the diarrhoea.

To help with these symptoms you can:

- Drink 10-12 glasses of fluid – de-caffeinated and non-alcoholic.
- Try oral rehydration sachets or supplements e.g. Dioralyte.
- Try including high potassium foods in your diet:
 - Fruit or vegetable juice
 - Banana
 - Dried fruit
 - Avocado
 - Beetroot
 - Tomato
 - Spinach/greens
 - Potato
 - Lentils
 - Beans
 - Nuts and seeds
 - Bran cereals

Glucagonoma or Somatostatinoma

These tumours can lead to glucose intolerance which can cause diabetes mellitus. Speak to your endocrinologist doctor or your GP for dietary advice.

Dietary changes for specific treatments

- Everolimus (Affinitor) – **avoid** grapefruit, Seville oranges, star fruit and their juices and St John’s Wort supplement.
- Radiotherapy and chemotherapy – you may want to stop taking antioxidant supplements such as Coenzyme Q10, selenium and the vitamins A, C and E. Ask your doctor or dietitian for more advice.
- Chemotherapy or Interferon – if your white blood cells become low you should receive advice on food safety and how to prevent food poisoning. Ask your doctor or dietitian for more advice.
- Surgery – dietary issues will depend on the type of surgery you have had. Whipple’s, bowel resection, stoma formation and gastrectomy require greater changes in diet and individual advice will be provided by your dietitian or doctor in these circumstances. You may be asked to follow a low fibre diet – see section on bowel obstruction (page 9). You can also see the booklet ‘Gut surgery: how diet can help’ which can be found here:
<https://www.netpatientfoundation.org/wp-content/uploads/Gut-surgery-How-diet-can-help.pdf>

Alternative diets

There are a lot of diets in the media that can claim to cure or improve cancer. Unfortunately, most of these diets are not scientifically proven to work and can even be unsafe for some people. Do not rule anything out from your diet unless your dietitian specifically tells you to. Following a dairy free, serotonin free, sugar free, alkaline or ketogenic diet is **not recommended**.

If there are any nutritional supplement drinks or tablets that you would like to take please discuss with your dietitian or medical team **first**.

Complementary therapies

There should not be any problems with most complementary therapies alongside your medical treatment, but you should always discuss the suitability of any therapy with your medical team beforehand.

Useful resources

Macmillan Cancer Support www.macmillan.org.uk or 0808 8080000
National cancer charity

NET Patient Foundation: www.netpatientfoundation.org
National charity for NET patients

Contact details

Neuroendocrine Oncology Clinical Nurse Specialists
Berkshire Cancer Centre, Royal Berkshire NHS Foundation Trust
Tel: 0118 322 7748
Email: UpperGICancerNurses@royalberkshire.nhs.uk

For further general health-related information, please ask the relevant department or at the Macmillan Information Centre.

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