

FOOD AND NEUROENDOCRINE TUMOURS (NETs)



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What about supplements?

Why am I losing weight?

Enzymes

Some foods make my diarrhoea worse

Nourish

What is healthy for one person may not be for another

I can't tolerate fat

Diabetes

What will give me some energy?



What should I eat?

This may be one of the first things you think about when you get to grips with your Neuroendocrine Tumour (NET) diagnosis. The information compiled in this booklet has been obtained from talking to patients about their concerns and incorporates the most frequently asked questions. Because the subject of nutrition is a vast one and not all specific problems could possibly be covered, if you feel like you need further advice please contact your nurse, doctor or dietitian.

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Dietary tips in Neuroendocrine Tumours

Benefits of eating well for your type of tumour

- It helps you cope better with treatment.
- It helps wounds and damaged tissues heal better. This is important after surgery, chemotherapy, radiotherapy or other medical treatment.
- It improves your body's immune system, its natural defence.
- Eating well will also help you stay a healthy weight and feel better in yourself. This is important even if you are not having treatment.

Neuroendocrine Tumours with Carcinoid Syndrome

Neuroendocrine tumours (NETs) can occur anywhere in the body. In some patients the NET makes hormones (chemicals) that can cause symptoms such as flushing, diarrhoea, wheezing and damage to heart valves and these will be discussed with you. These symptoms are caused by the large secretions of serotonin from neuroendocrine tumour cells. When the body makes large amounts of serotonin, tryptophan (a special chemical called an amino acid) becomes too low. When tryptophan stores are low it cannot be converted into the vitamin niacin (Vitamin B3), which may then cause deficiency in this vitamin.

As a result, diets should aim to provide increased amounts of dietary protein (contains the amino acid tryptophan) and niacin (B3) without the risk of triggering carcinoid syndrome:

- Have 4-6 small high protein meals/snacks. High protein includes:
Fish, poultry, lean meat, eggs, low fat dairy, whey protein powder/products.
- You should take a daily niacin (B3) containing tablet such as Vitamin B Strong compound.
- Record and avoid carcinoid 'trigger' foods if you notice a problem (see below).

Carcinoid 'Trigger' Foods

Studies have shown that for some patients certain foods and drinks can 'trigger' symptoms such as abdominal pain, diarrhoea and flushing. The types of foods/drinks that cause this reaction are individual in nature and the most reliable method of identifying possible "trigger foods" is with a food and symptom diary. The diary is completed by the patient over a 2-week period including food intake, medications and then the symptoms experienced afterwards. If you find that something triggers your symptoms, try reducing the portion size and if this does not help, stop having it. You may want to speak with the NET Dietitian if you are having problems with your dietary adjustments.

Possible common triggers:

- Size of the meal.
- Fat content.
- Spice and alcohol.
- Meals moderate to high in amines may also trigger symptoms in some people:
 - Foods high in amines: aged cheese, alcohol, smoked/salted fish & meat, yeast, fermented-tofu, miso, sauerkraut
 - Moderate in amines: large dose of caffeine, chocolate, peanuts, brazil nuts, coconut, avocado, banana, raspberries, most soybean products (soy sauce, tempeh), broad beans.



Healthy Eating

For those people who are not losing weight, have symptoms controlled well and are otherwise well on no other prescribed diet, it is appropriate to follow a healthy eating diet.

The diet should be high in foods such as fruit, vegetables and wholegrains but low in nutrients such as salt, saturated fat and added sugars. Choose from a range of natural colours - at least 3 vegetable and 2 fruit portions a day.

Please refer to the Macmillan 'Healthy Eating and Cancer' Booklet for further information.

Pancreatic NETs

Insulinomas

Insulinomas are rare pancreatic neuroendocrine tumours which pump out insulin intermittently leading to a low blood glucose level (hypoglycaemia) and altered brain function and behaviour (neuroglycopenia). This can result in feeling sweaty, faint and confused.

We know diet cannot control the release of insulin from the tumour, but it can help prevent low blood sugars. People with insulinomas tend to suffer from low blood sugar levels until the tumour has been treated to stop it releasing excess insulin.

Glycaemic index

- The glycaemic index (GI) is a measure of how quickly foods that contain carbohydrates will raise blood sugar levels. Foods are given a GI number or classed as low, medium or high GI.
- Low GI carbohydrates are released slowly into the blood and therefore are able to maintain blood glucose levels for longer. It is recommended that you try to choose low GI carbohydrates as much as possible during the day to prevent sharp peaks and troughs in your blood sugars.
- High GI carbohydrates are released very quickly into the blood and are very useful when you are experiencing a hypoglycaemic (very low blood sugar) episode.

How to switch to a low GI diet:

- 5 a day- 3 vegetables and 2 fruit
- Choose healthy fats e.g. a small handful of nuts, olive/nut/vegetable oils or spreads.
- Eat breakfast cereals based on oats, bran and wholegrain wheat.
- Use breads with wholegrain or sour dough.
- Include whole-wheat pasta, noodles, pearl barley or quinoa.
- Choose jacket potatoes and leave the skins on.
- Add in beans, lentils and other pulses to soups, stews, salads and other dishes.
- Use brown, basmati or long grain rice.
- Choose wholegrain crackers and crisp breads.

Hypoglycaemia (Hypo) Treatment

'Hypos' (blood glucose under 4mmol/l) normally make you feel unwell and if very low can be serious.

- Diet can help in slowing their onset.
- Have a bedtime snack to prevent hypos while asleep.
- Some people may need to set an alarm in the night to eat and test their blood.
- When treating a hypo, first have a high GI snack (below)

Step 1: High GI foods - suitable for treating hypo's immediately:

- Dextrose tablets (4-5)
- Wine Gums (6)
- Liquorice Allsorts (5)
- Lucozade Energy (115mls)
- Lucozade Sport (310mls)
- Ribena (1/2 carton)
- Coca Cola (180mls), Fanta (150mls)

Check your blood glucose again after 15–20 minutes and if still low repeat the treatment.

Step 2: Low-Medium GI Foods – suitable for maintaining a stable blood glucose level.

- If over 4mmol/l, eat some starchy carbohydrate (Low-Medium GI):
- 1 unripe banana
- 1 thick slice of toast / half a sandwich
- Small bowl of cereal
- Whole-wheat / oat biscuits and milk
- Eat the next meal if due

Some people gain weight as they exceed the amount of high GI products they need to treat a hypo episode. Any excess glucose in the body is stored as fat.

If you have gained or lost a significant amount of weight, please ask to see a dietitian.

Gastrinomas

A gastrinoma is a pancreatic/duodenal neuroendocrine tumour that secretes the hormone gastrin. This can result in very high acid levels, causing stomach ulcers and diarrhoea. These can lead to other symptoms.

The symptoms in which diet may be helpful:

- Diarrhoea (See diarrhoea section, pages 9-10)
- Indigestion / heartburn (See gastric acid and reflux section, page 12)
- Anaemia leading to tiredness- you may need to have a blood transfusion or take iron supplements.
- Feeling and being sick (See the nausea and vomiting section, page 12)
- Weight loss (Please refer to the sections on weight loss and building-up diet- pages 8-9).
- Dysphagia (problems swallowing) you may need to eat a smooth, soft or pureed diet.

Glucagonomas

This tumour can pump out large amounts of the hormone glucagon. This results in a distinctive rash, glucose intolerance (including diabetes) and weight loss.

The symptoms in which diet may be helpful:

- Weight loss (See weight loss and building-up diet- pages 8-9).
- Diabetes mellitus – This is best managed locally through your local endocrinologist / GP.
- A sore mouth (See sore mouth section, page 13).
- Diarrhoea (See section on diarrhoea, pages 9-10).

VIPomas

These are pancreatic tumours that produce the hormone 'vasoactive intestinal polypeptide' (VIP). This can lead to profuse watery diarrhoea which results in low potassium, phosphate and bicarbonate levels in the blood.

The symptoms in which diet may be helpful:

- Muscle aches, weakness and cramps (by replenishing potassium).
- Numbness caused by low levels of potassium in the blood (by replenishing potassium).
- Dehydration – causing thirst, dry skin, a dry mouth, tiredness, headaches, and dizziness. Drink 10-12 glasses/mugs of non-alcoholic, non caffeinated fluid per day.
- Weight loss (See weight loss and building-up diet, pages 8-9).

If you are losing weight or suspect carbohydrate intolerance, see your dietitian.

Oral rehydration sachets, supplements and sometimes intravenous fluids are used, but high potassium foods/fluids may also be a useful addition to the diet.



Here is a list of high potassium food/fluid portions to include in your diet:

- 1/3 Pint of tomato juice
- 120g Canned prunes
- 100g Avocado flesh
- 100g Swiss style muesli
- 100g Red kidney beans (dried then boiled in unsalted water)
- 70g Sultana Bran
- 65g Dried dates
- 60g Ready to eat prunes
- 60g Mixed nuts (excluding macadamia)
- 50g Dried figs / Molasses / All Bran
- 40g Raisin or sultanas
- 40g Pistachio nuts (roasted and salted)
- 35g Dried apricots
- 1 Small baked potato
- 2 Large kiwi fruit/large plums
- 1 Large orange
- 1 Medium banana
- 1 'Complan' milkshake / 'Build up' milkshake / 'Ensure Two Cal'

Somatostatinomas

These are pancreatic neuroendocrine tumours which are found in the head of pancreas and produce high levels of Somatostatin.

The symptoms in which diet may be helpful:

- Weight loss (See weight loss and building-up diet- pages 8-9).
- Diarrhoea (See diarrhoea, pages 9-10).
- Fatty stools (See fat malabsorption -steatorrhoea), page 10).
- Diabetes mellitus – This is best managed locally through you local endocrinologist / GP.
- Postprandial fullness (See feeling full, page 12)



Common problems for NET patients:

Weight loss

You may need to see a dietitian if your doctor is concerned you are losing weight progressively. Weight loss, especially muscle loss can be a result of disease progression. It is important that we have realistic goals for weight management.

There are 3 types of nutritional interventions your dietitian may suggest:

- Oral Nutrition support: milkshakes, yoghurt drinks, high energy shots and powder supplements.
- Enteral Nutrition involving liquid that are fed into your digestive system through a tube.
- Parenteral Nutrition (PN) is feeding a person intravenously, bypassing the usual process of eating and digestion.

High energy and high protein, symptom controlling diets help to maintain weight- see below.

The Building-up diet

Good nutrition continues to be important for all patients who are having active treatment or those with stable disease. Many patients experience poor appetite and weight loss. The weight loss may be as a result of a number of problems, so you should discuss this with your doctor, nurse specialist and dietitian. If the weight loss is a result of not being able to eat enough, then a building up diet should be followed, choosing foods high in protein and energy.

The goals of nutrition support for patients in active treatment and recovery are:

- Prevent or correct cancer-related under nutrition
- Prevent and treat micronutrient deficiencies
- Help tolerate the cancer treatment
- Maintain strength and energy
- Protect ability to fight infection
- Help recovery and healing
- Maintain or improve quality of life

The aim of this section is to show you how to have more protein and energy without having to increase the quantity of food that you are eating. Some people may not be able to gain weight with this diet, but it should help to slow down the weight loss or help you to maintain your weight. General tips to boost your intake: Eat “little and often”. Small, frequent meals and snacks may be easier for you to manage rather than the traditional 3 meals per day. Have snacks in between your meals. Eat when you feel hungry. Use convenience foods (ready meals, canned foods, frozen foods) if you are too tired to prepare meals.



Food fortification tips: to increase your protein and energy intake:

- Foods rich in protein: meat, poultry, fish, eggs, dairy products (milk, yoghurt, cheese), pulses and nuts.
- Foods rich in energy: oils, nuts, butter, margarine, and any other foods high in fat and sugar. Use full-fat dairy products, e.g. whole milk, full fat cheese, full cream yoghurts, double cream
- Fortified milk: add 3 – 4 tablespoons of skimmed milk powder to 1 pint of milk. Use in the same way that you would use ordinary milk.
- Breakfast cereals: use fortified milk or neutral flavoured supplement drinks. Try adding dried fruit, nuts, sugar, honey, yoghurt, evaporated milk or cream.
- Stews or Casseroles: add noodles, lentils or beans. Stir in cream or sour cream.
- Soups or sauces: Make with fortified milk or add grated cheese, double cream, butter or oil. Puddings: add ice cream, cream, evaporated milk, condensed milk, jam, honey, golden syrup, lemon curd, dried fruit, nuts or chocolate.
- Use fortified milk to make milky puddings, e.g. custard.
- Sandwiches, toast, plain biscuits or jacket potatoes: add butter, margarine, mayonnaise, cheese, peanut butter, olives or avocado.
- Vegetables: add grated cheese, oil, butter or margarine.
- Salads: use oil, mayonnaise, salad cream, salad dressing, Greek yoghurt, nuts or seeds.

Nourishing drinks

If you do not feel hungry or you are unable to eat much solid food it is often easier to drink rather than eat. Try drinking these between meals rather than with meals as they may fill you up. The following drinks are higher in nutrients:

- Milky drinks, such as hot chocolate, Horlicks, Ovaltine and Nesquick.
- Use fortified milk or whole milk and add a scoop of ice cream or whey protein powder.
- Try full fat milkshakes, yoghurt drinks, fruit smoothies, Complan, Build-Up or Nourishment (available from your local chemist or supermarket).
- If necessary, your dietitian may advise you to get a prescription of supplement drinks if you are not able to manage with a fortified diet alone.

Regular, exercise such as walking has been shown to reduce muscle wasting, fatigue, as well as nausea and vomiting, and can help some people sleep better.

Diarrhoea

Diarrhoea may be a result of many things in NETs including the tumour secreting hormones, treatment you have had intolerance to foods or an infection. Here are some things to try:

- If out of the ordinary and you have not started a new treatment see your doctor as you may have an infection.
- If your gall bladder has been removed, your doctor may prescribe a bile acid binding drug e.g. Questran.
- Eat little and often.
- Reduce insoluble fibre but increase soluble fibre in diet (oats, apricots, high fruit jams).
- Cook and peel fruit and vegetables.
- Juices 'without bits' rather than whole products/smoothies.
- Non-dairy, multi-strain probiotics that contain bifidobacteria or lactobacillus strains in over 2 billion parts per dose. If you are on chemotherapy, please refer to page 14.

If you are suffering diarrhoea predominant IBS and other treatments have been trialled, see a qualified dietitian for trial of the low fructose, Oligo-saccharide, Di-saccharide, Monosaccharide and polyol (FODMAP) diet. Tell your doctor if the diarrhoea is greasy or you are post pancreatic surgery and you will need to follow the advice below for steatorrhoea.

Fat Malabsorption (steatorrhoea)

This can be caused by one of a few factors, for example: the treatment you are having, or due to surgery. You will recognise this in your stools. They may be floating, foul smelling and greasy and frothy looking. It may be necessary to reduce the amount of fats and fatty foods that you eat until it is under control. Your doctors may prescribe pancreatic enzyme replacement therapy (PERT) to help break down the food so that it can be more easily absorbed into the body.

Steatorrhoea treatment:

Types of pancreatic enzyme replacement therapy (PERT): Creon®, Nutrizym®, Pancrease HL® or Pancrex®.

Take Proton pump inhibitors e.g. Omeprazole, 30 minutes before taking the enzymes.

• *Suggested starting dose:*

- One 25,000 units of lipase capsule with all snacks/drinks (except carbohydrate free and fat free drinks)
- Two 25,000 units of lipase capsule with all main meals.
- The dose can then be titrated upwards. Sometimes 75,000 to 80,000 units of lipase per main meal is enough, but some people may need more than this.
- Take with a cold drink before your first mouthful.
- They last 40 minutes to an hour before they do not work anymore.
- Avoid alcohol 1 hour before and after PERT and meals.

Fat malabsorption and vitamin deficiency

If you are not absorbing fat, it can lead to weight loss and micronutrient deficiencies of vitamins A, D, E, K and B12. These deficiencies will be treated with supplements.

Since we live in a colder climate we are at higher risk of vitamin D deficiency regardless of any NET diagnosis.

-The best source of vitamin D is sunshine.

-Dietary sources of vitamin D: dairy, oily fish, fortified foods, supplements.

Constipation

- The cause of this should be investigated by the healthcare team if it is a sudden change.
- Medications should be discussed to help regulate bowel motions.
- Prevent getting dehydrated. You will need to drink additional fluids e.g. a few more glasses a day over your normal 8-10 a day.
- Prune juice can improve symptoms.
- Gentle exercise/mobilising may also help.
- Follow a high fibre diet:

High Fibre Diet (roughage)

- Starchy Carbohydrate: Wholemeal/brown bread, rye bread, high-fibre white bread, granary bread, wholemeal/ brown/ soya flour, brown pasta, brown rice and jacket potatoes.
- Cereals: wholegrain breakfast cereals e.g. all bran, bran flakes, weetabix, porridge oats, muesli, puffed / shredded wheat.
- Vegetables: Beans, lentils, peas, pulses, roast/crisp potato, sweetcorn. All fresh, frozen or tinned vegetables have some fibre.
- Fruit: Avocado pear, banana, berries, currants, grapefruit, orange, tinned prunes dried fruit, fresh or tinned fruit with skins and edible seeds.
- Biscuits: Whole-wheat biscuits e.g. digestive, oat-based biscuits, flapjacks, biscuits containing nuts or dried fruit, oatcakes and ryvita.

Wind and Bloating

This problem can accompany diarrhoea and constipation. Here are some tips to help:

- Avoid gas-forming foods, e.g. onions, garlic, cabbage, pulses, cauliflower, broccoli, nuts and spicy foods. Not everyone reacts in the same way to foods, so try them out in small amounts and avoid them only if they cause symptoms.
- Trial a low fibre diet (See below).
- Avoid fizzy drinks and chewing/bubble gum.
- Skipping meals is more likely to cause wind, therefore eat regular meals.
- Chew your food well to reduce the amount of air swallowed.
- Monitor your bowel movements and speak to your doctor or nurse if the problem persists.

Bowel Surgery

If you have had bowel surgery, the extent and location of the surgery affects the symptoms that you may experience. Many people have constipation or diarrhoea initially after surgery, however the bowel will adapt over time. A low fibre diet is usually recommended straight after bowel surgery (See page 12). This is commenced under the guidance of the hospital. As the bowel recovers from the surgery, the level of fibre can be gradually increased. It is essential that you are monitored and followed up closely after surgery to ensure your nutritional requirements are met. Occasionally, alternative nutrition is required e.g. liquid diet of nutritious milkshakes, or you may be fed through a tube into the gut or directly into the bloodstream.

A Narrowing Bowel

This is possible in bowel NETs when the tumour causing the problem cannot be removed and desmoplasia occurs (a fibrous tissue network that can affect the surrounding bowel). Sometimes the bowel narrows and obstructs the passage of food through the body. Here some dietary tips to help prevent blockages:

- Follow a low fibre diet (low roughage) to minimise risk of blockages. If you have recurrent blockages, it is a good idea to puree/liquidise low fibre foods.
- Chew everything really well.
- Drink plenty of fluids to prevent constipation.
- If you are used to eating a healthy diet, this diet may be difficult to follow and supplemental drinks could help bridge the gap.

Low Fibre Diet (refined)

- Starchy products: White bread, pita bread, plain Nan bread, croissants, crumpets, white scones, white muffins, Yorkshire pudding white flour, white pasta, white rice, tapioca, semolina, cornflour, custard powder.
- Cereals: rice krispies, coco pops, cornflakes, frosted flakes.
- Biscuits: plain white biscuits e.g. rich tea, custard creams.
- Vegetables: Small portions of the following without skins, seeds or stalks: Asparagus, beetroot, broccoli florets, carrot, cauliflower tops, celery, courgettes, cucumber, lettuce, marrow, mushrooms, onion, parsnip, peppers, potato, runner beans, squash, swede, tinned tomato.
- Fruit: Small portions of the following without skins or seeds (fresh, tinned or stewed): apple, apricot, grapes, lychees, mango, melon, nectarine, peach.

Gastric Acid and Reflux

This is a common symptom but can be helped by diet and posture.

- Avoid acidic foods such as citrus fruits and juices, tomato-based products.
- Avoid spicy foods.
- Try not to lie down immediately after eating as this may exacerbate the sensation.

Nausea and Vomiting

You may feel nauseous or vomit for several reasons (please ensure your NET team is informed and possible causes investigated)

- Eat small, frequent meals throughout the day to avoid feeling full.
- Take little sips of nutritious drinks between meals rather than with them.
- Cold food and drinks usually have less smell than hot cooked foods.
- Avoid cooking smells if possible.
- Tart flavours e.g. Citrus juices, sorbets and lemon curd.
- Salty and minty flavours.
- Plain biscuits, crackers or dry toast.
- Avoid greasy or fatty foods.
- Try ginger extract in foods or drinks e.g. crystallised stem and fresh ginger in stir fry's / juices / grated onto salads.

Feeling Full

Stomach resection, abdominal tumours, ascites (fluid in the abdomen) or enlarged liver can result in you feeling full after consuming only a small amount of food. Here are some helpful hints:

- Eat smaller meals and snacks more often.
- Avoid drinking fluids with meals or for an hour before-hand.
- Avoid fatty, greasy or 'rich' foods.
- Have puddings between meals if you are unable to have immediately after your meal.

Loss of Taste

- Choose foods which have a strong taste and smell.
- Hot foods are often better.
- Use plenty of seasonings, herbs, spices and marinades.
- Try sharp/sour tasting foods and drinks.
- Enhance the flavour of salads and vegetables by adding onions, orange, lemon juice or vinaigrette dressings.

Changes in Flavour

- Allow food to cool a little before being eaten.
- If meat tastes unpleasant, try alternatives such as fish, eggs, cheese and dairy products. Cold meats may taste better than hot meats.
- If bitterness is a problem, avoid foods sweetened with saccharin.
- If food tastes metallic, a gargle of lemon juice in water may help or try using plastic cutlery.

Sore Mouth

A sore, dry or painful mouth can be caused by ulcers, candida, gum disease or radiotherapy and some drug therapies.

Try to avoid food that can make the pain worse:

- Very hot foods and drinks.
- Food is best eaten at room temperature, however cold foods and drinks can be soothing.
- Salty or spicy foods as these may sting your mouth, e.g. crisps, chilli, curry, mustard.
- Rough textured, dry or crispy foods as they can be abrasive, e.g. toast, crackers, crisps, nuts.
- Acidic foods, e.g. citrus fruits and juices, vinegar.
- Sticky textured foods, e.g. peanut butter, chocolate.

The following may make eating and drinking easier:

- Have soft, moist foods with plenty of sauce or gravy, e.g. mashed potatoes, well-cooked pasta, noodles, milk puddings, soft sponge.
- Pureed fruit and vegetables may be easier to eat.
- You can add sugar and cream to the fruit to make it less acidic, easier to swallow and to increase the energy content.
- Eat small snacks between meals.
- Drink plenty of fluids to keep the mouth moist.
- Try drinking through a straw. If you are unable to eat normally choose nourishing drinks, e.g. milkshakes, supplement drinks.
- Sucking crushed ice, ice cream or ice lollies may numb your mouth before eating.
- Your doctor may be able to prescribe some medicine to help. Mouthwashes can be useful to clean and numb your mouth.

Tiredness/Fatigue

You may feel tired and fatigued but you can minimise this through diet and exercise. A low GI (glycaemic index) diet is one where the release of glucose into the blood is slow. This keeps your energy level more constant. Having a diet that is based on starchy carbohydrate, proteins and a moderate amount of healthy fats may help in minimising tiredness and fatigue. Light-moderate exercise is one of the best management strategies for fatigue.

NET Treatment and Management

Some side effects of drugs can impact on your nutritional status. You may need to use food and fluids to help prevent and treat some symptoms.

Chemotherapy

Streptozocin, carboplatin, oxaliplatin, irinotecan, temozolamide, capecitabine, etoposide, vincristine, doxorubicin, 5-fluorouracil and cisplatin are chemotherapy agents that can be used to treat NETs.

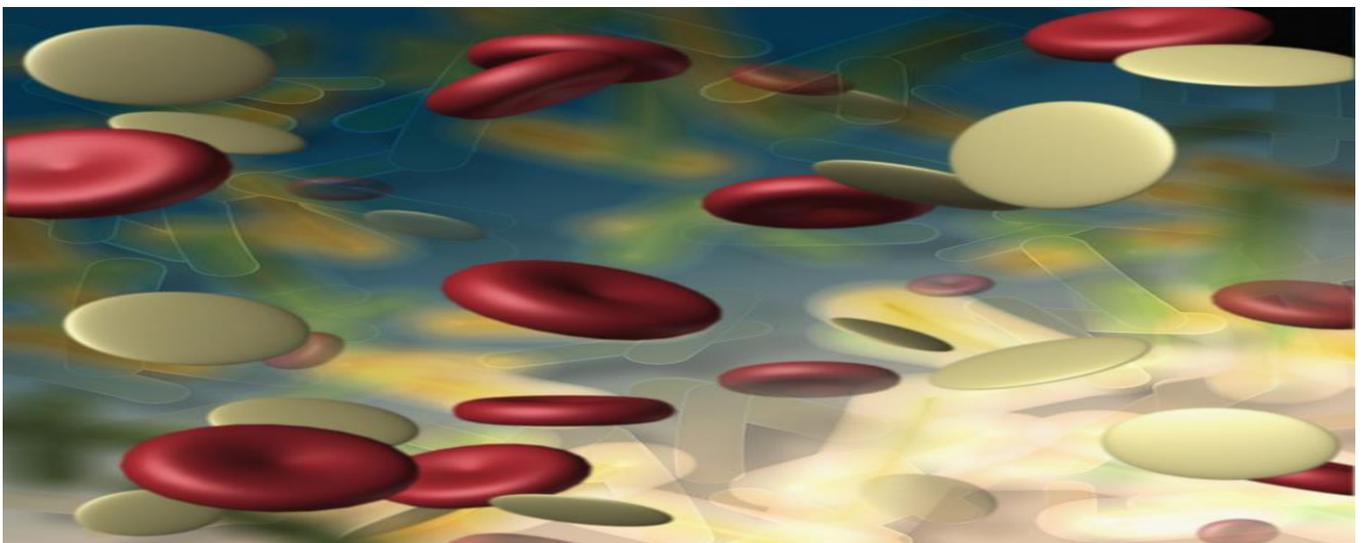
It is safer to exclude antioxidant vitamin supplements A, C, E and Coenzyme Q10 during the chemotherapy and radiotherapy period. To date, dietetic advice has been to avoid probiotic use during chemotherapy due to the theoretical risks posed to an immunocompromised patient. However, the actual evidence base is lacking to support this recommendation. Therefore, should you wish to take probiotics during chemotherapy, please discuss this with your medical team.

Possible side effects include:

- **Nausea and vomiting**
(See Nausea and Vomiting, page 12).
- **Diarrhoea**
(See the Diarrhoea, pages 9-10).
- **Weight loss**
(Please refer to the sections on weight loss and building-up diet, pages 8-9).

Neutropenia

If the chemotherapy causes the neutrophil white blood cells (cells which fight infection) to become too low, we call this neutropenia. This will mean that your chemotherapy may be delayed and you should follow the neutropenia diet booklet, excluding high food poisoning risk foods and probiotics, until your neutrophils return to a normal range.



Somatostatin Analogues

Short acting Octreotide, Sandostatin- LAR (Ocreotide) and Somatuline® Autogel (Lanreotide)

Possible side effects which affect nutrition:

Fat Malabsorption and Ocreotide therapy

Octreotide may alter absorption of dietary fats in some patients because it reduces pancreatic enzyme release. If your pancreas does not produce enough digestive enzymes, you may see stools that are pale, floating, loose, greasy, foul smelling and frothy.

- Pancreatic Enzyme Replacement Therapy (PERT) is sometimes required. (See Steatorrhoea treatment, page 10).

Fat malabsorption and weight loss in Octreotide therapy

Fat of any kind is high in dietary energy. If you are not absorbing fat, it ends up being wasted in your stools. Having fat in the stools or steatorrhoea can therefore lead to weight loss. It is important that you take your pancreatic enzymes correctly to stop this happening. (See Steatorrhoea treatment, page 10).

Fat Soluble Vitamin Deficiency in Octreotide therapy

Fat soluble vitamin deficiency may result in problems with your eyes, skin, bones, teeth and immunity. If you are not absorbing fat, it can lead to micronutrient deficiencies of vitamin A, D, E and K. It is important that you take your pancreatic enzymes correctly. If you have been on the drug for a long time, these blood tests will be undertaken and your Doctor will assess if you require vitamin supplements.

Vitamin B12 Deficiency in Octreotide therapy

Low vitamin B12 levels have been observed in some patients receiving octreotide therapy. Monitoring of vitamin B12 levels is recommended during therapy with Sandostatin LAR in patients who have a history of vitamin B12 deprivation.

Diarrhoea and discolouration of stools in Somatostatin Analogues

(See the diarrhoea, pages 9-10).

Nausea and vomiting in Somatostatin Analogues

(See nausea and vomiting, page 12).

Constipation, Trapped wind and Flatulence in Octreotide Therapy

(See constipation, wind and bloating, pages 10-11).

Gallbladder Problems with Somatostatin Analogues

Development of gallstones has been reported in people on somatostatin analogues, however they do not normally cause any problems. Unfortunately changing your diet is not effective in preventing drug-related gallstones.

Glucose metabolism in Octreotide Therapy

Your doctor will monitor the level of glucose in your blood. If you have diabetes, an Insulinoma, or you develop impaired glucose tolerance you may be told to monitor your own blood glucose levels and see a diabetes dietitian.

Afinitor (Everolimus)

This drug is used to treat adults with pancreatic neuroendocrine tumours (PNET's) that have progressed and cannot be treated with surgery.

Possible side effects include:

- **Tiredness/Fatigue**
(See Tiredness and Fatigue, page 13).
- **Inflammation of the lining of the digestive system**
Inflammation of the digestive system may lead to symptoms which can affect your nutritional status. These are listed below:
 - - **Diarrhoea**- See pages 9-10.
 - **Constipation**- See page 10-11.
 - **Nausea and vomiting**- See page 12.
- **Changes in blood sugar levels.**
Tell your Doctor or Nurse Specialist if your blood glucose results have changed their pattern since starting this treatment.
- **Fever**
If you develop a fever, tell your doctor. You will need to drink additional fluids e.g. a few more glasses a day over your normal 8-10 a day. If you are admitted to hospital you may have fluids replaced intravenously.
- **Loss of appetite**
(See symptom pages which you feel are causing this).
- **Weight loss**
(Please refer to the sections on weight loss and building-up diet- pages 8-9).
- **Taste changes**
(See Loss of Taste and changes in flavour sections, page 13).
- **Dry mouth, Mouth Ulcers and Sores**
Your Doctor may tell you to use a special mouthwash or gel.
(Please refer to the sore mouth, page 13).

! Drug –Nutrient interactions with Afinitor !

Please do not eat grapefruit, seville oranges, star fruit juice or drink their juices. St John's Wort supplement should also be avoided.

Sunitinib (Sutent)

This is a biological therapy which attempts to block the growth of some pancreatic neuroendocrine tumours.

Side effects include:

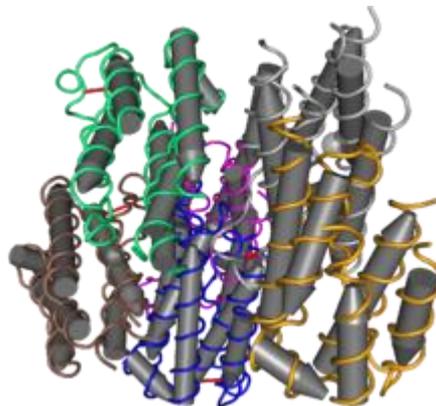
- **Nausea and vomiting** – this is usually well controlled with anti-sickness medicines. (See nausea and vomiting section, page 12).
- **Tiredness (fatigue)**
(See tiredness and fatigue, page 13).
- **Diarrhoea**
(See diarrhoea, pages 9-10).
- **A sore mouth**
(See sore mouth, page 13).
- **Loss of appetite**
(See symptom pages which you feel are causing this).
- **Weight loss**
(Please refer to the sections on weight loss and building-up diet- pages 8-9).
- **Indigestion and abdominal pain**
(See gastric acid and reflux, page 12).
- **Constipation**
(See constipation, page 10-11).
- **Anaemia** causing tiredness and breathlessness– you may occasionally need a blood transfusion or iron tablets.
- **Piles (haemorrhoids)**, causing pain in the back passage (rectum). This may be caused by constipation.
(See constipation page 10-11).

Interferon

Interferon stimulates the immune system to fight cancer.

Side effects include:

- **Neutropenia** (low neutrophil white blood cell level). You will need to refer to the Neutropenia Diet booklet to help exclude foods which are at high risk of causing food poisoning.
- **Anaemia** – you may need a blood transfusion, iron tablets or erythropoietin (EPO) injections.
- **Tiredness and Fatigue** during and after treatment – most people find that their energy levels are back to normal from 6 months to a year after their treatment ends. (Please refer to the tiredness and fatigue section, page 13).
- **Nausea and Vomiting** – this happens to about half the people treated. Your doctor or nurse may give you anti sickness medicines (anti emetics). Let them know if it is not controlled as you could try other anti-sickness drugs. (Refer to nausea and vomiting, page 12).
- **Diarrhoea** – you should drink plenty of fluids. If diarrhoea is severe or continues you could get dehydrated, so tell your doctor or nurse. (See diarrhoea section, pages 9-10).
- **Loss of appetite** – this may increase as your course of treatment goes on. (Please refer to the sections on weight loss and building-up diet, pages 8-9).
- **Taste changes or a metallic taste** in your mouth (See changes in flavour section, page 13).
- **A sore throat and pain on swallowing.** You may want to swap to a soft diet or a liquid diet.
- **Weight loss** (Please refer to the sections on weight loss and building-up diet- pages 8-9).



Radionuclide therapy

Radionuclide therapy may be of benefit in patients who have positive scans, i.e. patients who have positive I-123 mIBG scans may benefit from therapeutic I-131 mIBG therapy. Similarly, patients who have positive Octreotide scans or Ga68 Octreotate PET scans may benefit from agents such as Yttrium-90 DOTA Octreotide / Lutetium-177 DOTA Octreotate.

Some side effects following radionuclide therapy may include:

- Tiredness (See tiredness and fatigue page 13).
- Nausea and vomiting (See nausea and vomiting, page 12).
- Neutropenia (See neutropenia, page 14)

Some of these side effects can be life threatening, particularly infections. Contact your doctor or nurse if you are worried about side effects that bother you or do not go away.

Complementary Therapies

There are many types of complementary therapies. It is always best to check them out before you start using one. Take the name and any details you have to your dietitian / nurse / doctor. Most people who work in cancer care are more than happy for people to try complementary therapies – that is, therapies that can be used alongside conventional medical treatment. Many people benefit from these by having a bit of 'me' time and improving their sense of wellbeing and ability to cope with their situation. For example relaxation techniques such as visualisation control nausea, particularly when used in combination with anti-sickness drugs.

Special 'Cancer Diets' (Alternative Therapies)

When cancer diets are used instead of conventional treatment, we refer to them as alternative therapy (rather than complementary therapy). For example, following dairy free, serotonin free, sugar free, juice diets and having Vitamin C injections are not recommended. They may not be safe and may potentially reduce your health. Some diets may be too restrictive, especially if you are ill or not eating well. If you have any questions concerning specific diets, please discuss these with your Dietitian or medical team before you make any changes.

To date there are some promising early studies which involve potent pharmacological-like nutrients called nutraceuticals. Some of these nutraceuticals such as curcumin and green tea compounds and have shown anti-tumour effects in several other cancers and Xanthohumol, an extract from hops has shown promising anti-tumour effects in neuroendocrine tumour cells.

Neutraceuticals are currently not for use alone but they may be useful alongside your medical, conventional cancer treatment. It is important you tell your medical team if you decide to take any nutraceuticals or nutritional supplements.

Support

Carers

Carers play a very important role when it comes to nutrition and it is important that they look after themselves so they are able to cope with what life throws at them. Carers often feel stressed and frustrated especially when it comes to helping to nourish a loved one. Here are some supportive tips:

- Be there to offer help.
- Cook and chat about non cancer related things as this relaxes people.
- Set a relaxing environment at mealtimes e.g. scented candles and music.
- Don't feel deflated if food is avoided, everyone does their best. Step away and try cooking/buying another meal next meal time.
- If it is not possible for your loved one to eat, an occasional nourishing drink can take the place of a meal.

Peer support

Peer support groups are a great way for patients and carers to share ideas and reduce anxiety.

- Check any medical or dietary ideas with your medical team before trying them.

Useful resources

- NET Patient Foundation via www.netpatientfoundation.org
- Macmillan Cancer Support **Tel: 0808 8080000** or www.macmillan.org.uk

Questions you may like to ask your doctor, nurse or dietitian

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2

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5

**Royal Free Hospital Neuroendocrine Tumour Unit,
European Neuroendocrine Tumour Society Centre of Excellence
Royal Free London NHS Foundation Trust, Pond Street, London, NW3 2QG**

Positively **welcoming** *Actively* **respectful** *Clearly* **communicating** *Visibly* **reassuring**

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