

This booklet is part of the Paul Hunter Information Library, a series of patient friendly publications about neuroendocrine tumours, and related conditions treatments and tests, produced in memory of the late snooker player Paul Hunter, 1979-2006.

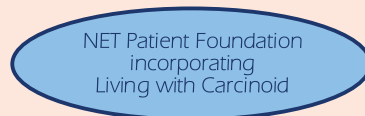


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The NET Patient Foundation supports people diagnosed with neuroendocrine tumours and their families.

For further information and to make contact visit our website:
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Nutrition in NETs

(Neuroendocrine Tumours)

NET Patient Foundation





There are many different types of neuroendocrine tumours, and each one affects the individual differently.

There are several issues surrounding this subject; therefore this booklet has been split into 3 categories:

1. Healthy Eating Guidelines

2. Nutritional Issues for NET Patients

3. Complementary Therapies

1. Healthy Eating Guidelines

A balanced diet is essential to provide all the nutrients that your body requires to function well. These nutrients include protein, carbohydrates, fats, vitamins and minerals. Protein is necessary to maintain or build your muscles. Carbohydrates are used in the body to provide energy. A small amount of fat is necessary in your diet to provide some of the essential fats and fat-soluble vitamins that your body needs.

In order to keep your weight stable, you need to consume the same amount of energy that your body uses. Equally, if you want to lose weight, then you need to consume less energy than your body needs, so your fat stores can be used up. If you are unwell or losing weight, then you will need to increase your energy consumption (see Building-Up diet).

A good diet is one that provides your body with everything it needs to keep it functioning well. In order to have a balanced diet, you need to choose foods every day from the following 5 food groups:

Bread, Cereals & Potatoes

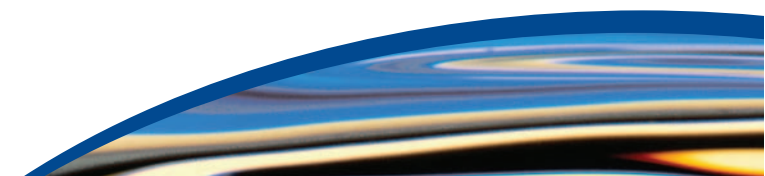
This group includes bread, potatoes, breakfast cereals, pasta, rice, noodles, oats and other cereals. Wholemeal and whole grain varieties are high in fibre.

You should aim to base your meals on starchy foods, therefore include at least one food from this group at each meal. If your bowels are functioning well, you should aim for the high fibre choices. However, some people may be advised by their doctor or dietitian to choose the low fibre varieties due to bowel problems (see Dietary Fibre section).

Fruit & Vegetables

This includes fresh, canned and frozen fruit and vegetables. Dried fruit and fruit juices also count.

The different colour fruit and vegetables provide different vitamins and minerals. The key for good health is to choose a wide variety, aiming for five portions of fruit or vegetables per day. This group provides soluble and insoluble (roughage) fibres.



Milk & dairy foods

Milk, cheese, yoghurt and fromage frais are included in this group. This group provides your body with protein and calcium. Aim for full fat varieties if you need to gain weight or low fat varieties if you need to lose or maintain your weight.

Meat, fish & alternatives

This group includes meat, poultry, fish, eggs, nuts, beans and pulses. Some of these products can be high in fat. Choose lean meats and lower fat versions of products. Vegetarians can use the following as a source of protein: nuts, tofu, mycoprotein, textured vegetable protein (TVP) and kidney beans.

It is essential to include at least one food from either the dairy or the meat group at each meal as your source of protein.

Foods containing fat & foods containing sugar

Foods containing fat: Margarine, butter, other spreading fats and low fat spreads, cooking oils, oil-based salad dressings, mayonnaise, cream, chocolate, crisps, biscuits, pastries, cakes, puddings, ice cream, rich sauces and gravies.

Foods and drinks containing sugar: Soft drinks, sweets, jam, honey and sugar, as well as foods such as cakes, puddings, biscuits, pastries and ice cream.

The emphasis should be on unsaturated fat e.g. olive, sunflower and corn oil, rather than saturated fat that tend to come from animal products, cakes, biscuits and pastries. If you are well and not losing weight, then you should only consume small quantities of foods from this group. If you are losing weight these foods should be added to increase the energy in your diet, in order to stabilise your weight or help you gain weight.

If you are well and not losing weight or having any dietary concerns then keep following the same diet. Do not try to change anything that does not need changing because you think you should.

Dietary fibre

Dietary fibre is roughage found in fruit, vegetables, wholegrain cereals, beans and lentils. Fibre is divided into two groups: soluble and insoluble fibre. Soluble fibre is partially digested by the gut and helps to lower cholesterol and control blood sugar. Oats, fruit, vegetables and pulses (beans, lentils, chickpeas) are sources of soluble fibre. Insoluble fibre is not digested and therefore passes through the gut helping your bowel to pass food by making stools soft and bulky and preventing constipation. Wholegrain cereals, wholemeal bread, skins of fruit and vegetables are good sources of insoluble fibre.

You should include high fibre varieties of food in your diet to keep your bowels functioning well, unless you have been instructed to follow a low fibre diet by your doctor or dietitian.

High Fibre foods	Low Fibre foods
Bread and Cereal Products	
Wholemeal/brown bread, rye bread, high-fibre white bread, granary bread Wholemeal/brown/soya flour Wholewheat pasta Brown/savoury rice Cereals: Wholegrain breakfast cereals e.g. All Bran, Bran Flakes, Weetabix, porridge oats, muesli, puffed/shredded wheat Biscuits: Wholewheat biscuits e.g. Digestive, oat-based biscuits, flapjacks, biscuits containing nuts or dried fruit, oatcakes, Ryvita	White bread, pita bread, plain Naan 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, Frosties Biscuits: White plain biscuits e.g. Rich Tea, Custard cream
Vegetables	
Beans, lentils, peas, pulses, roast/crisp potato, sweetcorn All fresh, frozen or tinned vegetables have some fibre. Leave skins on potatoes.	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	
Avocado pear, banana, berries, currants, grapefruit, orange Tinned prunes Dried fruit Fresh or tinned fruit with skins and edible seeds	Small portions of the following without skins or seeds (fresh, tinned or stewed): Apple, apricot, grapes, lychees, mango, melon, nectarine, peach, pear, plum Fruit juice

2. Nutritional Issues for NET Patients

The list that has been compiled for this booklet has been obtained from talking to patients about their concerns and incorporating the most frequently asked questions. The subject of nutrition is a vast one and not all specific problems could possibly be covered, so if you feel like you need further advice please contact your nurse, doctor or dietitian.

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

- prevent or correct cancer-related undernutrition;
- help tolerate the cancer treatment;
- maintain strength and energy;
- protect ability to fight infection;
- help recovery and healing;
- maintain or improve quality of life.

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 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.

Building-up diet

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, Nesquik. Use fortified milk or whole milk.
- Full fat milkshakes, yoghurt drinks, fruit smoothies
- Supermalt
- Complan, Build-Up, Nutriment 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.

Other common problems for NET patients:

Diarrhoea

Ensure that the cause of the diarrhoea has been investigated by your medical team and treated appropriately.

- Rehydration sachets may be useful to replace water and salts lost (discuss with healthcare team before commencing).
- Avoid alcohol and high caffeine drinks.
- Eat small, frequent meals and eat slowly.
- Bland foods such as white bread, pasta, rice, well-cooked eggs, poultry, white fish and dairy products may be better tolerated during periods of diarrhoea.
- You may need to adjust your fat intake, but do not do this without advice from your dietitian.
- Your doctor may advise taking anti-diarrhoeal agents such as Imodium/Loperamide.
- Your doctor may recommend pancreatic enzyme supplements if you have fat malabsorption or cholestyramine (Questran) if you have bile salt malabsorption to help treat the associated diarrhoea.
- In extreme cases you may need intravenous fluids for rehydration.

Fat Malabsorption

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 light in colour, foul smelling and greasy looking. They are difficult to flush down the toilet. If this is the case, you should discuss it with your nurse or doctor.

It may be necessary to reduce the amount of fats and fatty foods that you eat until it is under control.

The doctors may prescribe pancreatic enzymes to help break down the food so that it can be more easily absorbed into the body. It is important to remember to take these *with* your food.

Constipation

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

- It is important to drink plenty of fluids as dehydration can make this symptom worse.
- A high fibre diet can improve symptoms (see Dietary Fibre section).
- A traditional drink of prune juice may help.
- Gentle exercise may also help.
- Constipation can be caused by some medication, therefore discuss with your medical team as regular laxatives may be required.

Bowel Surgery

The extent and location of bowel 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 after bowel surgery. This is commenced under the guidance of the hospital dietitian. 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 given through a tube into the gut or directly into the bloodstream and/or supplements may be required during this period.

Bowel Narrowing

The cause of this needs to be fully investigated by the specialist team and possible interventions discussed. This may include a review by your local surgeons.

- The diet should aim to prevent any blockage within the narrowed bowel, thus may need to be slightly soft. A low fibre diet will help reduce the pressure on the bowel.
- It is important to remain well hydrated by drinking plenty of fluids.
- Supplement drinks may be required to maintain nutritional wellbeing.

Regular monitoring by the specialist team, including the dietitian, is essential to ensure all needs are met and any complications dealt with quickly.

Gastric Acid

Ensure that the cause is investigated and discuss possible medical interventions with healthcare team.

- 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

Prevention of nausea

- Eat small, frequent meals throughout the day to avoid feeling full.
- Drink between meals rather than with them to avoid feeling full.
- Cold food and drinks usually have less smell than hot cooked foods. Avoid cooking smells if possible.
- Tart food and drinks can reduce nausea, e.g. grapefruit, lemon or lime squash, orange or pineapple juice, tinned fruit, yoghurt.
- Salty foods can help, e.g. crisps, crackers.
- Avoid greasy or fatty foods.
- Plain biscuits, crackers or dry toast are often better tolerated.
- Discuss with your GP about anti-sickness medication, which may be taken 30 minutes before meals to prevent nausea.

Bloating

- Avoid gas-forming foods, e.g. onions, cabbage, pulses, cauliflower, broccoli, nuts, 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.
- Avoid fizzy drinks
- Skipping meals is more likely to cause wind, therefore eat regular meals
- Chew your food well to reduce the amount of air swallowed
- Constipation can cause bloating. Monitor your bowel movements and speak to your doctor or nurse if you are constipated

Feeling full

Stomach resection, abdominal tumours, ascites or enlarged liver can result in you feeling full after consuming only a small amount of food.

- 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

Trigger Foods

Research is ongoing within this area for patients with Neuroendocrine Tumours. Studies have shown that for some patients certain foods and drinks can "trigger" symptoms such as abdominal pain, diarrhoea and flushing. Some common examples discussed by patients are large meals and alcohol. Patients with carcinoid syndrome should minimise their alcohol intake.

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. All food, drink and medication is documented alongside all symptoms experienced and their timings. The diary is then reviewed by the specialist nurse and dietitian with the patient to help identify potential "trigger foods" and to ensure that the diet is nutritionally balanced. Suggestions are then made about any necessary changes required to both diet and medication. It is essential that a dietitian is involved in this discussion to ensure that vital food groups are not removed from the diet to prevent any nutrient deficiencies.

Taste changes

Loss of taste:

- Choose foods full of flavour and aroma. Hot foods are often better.
- Use plenty of seasonings, especially herbs and spices.
- Add soups or sauce mixes to savoury dishes.
- Try sharp-tasting foods and drinks that are refreshing, for example fresh fruit, boiled sweets, mints, lemonade, fruit juice, tonic water, citrus fruits.
- Enhance the flavour of salads and vegetables by adding onions, orange or lemon juice or vinaigrette dressings
- Marinade food to enhance flavour

Changes in taste:

- Avoid any foods that taste unpleasant.
- 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 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. Try this before or during meals.
- ▣ Your Doctor may be able to prescribe some medicine to help. Mouthwashes can be useful to clean and numb your mouth.

3. 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.

People with cancer often ask about complementary therapies. Some of these are very safe and can be used in combination with standard treatments. For example, taking ginger or practicing relaxation techniques such as visualisation and hypnotherapy. Acupuncture can help control nausea, particularly when used in combination with anti-sickness drugs.

Some alternative therapists may claim to be able to cure your cancer or its symptoms with their treatments, even if conventional medical treatments have not been successful. Reputable therapists won't make these claims.

It is not possible to recommend alternative therapies in place of conventional medical therapy because there is little (if any) scientific or medical evidence to back up the claims that are made. If you have cancer, using these unproven methods instead of conventional medical treatment can have very serious consequences for your health. You should talk to your own specialist about any alternative or complementary therapies that you want to try.

Special 'cancer' diets

There are no diets that have been scientifically proven for NETs. Some unproven alternative diets may not be safe and may actually make things worse. Some 'special' cancer 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.

