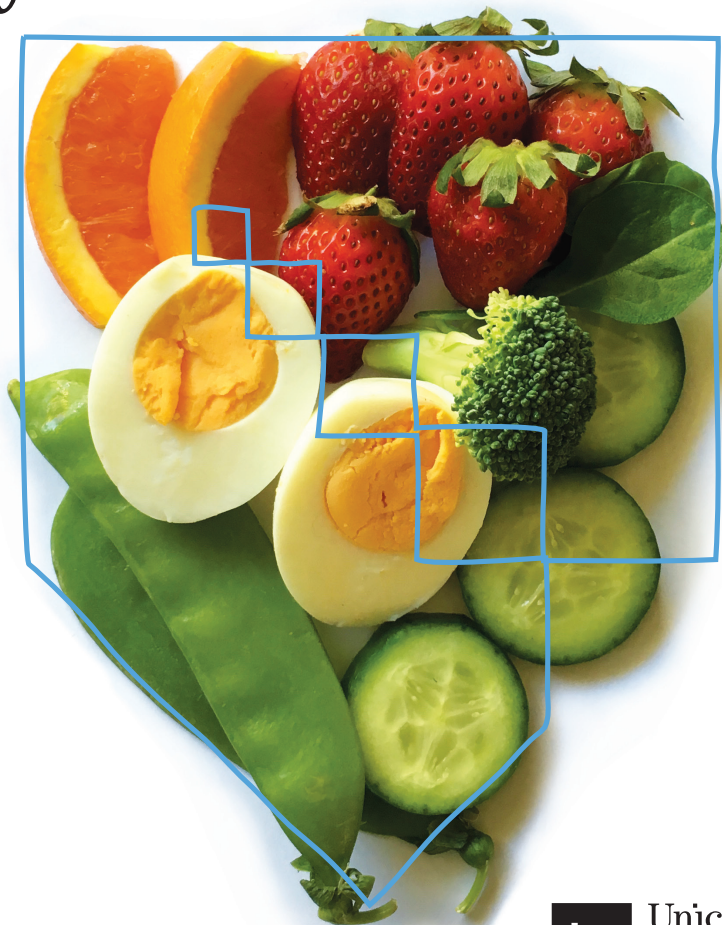


Nutrition & Neuroendocrine Tumours



Unicorn
Foundation

*Seeking the cure for
Neuroendocrine Cancers*



Nutrition and neuroendocrine tumours

Neuroendocrine tumours (NETs) can occur anywhere in the body. There are many different types of NETs and each type and its treatment can affect a person differently. Some people may experience symptoms or receive treatments that can affect their ability to eat or increase their nutritional needs.

This resource provides information on the nutritional needs of people with NETs and how to manage issues that can involve nutrition. The information in this resource is a guide for common nutritional concerns of people with NETs; however, as people with NETs can experience many different symptoms, not all issues may be covered. If you have concerns about your nutrition, including your diet, weight, symptoms or nutritional requirements, speak with your doctor, nurse or dietitian. If you are not already in contact with a dietitian, your doctor or nurse can provide a referral to a suitable dietitian in your area.

General dietary tips


Good nutrition can help with:


- maintaining a healthy weight and improving nutritional status
- improving response to and recovery from treatment
- helping to manage symptoms
- supporting the body's immune system and ability to fight infection
- maintaining your strength and energy
- improving or maintaining your quality of life.

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.
- Fat is necessary in your diet to provide some of the essential fats and fat-soluble vitamins that your body needs.
- Vitamins and minerals are essential for supporting the body's healthy function.

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

Food group	Suggestions
Bread, cereals and potatoes	<ul style="list-style-type: none"> • Includes bread, potatoes, pasta, rice, noodles, oats and other cereals. • Choose wholemeal and wholegrain varieties where possible.
<div data-bbox="107 678 375 949">  </div> Fruit and vegetables	<ul style="list-style-type: none"> • Includes fresh, canned, dried and frozen fruit and vegetables. • Choose a variety of different-coloured fruit and vegetables to ensure a range of vitamins and minerals. • Aim for at least five serves of vegetables per day. Some people (including men and breastfeeding women) will need to aim for five to six serves of vegetables per day. • Aim for two serves of fruit per day.
Milk and dairy foods (and alternatives)	<ul style="list-style-type: none"> • Includes milk, cheese, yoghurt and calcium-fortified alternatives such as soy. • Dairy foods provide your body with protein and calcium. Aim for full-fat varieties if you need to gain weight or low-fat varieties for general health. • Aim for two to three portions of dairy per day.

Food group	Suggestions
Meat, fish and alternatives	<ul style="list-style-type: none"> • Includes meat, poultry, fish, eggs, nuts, beans and pulses. • This group is high in protein, but some foods in this group can be high in saturated fat so it is better to choose low-fat varieties.
Extra foods (containing fat and sugar) 	<ul style="list-style-type: none"> • Includes any foods containing high amounts of fat and sugar such as margarine, butter, cooking oils, salad dressings, cream, chocolate, chips, cakes, ice-cream, soft-drinks and jam. • Focus on foods containing unsaturated fats from plant sources (e.g. nuts and avocado, and olive, sunflower and corn oils) rather than fats that come from animal products (e.g. butter). You could try swapping avocado for butter. • Only consume small quantities from this group, and only on some days. Large amounts can lead to weight gain. If you are losing weight, adding these items may help you gain weight.

Following a Mediterranean diet can be a good way to achieve a healthy diet. A Mediterranean diet includes lots of plant-based foods and vegetables; healthy unsaturated fats such as olive oil, avocado and nuts; and lean protein foods. If you would like more information on healthy eating and a Mediterranean diet, speak with a dietitian.

Managing your weight

In order to keep your weight stable, you need to consume the same amount of energy that your body uses.

If you want to lose weight, 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, you need to increase your energy consumption.

Maintaining a healthy weight

If you are not losing weight and your symptoms are well controlled, keep eating as you do normally and follow a healthy eating diet. Do not try to change anything that does not need changing unless you are advised to do so by your doctor or dietitian. You can follow the suggestions in the table above to ensure you are eating a variety of foods from each food group.

Choose foods with a range of colours and try to include at least five vegetable and two fruit serves per day.

Preventing weight gain

If you are gaining weight or wish to lose weight then you should follow a healthy eating diet and try to avoid foods that contain high amounts of energy, such as those with fat, sugar and alcohol. Fat contains more energy than other nutrients such as carbohydrate and protein, so reducing fat in your diet is an easy way to decrease your energy intake. Sugar and alcohol contain little nutritional value but are high in energy, so reduce them where you can.

The following tips may help manage weight gain:

- Avoid foods containing high amounts of fat such as butter, oils, cheese, cream, fried foods and baked goods (e.g. cakes, biscuits and pastries).
- Avoid foods containing high amounts of sugar such as soft drink, lollies, jam, honey, puddings and ice-cream.
- Choose lean meat varieties and remove the fat from meat before you cook it.
- Add less fat when cooking and choose healthier fats such as olive oil or canola oil. Note: Using a spray oil can reduce the fat needed for cooking.
- Reduce the size of your meals where possible and snack less.
- Choose foods high in fibre or protein, which will keep you feeling full for longer and reduce the urge to snack.
- Reduce alcohol intake.

Increasing the energy your body burns will also help you lose weight or prevent weight gain. Any exercise is good to include in your daily routine. If you want more advice about suitable exercise and options, speak with your doctor, dietitian or an exercise physiologist.

Preventing weight loss

Many people experience poor appetite and weight loss as a result of their NET and treatment. Weight loss may be a result of a number of problems, so any weight loss should be discussed with your doctor or nurse, who will arrange an appointment with a dietitian to discuss it further. If you are losing weight due to eating less, then choosing foods high in energy and protein may be helpful.

General tips for increasing your energy and protein intake

- Eat smaller amounts more often. Frequent meals and snacks may be easier for you to manage than three larger meals each day.
- Add snacks in between meals if you don't usually do so.
- Make eating a regular habit and try to eat something at each meal even if you don't feel hungry.
- Use convenience foods (e.g. ready-made meals, frozen products and canned foods) if you are too tired to prepare meals.
- Add extra fats or energy to foods when cooking or before you eat them to increase the energy intake (e.g. butter, olive oil, cream or grated cheese).
- Choose full-fat products rather than low-fat varieties.

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Increasing your protein intake

Protein is used to build and repair tissue and muscle in the body. Increasing your protein intake can be helpful to maintain or improve your muscle stores and prevent weight loss. The following foods are high in protein and can be added to your diet to increase your protein intake:

- meat, poultry, fish and eggs
- dairy or dairy-substitute (e.g. soy) milk, yoghurt, cheese and ice-cream
- nuts and seeds
- legumes such as chickpeas, lentils or kidney beans.

Nourishing drinks

If you do not feel hungry or are unable to eat much solid food, it may be easier to drink fluids that are high in energy and protein. Drinking between meals can help if you have a low appetite so the fluids don't fill you up too much.

Suggestions for nourishing drinks include:

- full-fat milk drinks, such as hot chocolate, Milo and malt powder
- milkshakes or fruit smoothies containing full-fat milk or yoghurt (or protein-fortified dairy substitutes)
- commercially made milk drinks, such as Sustagen, Ensure and Proform, which are available from the chemist in powder or liquid form, and in different flavours. These contain vitamins, minerals, energy and protein and are useful to add to your diet to help you gain weight.

If you require more information, your dietitian can suggest other ways to modify the energy and protein in your diet, and suggest supplements and meal plans for your individual needs.



Managing common problems

NETs and their treatments can cause symptoms in some people. Below is a guide to common symptoms and some tips on how to manage them.

If you experience a new symptom or your condition gets worse, speak immediately with your doctor.

Diarrhoea

Ensure that the cause of diarrhoea has been investigated by your doctor and nurse and treated appropriately. If you haven't discussed the diarrhoea with your doctor, do so before trying to change your diet.

The following tips may help manage diarrhoea:

- Eat small, frequent meals and eat slowly.
- Avoid alcohol and high caffeine drinks.
- Avoid foods high in some fibres such as grainy bread and cereals, skins and seeds on fruits and vegetables, and nuts.
- Bland foods such as white bread, pasta, rice, eggs, poultry and white fish may be better tolerated.
- There is no need to avoid milk or dairy while experiencing diarrhoea, unless advised by your doctor or dietitian. Dairy foods are a good source of protein and are nourishing for the body.
- You may need to adjust your fat intake, but do not do so without discussing this with your dietitian.
- Drink more water and fluids to replace any losses from diarrhoea. Rehydration products (Hydralyte, GastrolYTE) may be useful to replace water and salts lost.

Your doctor may recommend anti-diarrhoeal medication such as loperamide (Gastro-Stop, Imodium), pancreatic enzyme capsules (Creon) or medication for bile salt malabsorption (Questran) to help treat your diarrhoea. Only take these medications if suggested by your doctor.

If you are concerned about dehydration, contact your doctor immediately.

Fat malabsorption

If your body is not digesting fat, you may notice any of the following when you go to the toilet:

- pale stools
- greasy/oily stools
- loose stools
- offensive-smelling stools
- floating stools that are difficult to flush away
- wind/bloating
- abdominal pain
- weight loss.

Fat malabsorption can lead to poor absorption of vitamins and is important to address. If you think you are experiencing fat malabsorption, speak with your doctor or dietitian, who will advise on suitable treatment and diet. You may be prescribed pancreatic enzyme capsules, which will help with the digestion and absorption of fat in your bowel. If you are prescribed these capsules, it is important to take them immediately before a meal to get the best effect.

If you are experiencing fat malabsorption, you may be at risk of deficiency in fat-soluble vitamins A, D, E and K. Discuss this with your doctor or dietitian if you are concerned. You may be advised to take vitamin supplements.

Constipation

The cause of constipation should be investigated by your doctor and treatment with medication discussed to help regulate your bowel motions. The following may help manage constipation:

- Drink plenty of fluids as dehydration can make constipation worse.
- A high-fibre diet can help improve symptoms. Try to increase foods high in fibre such as wholemeal or wholegrain breads and cereals, fruit, vegetables, nuts and legumes.

- Drinking prune juice or pear juice may help.
- Gentle exercise each day may help.
- Some constipation may be caused by medication; therefore, discuss this with your doctor in case you need to change your medication or start taking laxatives.

If your bowels have not opened for several days and you are feeling pain or vomiting, contact your doctor or hospital immediately.

Bowel surgery

You may experience some symptoms as a result of previous bowel surgery. The extent and location of your surgery will affect the symptoms you experience. If you are experiencing changes in your bowels, such as diarrhoea or constipation, discuss these with your doctor or surgeon.

Nausea and vomiting

Nausea and vomiting can affect your ability to eat and put you at risk of losing weight. The following may help you manage nausea:

- Eat small, frequent meals throughout the day to avoid feeling full.
- Don't skip meals; nausea is better controlled when there is something in your stomach.
- Drink between meals rather than with meals to avoid feeling full.
- Cold foods and drinks usually have less smell than hot cooked foods. Avoid cooking smells if possible.
- Plain and salty foods can help (e.g. chips, crackers, popcorn or dry toast).
- Avoid greasy or fatty foods.

If your nausea is not getting better, talk to your doctor about anti-sickness medication that you can take 30 minutes before meals to prevent nausea and help you eat.

Bloating

Bloating can make you feel full and affect your appetite and eating. The following may help reduce bloating:

- Avoid gas-forming foods or have them in small amounts (e.g. onions, cabbage, pulses, cauliflower, broccoli, nuts and spicy foods).
- Avoid fizzy drinks.
- Skipping meals is more likely to cause wind, therefore eat regular meals.
- Chew food well to reduce the amount of air swallowed.
- managing constipation if this is the issue.

Carcinoid syndrome and trigger foods

Some NETs cause increased production of certain chemicals from affected cancer cells. These chemicals can cause symptoms such as flushing, diarrhoea, abdominal pain, fatigue and wheezing, also referred to as carcinoid syndrome.

Some research has suggested that certain foods can ‘trigger’ these symptoms in some people. The types of foods and drinks that can cause these symptoms can be different in each person and therefore the best way to identify possible ‘trigger’ foods is to complete a food and symptom diary. A food and symptom diary is completed over two weeks by recording all food and drinks consumed, along with any symptoms experienced and when they happen. The diary can then be discussed with a specialist nurse or dietitian to determine whether there are particular foods or drinks that make your symptoms worse.

It is important not to remove foods or food groups from your diet unless recommended by a dietitian.

Some general tips for managing symptoms of carcinoid syndrome include:

- Avoid eating large meals. Small, frequent meals are usually better tolerated.
- Reduce alcohol intake as this can make symptoms worse.
- Reduce how much fat you consume.
- Avoid spicy foods.

Complementary medicine and supplements

People with cancer often ask about complementary medical and supplement therapies. Some of these are safe and can be used in combination with standard treatments; however, some can be harmful and are not recommended to use. If you are considering taking an alternative supplement or treatment, the safest action is to discuss it with your doctor before consuming it.

Special ‘cancer’ diets

There are no diets that have been scientifically proven for NETs. Some unproven alternative ‘cancer’ diets may not be safe and may actually make things worse. Alternative diets may be too restrictive, especially if you are ill or not eating well. If you have questions concerning specific or special diets, please discuss them with your doctor or dietitian before you make any changes.

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Quinoa grains



Chia seeds



Sunflower seeds

Useful resources

Australian guide to healthy eating.

Australian Government.

<https://www.eatforhealth.gov.au/guidelines/australian-guide-healthy-eating>

Complementary and alternative medicine:

making informed decisions. A fact sheet for people with cancer, their families and friends.

Cancer Council Victoria. 2012

<http://www.cancervic.org.au/downloads/resources/factsheets/CAM-informed-decisions.pdf>

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Healthier. Happier.

Queensland Government.

www.healthier.qld.gov.au

Food and neuroendocrine tumours (patient information).

Royal Free London NHS Foundation Trust.

<https://www.royalfree.nhs.uk/services/services-a-z/neuroendocrine-tumour-net-unit/#tab-patient-leaflets>

Unicorn Foundation

About Us

The Unicorn Foundation is the only not for profit Australian medical charity, directed towards patients with Neuroendocrine (NET) cancers. The five pillars of the Unicorn Foundation mission are:

Patient Support

Some of our support services include:

- NET Nurse Support 1300CURENETS (287 363)
or email netnurse@unicornfoundation.org.au
- Support groups in each capital city
- Facebook group
- Registry of Australian NET Doctors

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Awareness

- Raising awareness about NETs within the medical community
- World NET Cancer Day November 10

Education

- Patient seminars and lectures
- Webinars
- Conference presentations
- Publications

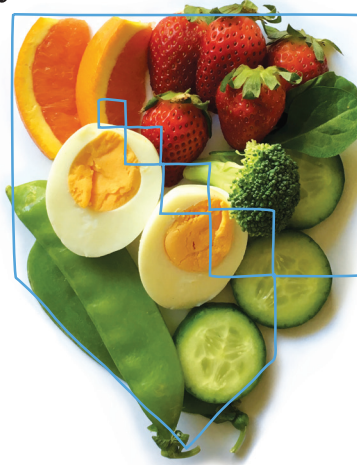
Research

- Provide funding to clinical trials
- Provide grants to Australian clinicians and researchers to enhance expertise in NET management
- Support the purchase of hospital equipment for treatment of NETs
- Investing in uniquely Australian NET research

Advocacy

- Lobbying government and regulatory bodies for access to new and appropriate treatments and diagnostics
- Unicorn Foundation Consumer Advisory Group (CAG), helping to improve outcomes for NET Cancer patients

Nutrition & Neuroendocrine Tumours



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Unicorn Foundation Consumer Advisory Group
CAG



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