

# NUTRITION AND NEUROENDOCRINE CANCER

## International Edition

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Dietitian

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# MENETS

Middle East Neuroendocrine Tumor Society

העמותה לניידולים באורזאנדוקרינים במזרח התיכון  
במסגרת ארגון הסניף המזרחי לחברת האסונד

[www.MENETS.org](http://www.MENETS.org)

## Foreword

This booklet is designed to provide in-depth definitions and recommendations for a range of Neuroendocrine Cancers.

This is an International Edition for all those who live with and around Neuroendocrine Cancer, the patients and caregivers.

I was diagnosed with Non-functional Pancreatic Cancer by accident (and who hasn't?) in 2006 and I was looking for diets and recipes for my post Whipple surgery life. The surgery also turned me into an insulin dependent diabetic. It is suffice to say that there is no applicable diet / recipe book for my particular body.

After founding MENETS – Middle East Neuroendocrine Tumor Society in 2018, together with Neuroendocrine Cancer Patients and Caregivers, we set a goal to minimize the mystery of Quality of Life of Neuroendocrine Cancer Patients and Caregivers. We realized that the Neuroendocrine Cancer nutrition is a significant juggling act, and that we should facilitate an understanding of the daily “balls in the air”.

I had become familiar with the work of Miss Tara Whyand via her publications and professional presentations and we asked her to write a very specific, layperson language Neuroendocrine Cancer Diet Guide for nonprofessionals like me and others like me.

As patients, we trust our medical carers to manage the Neuroendocrine Cancer disease. As patients and caregivers, we have the most control over our daily Quality of Life. We own the nutrition choices we make every day and are responsible for the consequences of our choices.

I trust that this booklet will provide you with succinct information which will assist you to make nutritional choices to improve the Quality of Your Life.

We still recommend you see a Dietitian to tailor nutrition to your exact needs.

Michael Rosenberg

Founder / CEO MENETS

**MENETS**

Middle East Neuroendocrine Tumor Society

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جمعية أورام الغدد الصماء العصبية للشرق الأوسط

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Nutrition and Neuroendocrine Cancer

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# Is There a Special Neuroendocrine Cancer Diet?

There's no one specific diet suitable for everybody who has a neuroendocrine cancer. There may be adjustments you need to make to what you eat and drink based on your cancer site, cancer activity, any metastases, or surgery and other treatments you choose. You may not be able to target or control the cancer activity with diet, however most people will need to see a dietitian at some point to help manage the symptoms and side effects that occur.

## Where to Start

A 'healthy diet' after cancer diagnosis is one that it is an appropriate diet for your personal situation. It includes your individual requirements for energy, protein, fluid, vitamins and minerals. This is based on your medical situation, your weight and lifestyle. It doesn't mean that you have to follow, eating guidelines, as eating that kind of diet will often not match your requirements and can cause unwanted symptoms. If you can tolerate a normal healthy diet, you are a healthy weight, and do not have unwanted side effects then continue with the diet you are on.



## **An appropriate healthy diet for you will help you to:**

- Stay at a healthy weight
- Maintain a healthy immune system, which can protect you from infections
- Cope with treatment and recover and heal quickly
- Maintain your fitness level, so you have the energy to exercise and do everyday tasks
- Minimise unwanted symptoms such as worsening diarrhoea and gas

It is important to note that if you have had curative surgery and your scans are clear, you should follow the World Cancer Research Fund guidelines: <https://www.wcrf-uk.org/uk/preventing-cancer/cancer-prevention-recommendations> for cancer prevention which involves resuming a typical healthy diet and way of lifestyle. Following the recommendations is also likely to reduce the risks of other diseases, such as heart disease and type 2 diabetes, which are important causes of ill health in people living beyond cancer.

## Protein

Nearly everyone requires a very high protein intake once diagnosed with a neuroendocrine cancer. This can be difficult if you choose to follow a plant based or any form of vegetarian diet, as animal products contain more protein gram for gram. It is not impossible though!

### **Here's a general idea of protein content:**

1x Chicken Breast = 30-50g

1x 150g/5oz Tinned Tuna (drained) = 40g

100g / 3 ½ oz Cheddar Cheese = 25g

100g / 3 ½ oz Nuts = 14-20g

100g / 3 ½ oz Cottage Cheese = 11g

1 Chicken Egg = 8g

100g / 3 ½ oz Chickpeas or Lentils = 7-8g

100g / 3 ½ oz Beans = 5-10g

100g / 3 ½ oz Tofu = 8g

100g / 3 ½ oz Quinoa = 4g

If you are struggling to get enough protein through eating, you can ask your dietitian for a prescribed protein supplement/shake, or buy a whey protein powder from a health store. Vegetarian powders such as pea protein may help those avoiding meat, but are not considered equal protein quality as whey.

## Carbohydrates

Carbohydrates, for example starch inside pasta or fructose from fruit, are broken down into glucose and travel to body cells for energy use or storage. Unless you are on a clinical trial or have had a lower carbohydrate diet prescribed by a Dietitian, it is not advisable to restrict your carbohydrate intake. Apart from it being unrealistic to starve yourself of carbohydrate, every cell in the body needs glucose to do its job and at the moment we have no reason to believe reducing carbohydrate will help with symptoms or neuroendocrine cancer growth.

## Fat

Everyone requires fat in their diet. Having some fat in our diet helps us to absorb vitamins A, D, E and K. Foods that are high in fat are also high in energy (calories).

There are two types of fat:

- Saturated fats are found mainly in fatty cuts of meat, sausages, pies, butter, ghee, cheese, cakes and biscuits. Try to limit these fats unless you are trying to gain weight or have a poor appetite.
- Unsaturated fats are found mainly in vegetable-based cooking oils and spreads, nuts, seeds and oily fish, such as sardines and mackerel. Unsaturated fats are still high-energy (high-calorie) foods. Try to include small amounts of these fats.

If you have trouble digesting fats, you may need further tests to see what the problem is. For example, you may be asked to try pancreatic enzyme replacement therapy, (pages 21-22), or to try oils called medium chain triglycerides (MCT's), / reduce your fat intake (see bile acid malabsorption pages 22-24).

# Vitamins and Minerals

## **Should I Take Vitamin and Mineral Supplements?**

Vitamin and mineral deficiencies are a common occurrence. Your neuroendocrine cancer type, cancer location, treatments and any surgery to the digestive system can lead to vitamin and mineral deficiencies. Like with protein, we all have our own personal requirements for micronutrients and blood testing; guessing is not encouraged. All food supplements should be discussed with your team and it is not advised to take high doses of any single or multi ingredient vitamins and minerals unless requested by your team to either prevent a deficiency; e.g. niacin, or treat a deficiency.

## **Multivitamins and Multiminerals**

It is generally considered safe to take general multivitamins and minerals that contain up to 100% of the daily recommended amount, without testing. If you are prescribed pancreatic enzyme replacement therapy, you may be told to take a multivitamin and mineral food supplement as you are at increased risk of developing a fat soluble vitamin deficiency, however it is better to test for these vitamins as if your levels are already low, a standard supplement will not correct them.

## Individual Vitamins and Minerals

Don't take high doses of vitamins and minerals unless you have had a blood test to show you actually need them. The general exception to this is vitamin D, and sometimes B3 and B12. If you are having chemotherapy, high doses of antioxidant vitamins and minerals (eg vitamin C, E, selenium) should be avoided to allow the chemotherapy to work on cells as it should. Vitamin B7 (biotin) supplements can affect the results of hormone and vitamin blood tests so stop supplementation a week before.

### A

Vitamin A is required for normal vision, the immune system, and reproduction. Those who have been taking somatostatin analogues for over 6 months, or those with insufficiently treated / untreated pancreatic exocrine insufficiency / treated bile acid malabsorption may be deficient in vitamin A. Early signs of deficiency include disturbed vision and night blindness, eye sores and dryness, poor wound healing, various infections, cracked lips and diarrhoea. Discuss with your team to see if you can have a blood test.

### B3, Niacin

Those with serotonin producing tumors, which is displayed by carcinoid syndrome symptoms, have a particular need for niacin. Deficiency when severe causes pellagra and presents as dementia, dermatitis and watery diarrhoea. Unfortunately most centers cannot accurately test for this and supplementation should be given as a preventative from diagnosis, or you should be treated with a higher dose if pellagra is diagnosed (See pages 34-36).

## **B9 (folate) and B12**

B9 and B12 are required for making blood cells, repairing cells, and synthesizing DNA. Those having surgery to remove large amounts of the stomach and / or the last part of the small bowel (ileum) are at risk of vitamin B12 deficiency. Most surgeons will request that you start vitamin B12 injections every 3 months without testing to see if you need this vitamin. If you have had these surgeries, have not had a prescription and wonder if you may be deficient, ask for a B12 blood test. Somatostatin analogue treatment may also increase your risk of B12 deficiency. Folate and vitamin B12 should be tested together if there are signs of anaemia. Vitamin B12 or folate deficiency anaemia can cause a wide range of symptoms, including extreme tiredness, a sore red tongue and muscle weakness. If your current supplements contain vitamin B7 (biotin), this may lead to incorrect results and you must stop these supplements around a week beforehand.

## **D**

Vitamin D is required for strong bones and teeth and immune function, and the main source is sunshine. Those on somatostatin analogues, those who live in the northern hemisphere or those that don't expose their skin to the sun in the summer, and those with intestinal neuroendocrine cancer are at risk of vitamin D deficiency. Signs of deficiency include weak bones and teeth and poor immunity. speak to your team to ask for a blood test. If your current supplements contain vitamin B7 (biotin) this may lead to incorrect results and you must stop these supplements around a

week beforehand. Don't forget that if your vitamin D is low, calcium absorption may have been hindered too, so speak to your team to see if testing is required.

## **E**

Vitamin E is a fat soluble antioxidant vitamin used to maintain healthy skin and immunity. Those who have been taking somatostatin analogues for over 6 months, or those with insufficiently treated / untreated pancreatic exocrine insufficiency/ treated bile acid malabsorption may be deficient in vitamin E. Signs of deficiency include loss of feeling in the arms and legs, loss of body movement control, muscle weakness, vision problems and a weakened immune system. Discuss with your team to see if you can have a blood test.

## **Iron**

Iron is used in every red blood cell. Iron deficiency is common if you have had sustained blood loss for any reason, have had chemotherapy, you avoid red meat, undertake long distance running or walking for several months, or eat too little food. A doctor will order a few blood tests including ferritin levels to see if you have iron deficiency anaemia. Signs include tiredness, pale skin, hair loss, breathlessness and restless legs, palpitations and mouth ulcers.

## **K1**

Vitamin K is required for blood clotting. Those who have been taking somatostatin analogues for over 6 months, or those with insufficiently treated / untreated pancreatic exocrine insufficiency/ treated bile acid malabsorption may be deficient in vitamin K1. Signs of deficiency include bruising and bleeding easily. Discuss with your team to see if you can have a K1 or Prothrombin time blood test.

## **Other Vitamins and Minerals**

Copper, selenium and zinc have been found to be low in those who have had continued malabsorption from diarrhoea, those who take somatostatin analogues and who have had surgery on the first part of the intestine, including surgery for pancreatic cancer, the Whipple's procedure. Selenium may also become low from PRRT treatment. It is likely that there are other micronutrients that could be low too, however these have not been studied yet.

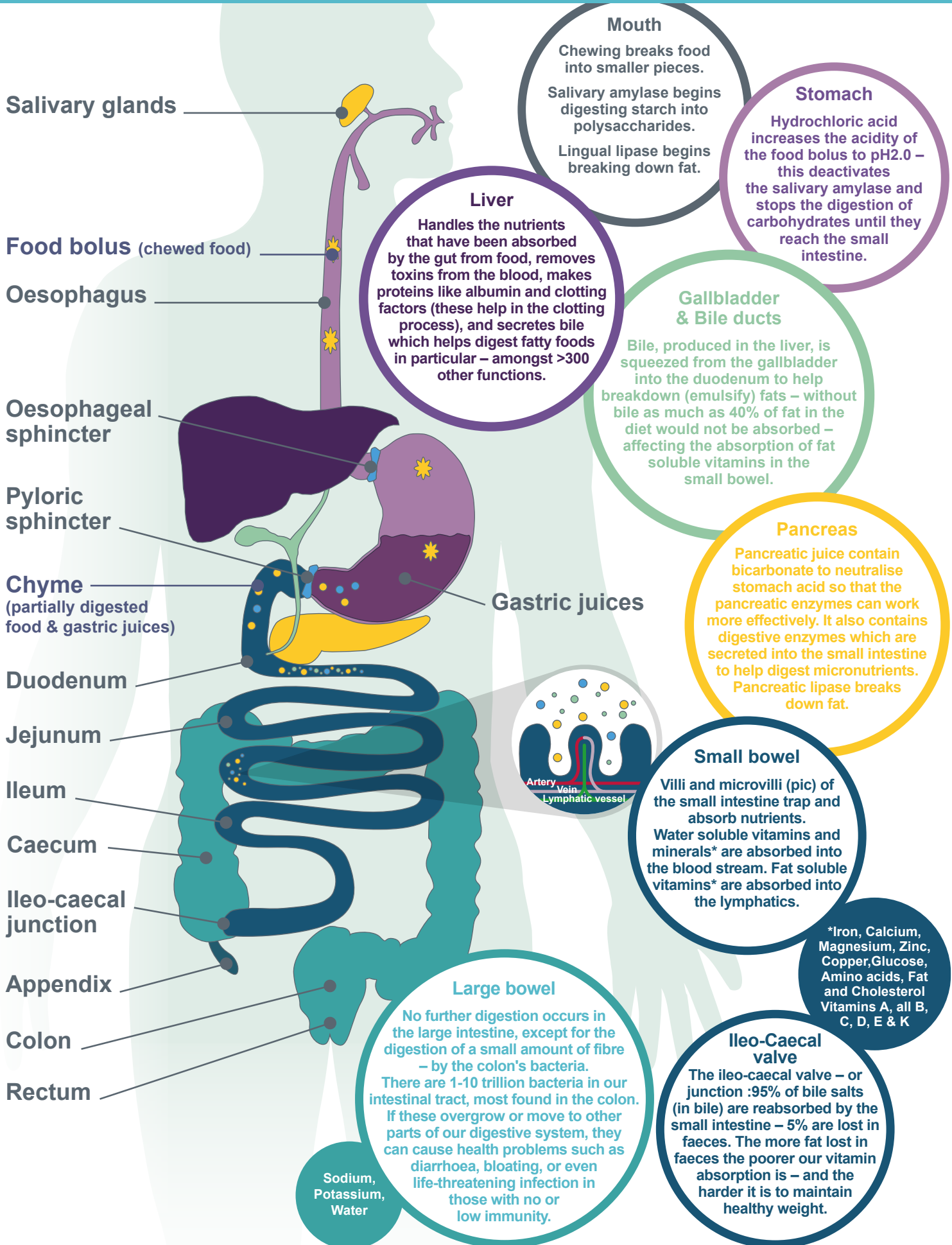
## **Other Blood Tests**

Other blood tests linked with diet are cholesterol, triglycerides and glucose. Elevations in these are common in the general population, and dietary management of high levels may be the same (depending on your health), however there are particular things to note during neuroendocrine cancer treatment.

- Everolimus treatment can cause high triglyceride levels
- You may have changes to glucose levels from treatments such as somatostatin analogues or Everolimus



# DIGESTIVE SYSTEM



# If You're Losing Weight

If you find yourself losing weight without trying to, you should let your care team know so they can refer you to a Dietitian for tailored advice. It can be difficult if people comment on your weight loss or what you're eating (or not eating). You may find that being encouraged to eat, especially when it's the last thing you want to do, irritating or upsetting. Talk about how you are feeling with your friends and family. Dietary choices can often cause problems in relationships and you will need to talk openly about this subject. Try to remember that food is your fuel - and if you want ice cream for breakfast or can only manage a few mouthfuls of a meal, that's far better than eating nothing at all.

## **A few tips:**

- Eat little and often - small, frequent meals and snacks rather than 3 large meals for breakfast, lunch and dinner.
- Use a side plate which can seem less daunting than a larger plate and help food seem more manageable and appetising.
- Eating when you feel hungry or at regular intervals (2-3 hourly) - rather than at set times.
- Chop food into small pieces - this may make it easier for you to eat, especially if you're feeling unwell.
- Not forcing it - if you really can't face a plateful of food, try a few bites, then wait an hour or 2 and try again later but try not to skip food.

## **Foods to Help You Maintain or Gain Weight**

If you can't eat enough food to maintain your weight, your dietitian can help you choose a supplemental drink, dessert, or powder to help bridge the gap. You can freeze some of them, or make them into ice cubes.

Because most people will require a very high protein intake, you'll need to eat enough protein, plus enough calories. Yes you can eat 'junk' food or fried and sugary things to get extra calories, but you don't have to if you don't want. For example, foods high in fat can be healthy fats, e.g. avocados, nuts, nut butters, olive oil, nut oils, avocado oil, oily fish.

If you would rather have cheese, deep fried foods, cake, biscuits, crisps, chips, butter, cream, full fat yoghurts, and ice cream, that is also fine to have in the short term as it takes a few months to start impacting cholesterol levels.

### **Oral Nutritional Supplements:**

If you can't eat enough food to maintain your weight, your dietitian can help you choose a supplemental drink, soup, dessert, or powder to help bridge the gap. You can freeze some of them, or make them into ice cubes.

# Gastrointestinal Problems

Excess hormones, infections, treatments including surgery and certain 'trigger foods' can all cause diarrhoea when you have a neuroendocrine cancer. It's important to try and understand what the cause is and whether it's likely to be temporary or a long-term issue. So, if you do get diarrhoea, you should always let your care team know and describe the details to them (how often it's happening, when it's happening, what it looks like, etc. There are specific medicines and treatments depending on what's causing the problems. If you have had part of your pancreas removed, the cause of diarrhoea may be different to having had part of your small bowel removed - and so the treatment will be different.

## **In general:**

- If diarrhoea is frequent, make sure you replace fluid and electrolytes with 'electrolyte replacement powders'
- Eat/drink high protein/low fibre items
- Eat/ drink little and often

Depending on the cause, see the relevant section within this booklet.

## Steatorrhoea

Steatorrhoea is an excess of fat in stools, and indicates a problem with either fat digestion or fat absorption. Your body becomes unable to absorb fat properly, so your stool becomes abnormally fatty. When severe, this makes it very yellow, smelly, greasy and frothy. It can also be difficult to flush away. Steatorrhoea can occur due to several problems in the digestive process.

## Pancreatic Exocrine Insufficiency (PEI)

If you're diagnosed with PEI, you might need to reduce the amount of fatty foods you eat until you start pancreatic enzyme replacement therapy (PERT). This involves taking capsules, just before and during the snack/meal, which contain the enzymes usually produced by your pancreas to help break down food. Your care team will let you know how many to take, but you'll probably start on a low dose eg 22/24/25,000 units lipase per snack, 44/48/50,000 units lipase per meal, and gradually increase it until your symptoms are under control. The maximum dose is 10,000 units lipase per kg body weight per day (70kg would be 700,000 units lipase per day). You need to alter how many capsules you take based on what you eat, as richer fatty foods/drinks require more PERT.

Note, if your blood fat soluble vitamins (ADEK1) are low and your weight is dropping, these are signs that you may require more PERT. This is because fat malabsorption is only visible when there is a severe deficiency in the number of enzymes made /taken. Your bowel symptoms may have resolved, but there are other signs that you are malabsorbing fat and therefore fat-soluble vitamins. If you are already taking a high dose with correct timing, you may need to try taking a proton pump inhibitor antacid to get the PERT to work better. Discuss this with your doctor.

### **Bile Acid Malabsorption (BAM):**

Resulting bile acid diarrhoea caused by BAM is a more acidic diarrhoea which burns, and is also made worse with fat intake. There are 3 types:

- **Type I:** This is when there is a problem in the part of the small intestine (ileum) where reabsorption takes place. Causes include inflammation/ disease/ removal of most of/all the last section of the small bowel (terminal ileum), due to cancer or Crohn's disease.
- **Type II:** This is when no definitive cause can be found and is known as primary bile acid malabsorption.

- **Type III:** This can result from other diseases or conditions within the abdomen such as gallbladder removal, coeliac disease, chronic pancreatitis, radiotherapy or small intestinal bacterial overgrowth (SIBO).

If you have had a SeHCAT scan and it shows bile acid malabsorption you will be offered a bile acid sequestrant medication, however you may also need to see a dietitian to change your fat intake if the medication doesn't work alone.

- **Low fat diet:** A strict, low fat diet (40g of fat per day) may improve bowel function to some degree even if you have severe bile salt malabsorption. A strict low fat diet should only be considered under the supervision of a dietitian. If you have a history of weight loss or a low body weight, it is not advisable to restrict your fat intake as fat is a valuable source of energy in the diet. The main problem with a low fat diet is that it is limiting and you will not know how much fat has been used in cooking especially if you go out for a meal.
- **MCT diets:** Replacing a large proportion of one specific type of fat in the diet (long chain triglycerides) with a different type of fat (medium chain triglycerides). Many people find medium chain triglycerides unpalatable. Do not try this type of dietary change without specialist supervision by a qualified dietitian.

- It is important to monitor fat soluble vitamins if you are on bile acid sequestrants. You should have a blood test after three months to look at the blood levels of vitamin A, D, E and K and have a repeat blood test yearly. If vitamin levels fall, this can be corrected with a vitamin supplement. Vitamin B12 levels should also be checked yearly.

### **Small Intestinal Bacterial Overgrowth (SIBO):**

The large bowel is where most bacteria should live. When bacteria move up to the small intestine or start growing at the top of the small intestine, this leads to digestive problems such as wind and diarrhoea. Where these bacteria produce methane gas, symptoms include constipation. However, when the bacteria produce hydrogen, diarrhoea and gas are the main symptoms. There is a hydrogen and methane breath test for diagnosing someone. Diarrhoea can be acidic or fatty as well as watery.

There are no proven dietary interventions yet, but probiotics, antimicrobial herbal treatments, low FODMAP diets and 4 hour meal gaps have been known to help. Fecal transplants, transplanting gut bacteria from a healthy person to someone with SIBO is unlikely to work long term. The monitoring of iron, folate, B12 and fat soluble vitamins may be recommended.



## Constipation

Talk to your care team if you get constipated - they'll be able to talk you through medications and dietary adjustments that can help to keep you regular.

### **It can also help to:**

- Drink plenty of water - ideally a few more glasses/cups on top of your normal requirement (the heavier you are the more you need).
- Have 2 tablespoons of flaxseeds / linseeds per day.
- Drink prune juice, or syrup of figs.
- Keep mobile and go for a walk after eating.
- Eat a high-fibre diet such as bran-based cereals with fruit and live yoghurts for breakfast, wholegrain breads, rice or pasta for lunch/dinner and plenty of fruit and vegetables spread throughout the day (if you tolerate this). If you don't drink enough fluid with a high fibre diet, you will make constipation worse.
- Probiotics and live yoghurts may help too as they contain bacteria which are mostly fluid, keeping the bowel moist.

## Wind and Feeling Bloating

These symptoms can be linked to both diarrhoea and constipation.

### **You might find it helps to:**

- Avoid foods that make you gassy. Different people react to different foods, but eating too much fibre, or particular foods, e.g. onions, garlic, artichoke, cabbage, cauliflower, broccoli, nuts and beans can all make you feel bloated, and pass wind. These are healthy foods and it is healthy to eat them, however if symptoms are affecting your quality of life, talk this through with your dietitian.
- Burping is normally related to overeating or undereating, swallowing air with fizzy drinks, chewing gum or eating quickly, or having excess stomach acid.

## Hiccuping

Occasional hiccups are normal. Always mention chronic hiccuping problems to your doctor as it may be a sign of a medical problem.

### **Dietary help includes:**

- Sip ice-cold water
- Swallow some granulated sugar
- Bite on a lemon or taste vinegar
- Hold your breath for a short time
- Do not drink alcoholic, fizzy or hot drinks

- Do not chew gum or smoke – these can cause you to swallow air
- Do not eat spicy food
- Do not eat food very quickly
- Do not eat or drink something very cold immediately after something hot

## **Bowel Obstructions**

If you have a small bowel neuroendocrine cancer that can't be removed, or serotonin released by a small bowel tumor causes fibrosis, for example, it can lead to narrowing or kinking of the bowel. If you've had surgery to remove part of your bowel (large or small), sometimes narrowing can occur where the surgeon has made a new connection. This can increase the risk of your bowel becoming partially or completely blocked.

If you have a narrowed bowel and you want to reduce the risk of bowel obstruction you will need to see a Dietitian. They will decide what kind of foods are likely to pass through your bowel with ease. Historically a 'low fibre' or 'low residue diet' may have been recommended, but the consistency of the food matters more than the fibre content. Depending on your obstruction risk, that can be found by looking at scans and colonoscopy reports, the consistency of food may need to change. For example, moving to very moist, soft, mashable fruit, veg and meat or fish. If it is not possible to eat enough

food safely, there are soup and supplemental drink options so you can take to get the nutrients you need. These can be useful if you usually eat a healthy, varied diet and are struggling to manage your nutritional intake. If your digestive system can no longer take food, there may be another option for providing energy and some other nutrients via 'parenteral nutrition' into the bloodstream.

Bowel obstruction is an emergency situation.

If you have a small bowel Cancer that can't be removed or have had bowel surgery and experience new (often severe) abdominal pain with vomiting and/or diarrhoea or constipation, you should go to your nearest Emergency room / A&E. Sometimes, by the time you get there the problem may appear to have resolved itself, but you may still need urgent treatment to ease the problem and protect the rest of your bowel.

## Feeling Full

Stomach and duodenal surgery, an enlarged liver, abdominal tumors and excess fluid in your belly (known as ascites) can all leave you feeling full when you've not actually eaten much. Bloating, constipation and wind can have the same effect. **To ensure you get the nutrients you need, try to:**

- Treat any constipation with 2 tablespoons of flaxseeds a day, plus physical activity and plenty of fluid.
- Eat little and often, having smaller snacks and meals.
- Don't drink with or before food. It can make you feel fuller faster, so wait until after you've eaten to have a drink.
- Avoid fatty, greasy and rich foods, as these can make you feel fuller sooner.
- Wait to have dessert. Leave it a couple of hours rather than trying to force it down straight after your meal.

## Losing your Sense of Taste

This can happen as a result of cancer treatment, often causing people to lose their appetite as they no longer get any pleasure from eating.

**To help prevent that from happening you can try to:**

- Choose foods which have a strong taste and smell.
- Eat foods when they're hot, because that's often when the taste is strongest.

- Use plenty of seasoning, herbs, spices and marinades. It's a good time to experiment with new combinations. Try sharp and sour foods and drinks. You might find you now enjoy things that you didn't use to.
- Add strong-tasting foods to plain dishes. For example - fresh basil to salads, Dijon mustard and butter to mashed potato or vegetables, coriander and lemon to rice.
- Try palate-cleansing foods before eating, such as sorbet (but not the citrus ones, which may trigger indigestion), water crackers, fresh mint or parsley.

## Altered Taste

Changes to your tongue or certain drugs or treatments can alter how things taste, which can be frustrating, unpleasant or surprising - you may even discover a sweet tooth for the first time, or no longer have one.

**To make changes easier to deal with, you can:**

- Leave food to cool before you eat it. Things often taste stronger when they're straight out of the oven.
- People often find the taste of meat changes, but you might find cold cuts more palatable. Or try high-protein alternatives like fish, eggs, cheese and dairy products.
- Avoid foods that contain saccharin if you find things taste bitter.

- Gargle water with a squeeze of lemon juice before eating if you find things taste metallic. Using plastic cutlery can help too.
- Explore new tastes. Try food you've not tried or didn't like before. You may find you now taste things differently.

## Feeling Nauseous

Speak to your team about anti-sickness drugs. **Here are some things to try also:**

- Add ginger to your diet- ginger tablets, fresh or crystalised ginger.
- Avoid baths, have a shower instead and use mint or menthol products.
- Drink peppermint tea, suck on mints.
- Eat small meals and snacks throughout the day instead of three big meals.
- Avoid fried food, fatty food and foods that have a strong smell. Experiment with cold vs hot meat as they smell very different.
- Do not eat or prepare food when you feel nauseous.
- Take it easy straight after eating.
- Eat with other people to take your mind off how you're

feeling.

- Some will crave spice or salty food, others prefer plain or sweet food.
- Have small sips of drink throughout the day.
- Still or non-carbonated, full calorie soft drinks like cola, lemonade and Lucozade can really help for short bursts of energy.
- Avoid brushing your teeth straight after a meal.
- Wear an anti-sickness bracelet or try complementary therapies like hypnotherapy or acupuncture.

## **Pain in Your Mouth or Throat**

**If this is a problem you experience, you can try to:**

- Clean your teeth gently in the morning, before bed and after every meal using a soft toothbrush. If brushing your teeth stings or makes you feel sick, try gargling with a bicarbonate of soda mouthwash (dissolve one teaspoon in a mug of warm water), or ask for a medicated wash to numb your mouth. Avoid mouthwashes that have alcohol in them.
- Keep your lips moist with lip balm.
- Eat stews, soups, yoghurts, and other soft food.
- Suck on ice cubes, eat frozen yoghurt or ice cream.
- Avoid acidic fruits like oranges, grapefruits and lemons.
- Avoid spirits, tobacco, spicy and salty food, garlic, onions and vinegar.



## Fatigue

Extreme tiredness is experienced by almost everyone with neuroendocrine cancer at some time, caused either by the disease itself or by treatments. Where fatigue has an obvious solvable cause such as iron deficiency, treatment should be given. There are many excellent apps available for smartphones which help with cancer fatigue. As well as getting quality sleep, eating enough energy-rich foods regularly throughout the day helps prevent peaks and troughs in blood glucose. Physical activity and getting outdoors also helps although you may not feel like doing this initially.

**Batch Cooking:** When you feel well, try to cook and freeze or refrigerate a batch of meals. Then, on the days when you really don't have the energy to cook, you just need to turn on the microwave, reheat in the oven or on the hob to make a healthy meal. Alternatively, you could always take up friends and family on any offers to cook for you. People are often very keen to help, and cooking is a simple way to make a big difference.

# Carcinoid Syndrome

Carcinoid syndrome can occur where a diagnosis of a functioning, normally gastrointestinal, neuroendocrine cancer tumor releases serotonin and other natural chemical messengers into the bloodstream. Serotonin is made from conversion of an amino acid called tryptophan. In a healthy person, most tryptophan is turned into vitamin B3 (niacin), not serotonin. In carcinoid syndrome, 99% of tryptophan is converted to serotonin. Therefore, if you have carcinoid syndrome, your levels of niacin might be too low. Most hospitals cannot test your blood niacin levels, but in research studies many patients with carcinoid syndrome had low levels at diagnosis. If low niacin status is not corrected, the deficiency can cause something called pellagra, which causes memory problems (dementia), dermatitis and watery diarrhoea.

## Triggers

You might find that certain foods trigger carcinoid syndrome symptoms - diarrhoea and/or flushing. Foods and drinks high in vasoactive amines from the aging of proteins may trigger carcinoid syndrome, especially flushing:

**Meat, poultry and fish:** All cured meat, especially pork products, e.g. ham, salami, pepperoni, game, bacon, sausages, fresh pork, fresh or canned (salted) tuna, canned sardines, anchovies, mackerel, salmon, herring, processed fish products (fish pastes, smoked, dried or pickled fish), fish sauce.

**Dairy:** Blue cheese, parmesan, brie, camembert, emmenthal, old gouda, mature cheddar and other hard cheeses. Milk needs to be fresh.

**Fruit:** Oranges, bananas, tangerines, pineapple, grapes, strawberries, tomatoes.

**Vegetables, beans and nuts:** Pickled cabbage, aubergine, spinach, broad beans, peanuts, almonds, Brazil nuts, cashews, chestnuts, hazelnuts, macadamia nuts, pecans, pistachios, and walnuts.

**Soya:** Fermented soy products including miso and tempeh

**Drinks:** Green tea, champagne, wine (especially fermented in oak barrels), coffee, cocoa, chocolate, beer, fresh fruit juices (from fruit list) and smoothies, e.g. strawberry and banana.

Different foods affect different people, so the best way to identify any problems is to keep a food and symptom diary for 1-2 weeks and discuss with your Dietitian. Keep a record of when and what you eat and drink, then record any symptoms and what time they occur. Only exclude high vasoactive amine products if they trigger carcinoid syndrome.

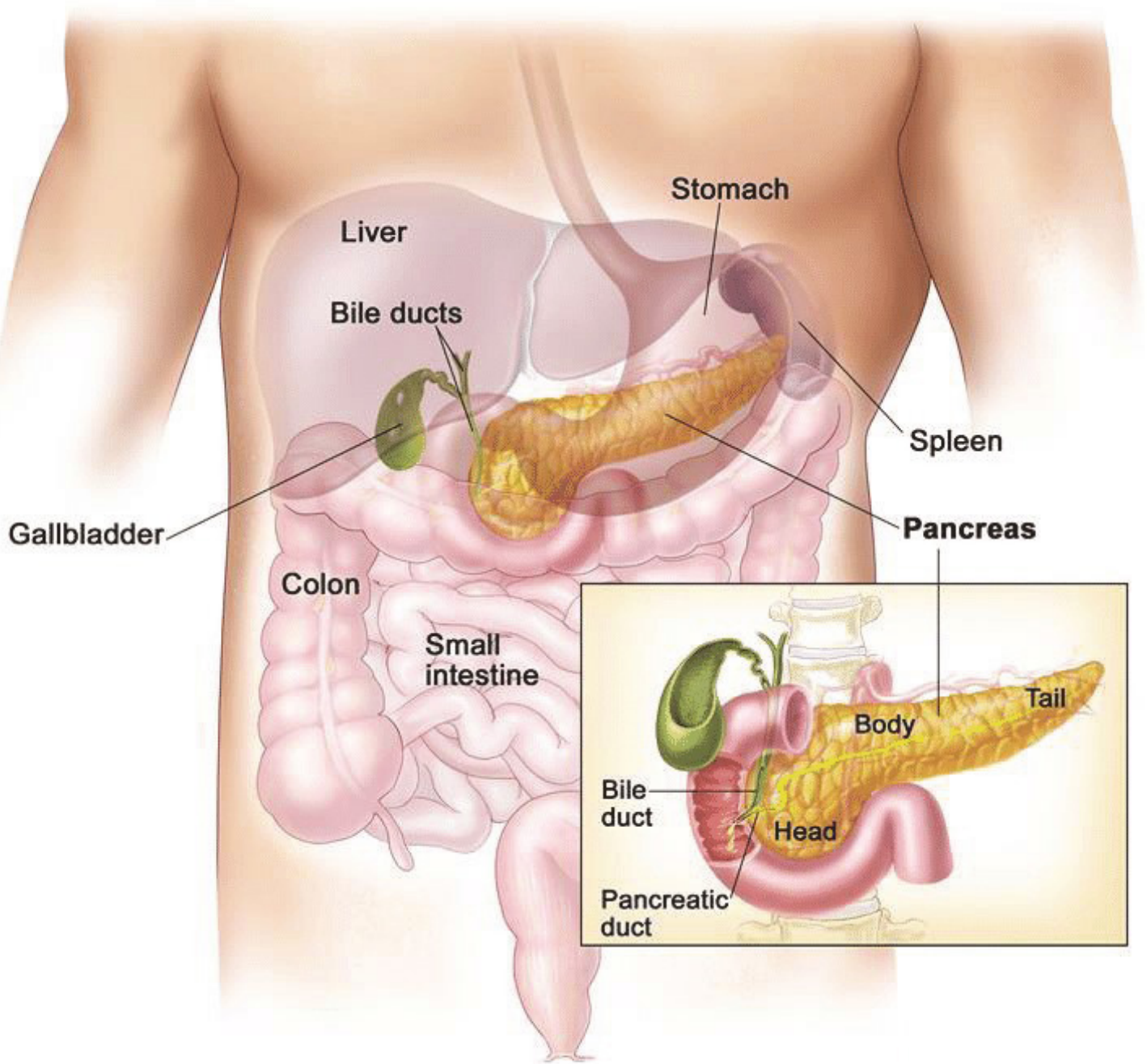


If you find that high fibre foods or high fat foods are causing diarrhoea, this is not carcinoid syndrome! Speak to your dietitian about investigating and managing these different problems.

## Dealing with Deficiencies

Eat enough protein to get a regular supply of tryptophan: fish, e.g. 2 x cans of tuna per week, daily lean turkey or chicken, fresh /mild cheese and milk, nuts and seeds.

Ask your Dietitian and medical team about niacin tablets (nicotinamide). If you are at risk of other B vitamin deficiencies, it is recommended you take a B complex or B compound tablet. If you are only at risk of niacin deficiency, look for a nicotinamide tablet. Everyone will have a different requirement, however 100mg nicotinamide a day will be sufficient to prevent deficiency in most people. The World Health Organisation (WHO) recommends treating pellagra symptoms with 300mg nicotinamide per day in split doses to avoid 'niacin flushes'.



# Non-functioning Pancreatic Neuroendocrine Cancers

Depending on the site within the pancreas, if you have surgery to remove the tissue and what other treatments you start, you are likely to need a dietitian much of the way through the cancer journey.

- Ask your dietitian if you require pancreatic enzyme replacement therapy (PERT). Some people with a pancreatic tumor will require additional help to break down food, depending on the site of the tumor and the treatment you are on. If you have enzymes prescribed, they will also help break down starchy carbohydrate to release glucose from food. It will also help keep your weight stable and your fat-soluble vitamin levels within range.
- If you develop diabetes, you will need to see a diabetes dietitian for dietary advice.



## **Those taking AFINITOR® (everolimus)**

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

# Functioning Pancreatic and Duodenal Neuroendocrine Cancers

You might need to change your diet, depending on the type of pancreatic or duodenal NET you're diagnosed with:

## **Insulinomas (pancreatic)**

A functioning Insulinoma releases insulin into the bloodstream, which lowers blood glucose (sugar) levels. Changing your diet can't stop an insulinoma from doing this, but it can help you to have more control over your blood sugar levels.

At diagnosis:

- Follow your medical team's advice on checking your blood glucose levels. There are a range of monitoring techniques available.
- When you are diagnosed with a functioning insulinoma, it is important that you are referred to a dietitian.

## Dietary Management of Blood Glucose

The glycaemic index (GI) is a rating system for foods containing carbohydrates. It shows how quickly each food affects your blood sugar (glucose) level when that food is eaten on its own.

- Every day eating: Eating low-glycaemic index (GI) or “slow-release” carbs helps to keep your blood sugar levels stable for longer, avoiding highs and lows. Eating a low-GI diet is a great way to keep your energy levels more constant, which can help you to overcome tiredness - one of the major side effects of neuroendocrine cancer.
- Anyone with a blood-glucose concentration less than 4 mmol/litre, with or without symptoms, and who is conscious and able to swallow, should have 15–20 g of fast-acting carbohydrate. This is available in approximately 3–4 heaped teaspoonfuls of granulated sugar dissolved in water, 4–7 glucose tablets, or 150–200 mL of pure fruit juice.
- Wait 15–20 minutes and retest blood. If still under 4 mmol/litre, repeat the step above and consume another 20g fast acting carbohydrate.
- If blood glucose is over 4 mmol/litre, eat a low GI carbohydrate rich meal including bread made with wholegrain or sourdough, bran-based and wholegrain cereals, whole-wheat pasta, noodles, pearl barley or quinoa, jacket potatoes with the skins on, beans, lentils and pulses,



brown and basmati rice, wholegrain crackers and crisp breads.

- To avoid regular alarm setting during the night, a bedtime snack needs to be taken. A large low GI snack, e.g. a bowl of plain porridge oats with milk, should be eaten. If overnight hypoglycaemia becomes a regular problem in disrupting sleep and quality of life, it may be possible to trial a modified maize starch powder such as Glycosade, or add further corn starch to the bedtime snack.
- Eating high-GI carbs are the main way to get your blood glucose level back up if it drops very low. If you need to have high GI foods regularly to prevent low blood sugar levels, it can be easy to gain weight - as the body stores excess glucose as fat. If you're worried about managing your weight, speak with your dietitian.
- Ask your dietitian if you require pancreatic enzyme replacement therapy (PERT, pages 21-22). Most people with an insulinoma will require additional help to break down food, depending on the site of the insulinoma and the treatment you are on. If you have enzymes prescribed, they will also help break down starchy carbohydrate to release glucose from food.

## Exercise

Keep active. Do not give up exercise as this is important to help control your weight and keep your muscle mass and strength. Keep a close eye on glucose levels and have your hypoglycaemia foods and drinks available at all times if it occurs.

Glucagon injection kits should be available for use by carers and family members when someone is suffering severe hypoglycemia and is unable to treat themselves.

## Gastrinomas (pancreatic and duodenal)

Gastrinomas produce the hormone gastrin, which stimulates secretion of gastric acid (HCl). It is released by G cells in the stomach, the duodenum, and the pancreas. This can cause indigestion, sickness, diarrhoea, and weight loss. You may also experience difficulty in swallowing (dysphagia). Too much gastrin can lead to stomach and/or duodenal irritation, ulcers and/or bleeding, which can lead to iron deficiency anaemia. If you have a gastrinoma, you may be prescribed medications to reduce or block the production of acid and to help correct anaemia (either in tablet or injection form).

You can't change the activity of a tumor, however you can avoid foods that might increase symptoms of heartburn or indigestion, these include:

- Large meals
- 'Hot' spices e.g., chilli
- Citrus fruits and juices
- High fat foods
- High fibre foods
- Pickles or vinegar
- If you are having difficulty in swallowing - soft or puréed foods may be easier to eat and you may need to see both a Dietitian and Speech and Language therapist to advise on the consistency of food and fluid.
- Ask your dietitian if you require pancreatic enzyme replacement therapy (PERT, pages 21-22). Some people with a gastrinoma will require additional help to break down food, depending on the site of the gastrinoma and the treatment you are on. If you have enzymes prescribed, they will also help break down starchy carbohydrate to release glucose from food.

## Glucagonomas (pancreas)

Because glucagonomas produce large amounts of the hormone glucagon - which increases blood sugar levels, they can cause a range of issues related to blood sugar, including diabetes.

- Glucagonomas can also cause diarrhoea, a sore mouth and weight loss - all of which are covered later.
- You will be put on medication to help lower your blood glucose levels, thus reducing the need to change your carbohydrate intake.
- Ask your dietitian if you require pancreatic enzyme replacement therapy (PERT). Most people with a glucagonoma will require additional help to break down food, depending on the site of the glucagonoma and the treatment you are on.

## VIPomas (pancreas and other sites)

VIP, the hormone produced by VIPomas, causes very watery frequent diarrhoea. This can lead to low levels of potassium, magnesium, sodium, phosphate and bicarbonate in the blood, and cause symptoms including muscle aches and weakness, cramps, numbness and dehydration. If you're diagnosed with a VIPoma, and are found to be dehydrated and to have low potassium levels they will treat this in hospital.

When you are at home, it may help to:

- Increase the amount of potassium rich food and drink in your diet (high potassium food and drinks - tomato juice, prunes, avocados, kidney beans, dried dates, nuts, figs, raisins and sultanas, dried apricots, potatoes, oranges, bananas)
- Drink 10-12 cups/glasses of non-alcoholic, caffeine-free drinks every day.

VIP-related diarrhoea can be severe. You may find that electrolyte rehydration sachets and/or supplements - taken alongside potassium-rich food and drinks help but you will also need prescribed tablets. You may need to go into hospital for rehydration via a drip or to have a treatment such as potassium replacement. Health problems can also be caused if potassium levels are raised too quickly or go too high, so speak to your care team if you're worried about this.

- VIPomas can also lead to weight loss and deficiencies, so it is important to see an experienced dietitian.
- Ask your dietitian if you require pancreatic enzyme replacement therapy (PERT). Some people with a VIPoma will require additional help to break down food, depending on the site of the VIPoma and the treatment you are on. If you have enzymes prescribed, they will also help break down starchy carbohydrate to release glucose from food.

## **Somatostatinomas (pancreas or duodenum)**

Somatostatinomas produce somatostatin, a hormone that regulates other hormones involved in managing blood sugar levels and digesting food. As a result, these cancers can cause problems including weight loss and diarrhoea.

- You may also notice that your stools are pale, float in the toilet and/or are difficult to flush away. See the section on 'steatorrhoea'. Ask your dietitian if you require pancreatic enzyme replacement therapy (PERT). Some people with a somatostatinoma will require additional help to break down food, depending on the site of the somatostatinoma and the treatment you are on. If you have enzymes prescribed, they will also help break down starchy carbohydrate to release glucose from food.

# **A Final Word on Food**

**We started this booklet by saying, that there is no one diet suitable for everyone with a neuroendocrine cancer. But whether or not you need to make adjustments or additions to what you eat, try to remember that food should always be more than fuel.**

**Eating is a social activity, and the many forms and flavours of food are there to be enjoyed. We know there might be times when your relationship with food changes. There might be times when eating is the last thing you want to do. But remember that you're the one in control - and finding ways to use your diet to control your symptoms and improve how you feel can give your confidence and your quality of life a real boost.**

## Common Dietary Myths

None of the below have been clinically trialled in neuroendocrine cancers at the time of writing and many myths have been around for centuries without any evidence base.

- Sugar feeds neuroendocrine cancer and you should avoid all sugar and 'white carbs'
- Ketogenic diets should be used in neuroendocrine cancer
- Try intermittent fasting in neuroendocrine cancer
- Protein feeds cancer
- I need to cut out red meat
- I should try to eat 'superfoods'
- I need to cut out dairy
- I need to eat organic food
- I need to cut out gluten
- I need to follow a vegan diet
- I need to switch to a juicing diet
- I need to detox my liver
- The higher the dose of vitamins and minerals the better
- I need to avoid all high vasoactive amine foods
- I need to eat a low fibre diet for the rest of my life following bowel surgery
- Plant based digestive enzymes work as well as the medically tested and prescribed enzymes



## Acknowledgements:

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