my NET journey

Nutritional Guide for People living with NETs

An eBook for patients, families and friends

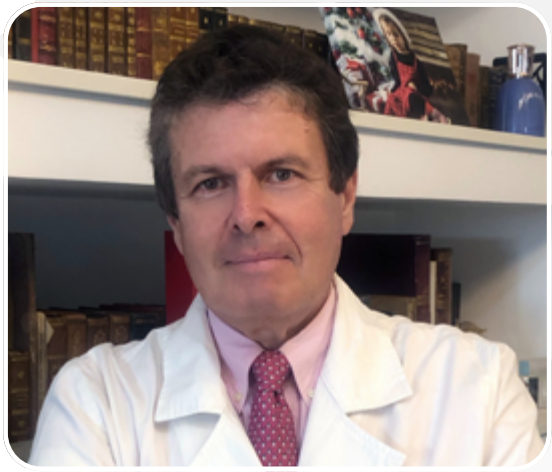
Welcome and Introduction

Nutrition and NETs

NET Services

1. Welcome

1.1 Introduction and greetings from our consulting expert Alessandro Laviano, MD, PhD



Cancer is a systemic disease that affects organs and tissues beyond those in which the tumor grows. This fundamental evidence is becoming a key issue in the optimal management of patients with cancer. Over the last few decades, there has been a progressive improvement in survival observed for most cancers. This highlights the relevance and efficacy of research targeting the molecular vulnerabilities of cancer cells. During the same period, there has been a progressive increase of cancer survivors living with functional limitations, which raises questions about whether an imbalance occurred in the scientific efforts to fight cancer cells and support the patients.

Neuroendocrine tumors are rare, but nonetheless they have a distinct impact on the lives of patients and their families. Similar to other types of tumors, neuroendocrine tumors frequently affect the nutritional status of patients, either through the direct effect of the tumor or the side effects of anticancer therapies on intake, digestion, and absorption of food. Consequently, there is a progressive decline in body weight, muscle mass and strength, which in turn reduces functional autonomy and quality of life, as well as resistance to the side effects of the therapies. From the patient's perspective, this negative cascade of events impacts their quality of life. From the clinician's perspective, malnutrition reduces efficacy of treatment and overall survival.

It is important to remember that the optimal management of any disease, including neuroendocrine tumors, should include therapies that both target cancer cells and address the needs of patients. Also, the management of treatable negative prognostic factors improves patient outcomes. Malnutrition is a preventable and treatable clinical condition, the treatment of which primarily aims to improve quality of life. In addition, it frequently allows the completion of anticancer treatments by optimizing the patients' clinical status, and therefore it plays a role in survival as well.

Unfortunately, nutrition-related issues are frequently overlooked in the management of patients with neuroendocrine tumors, and patients are often given general and hard-to-implement advice. Nutritional care is a scientific discipline which requires knowledge and training and cannot be reduced to the standard recommendation “To treat your malnutrition, eat more”! When not properly advised, patients tend to search the internet to find solutions for their compromised nutritional status, receiving many recommendations that are not evidence-based.

The idea for this eBook stemmed from an analysis of the real world, which highlighted the lack of evidence-based information given to patients and the fact that nutrition does not appear to be a priority for all healthcare professionals involved in the management of patients with cancer. Therefore, this eBook is particularly intended for patients and provides easily implementable advice to tackle nutrition-related symptoms (e.g., poor appetite, changes in taste and smell, diarrhea, weight loss, etc.) and improve their diet and nutritional status. In this respect, it should not be considered as a cookbook but rather as a comprehensive and portable source of information meant to accompany patients during their long clinical journey. Of course, the information in this eBook should be shared with attending physicians to help healthcare professionals without specific nutritional training in better guiding their patients on how to prevent and treat malnutrition.

The secret to achieving the most out of this eBook is to implement the advice as soon as nutrition-related symptoms develop and to share it with other patients with neuroendocrine tumors.

Prof. Alessandro Laviano, MD, PhD
Department of Translational and Precision Medicine
Sapienza University, Rome

1.2 Introduction from ITM

Dear Reader,

Neuroendocrine tumors (NETs) are rare cancers that can occur anywhere in the body. However, one of the most common locations of NETs is the gastrointestinal tract, which can have a huge impact on the nutrition of those affected.

When eating is suddenly paired with significant digestive issues caused by NETs or NET treatment, your overall well-being is affected.

Our nutrition eBook has been developed to offer valuable guidance on managing your diet to relieve and lessen NET symptoms, to help you get through the nutritional challenges that go along with gastro-intestinal surgery, and to provide information about nutrition and specific NET treatments to improve your quality of life.

With this eBook, we hope to support you on your NET journey. We hope you can quickly and easily find answers to many of your questions.

All the best,
Your ITM Team

This ebook is not intended to provide medical advice. You should discuss any treatment and nutrition plans with your healthcare provider.

2. Introduction

Welcome to the “Nutritional Guide for People living with NETs – An eBook for patients, families and friends”.

There is no doubt that neuroendocrine tumors (NETs) have a wide-reaching impact far beyond the individual patient, therefore, this eBook seeks to provide valuable insights to anyone involved in the patient’s support network.

Whether you are a patient yourself, a family member, a friend or anyone who wishes to learn more about nutrition in NETs, this eBook is designed for you!

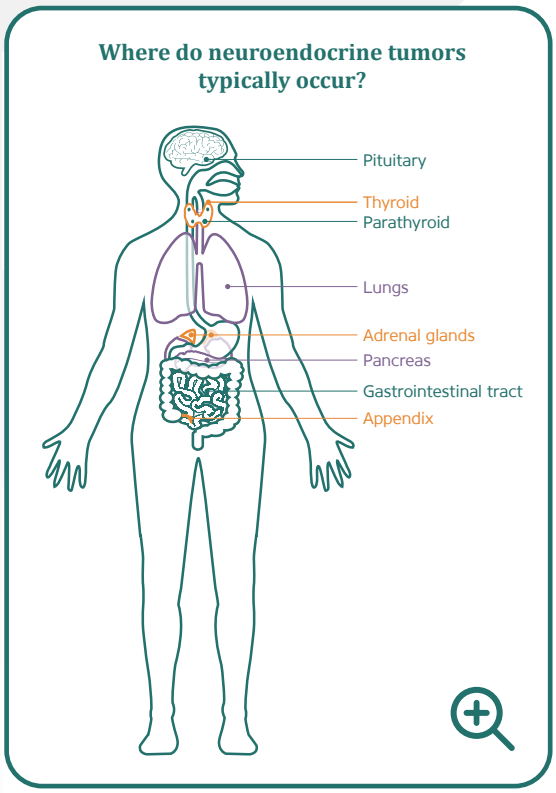
“Nutrition in NET” aims to:

- Educate about the significant role of nutrition and healthy eating with NETs
- Give advice about managing diet to help with NET-related symptoms or side effects of NET treatment
- Inform about the dietary impact of specific NETs
- Provide information about the dietary impact of gastrointestinal surgery
- Offer practical information, useful tips, and evidence-based dietary recommendations in cooperation with renowned experts in the field
- Support patients and those close to them in making informed dietary choices

By combining scientific research and practical advice, this eBook aims to be a valuable resource for anyone affected by NETs. Together, let’s embark on a journey towards a better understanding, health and hope.

3. About NET

A neuroendocrine tumor (NET) is an uncommon cancer that affects neuroendocrine cells, which are specialized cells that release hormones into the bloodstream.



NETs can develop in many different organs of the body, but most occur within the gastrointestinal tract, the lungs, and the pancreas.

NETs are often very small and slow-growing. The symptoms of a NET depend on its location and can be vague or behave like other disorders. For example, NETs in the gastrointestinal tract may cause diarrhea, constipation, or abdominal pain.

When a NET spreads from its primary site to other places, such as the lymph nodes or liver, it is known as metastasis.

If you want to learn more about the definition and the different types of NETs, please take a look at myNETjourney.com.

4. Eating well with NETs

4.1 Benefits of eating well with NETs

More than half of the food an average person consumes every day comes from so called ultra-processed foods, which have been heavily processed during their production.

Although ultra-processed foods can be convenient, foods like soft drinks, pizza, sweetened breakfast cereals or packaged soups are generally high in salt, fat, sugar, and artificial additives and do not provide the body with the nutrients it needs.

There is now strong evidence that ultra-processed foods can impact our health and are especially associated with an increased risk of developing cancer, as well as obesity, type 2 diabetes, and heart disease.

Classification of processed food

Based on the amount of processing, nutritionists divide foods into four categories:

Unprocessed or minimally processed foods

Any food that is not changed from its original state or has undergone minimal processing steps.

Processed ingredients

Ingredients made from natural sources or minimally processed foods that are added to other foods for the preparation of dishes.

Processed foods

Any foods which have been changed from their original state and have gone through at least one level of processing.

Ultra-processed foods

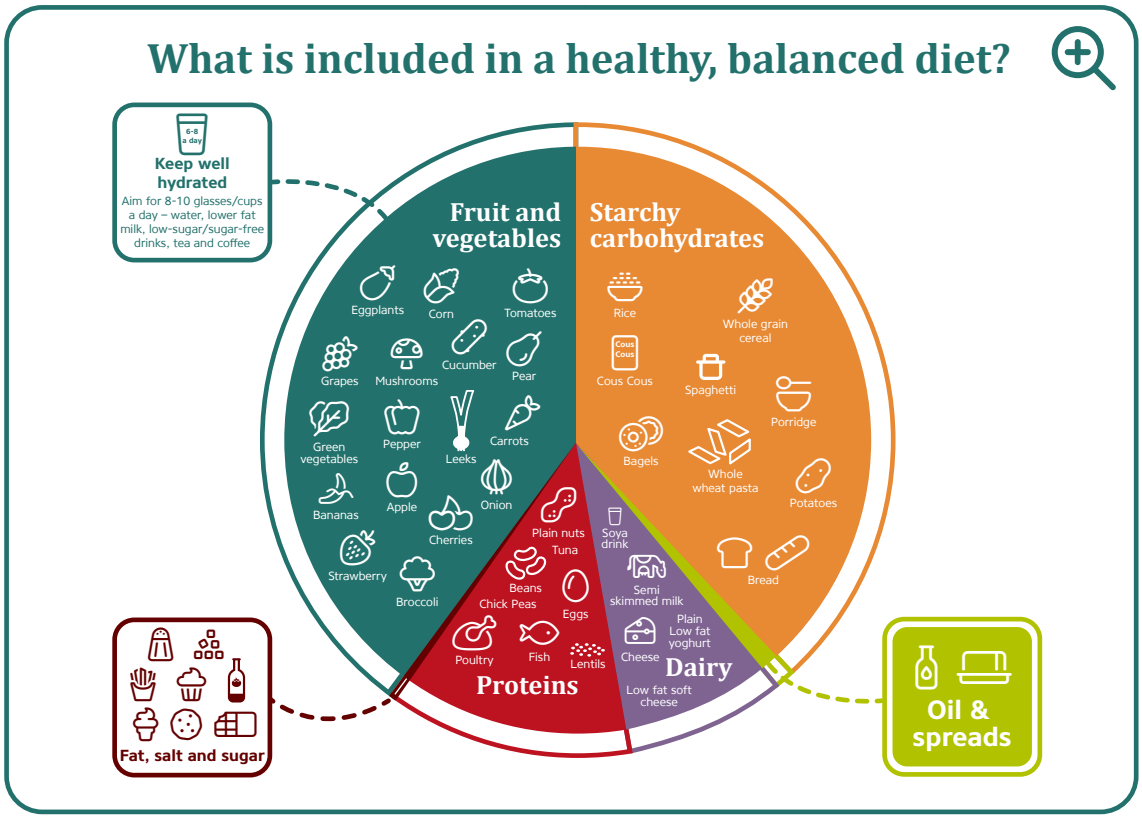
Foods that have gone through multiple levels of processing and typically contain a lot of added salt, sugar, fat, and industrial chemical additives.

In short, the type of food we eat is central to our health. This is especially true for people with NET. Following a healthy diet can improve your quality of life in many ways.

Eating well can:

- Help you handle treatment better.
- Help wounds and damaged tissue heal after treatment, including surgery, chemotherapy and radiotherapy.
- Improve your immune system, which protects you from infections.
- Help you maintain your weight and provide valuable energy to carry out your everyday tasks, which is important even if you are not undergoing treatment.

Patients whose symptoms are well controlled without any other specifically prescribed diet should follow a healthy, well-balanced diet. This should be high in fruit and vegetables (at least two fruit and three vegetable portions a day) and whole grains, but low in nutrients such as salt, saturated fat and added sugar. A healthy diet should also include lean proteins (at least two portions of chicken a week), low-fat dairy and a small amount of oils and spreads (preferably unsaturated). Unless diarrhea, fever, vomiting or other health issues have caused the body to lose water, an adult should drink around 1 ounce for every 2 pounds of body weight each day. This would mean, a person weighing 130 pounds would need approximately 64 ounces (or 8 cups) of fluids per day. Someone who weighs 150 pounds would need 75 ounces (or nearly 9.5 cups) per day and someone who weighs 200 pounds would need 100 ounces (12.5 cups) per day.



4.2 Nutrition recommendations for patients with cancer/NETs

4.2.1 Nutrition Recommendations for Cancer Prevention

If you have had curative surgery and your scans are clear, you should follow the World Cancer Research Fund Cancer Prevention Recommendations or the American Cancer Society Guideline for Diet and Physical Activity for Cancer Prevention. Both of these recommend a typical healthy diet and lifestyle. Following these recommendations will also likely reduce the risk of other diseases, such as heart disease or diabetes. For more information, please visit:

https://www.wcrf-uk.org/preventing-cancer/our-cancer-prevention-recommendations/

https://www.cancer.org/cancer/risk-prevention/diet-physical-activity/acs-guidelines-nutrition-physical-activity-cancer-prevention/guidelines.html

4.2.2 Nutrition Guidance for People with Cancer

Your medical team will provide nutrition advice based on consensus guidelines published by cancer societies. The American Cancer Society has developed practical guidelines on nutrition for people with cancer.

For more information, please visit:

https://www.cancer.org/cancer/survivorship/coping/nutrition.html

4.2.3 ENETS Guidelines

Guidelines from the European Neuroendocrine Tumor Society (ENETS) include recommendations on the management of NET-related symptoms associated with specific tumors and treatments which may affect your nutritional status. Based on these guidelines, your medical team will be able to recommend the best course of treatment for your specific NET as well as a personalized approach to improve your nutritional status. ENETS guidelines are available at:
https://www.enets.org/guidelines.html

4.3 Every patient is different: Need for tailored diets

There's no one specific diet which is suitable for every patient with a NET, or even for the whole journey of an individual patient. Your diet should be appropriate for your personal situation at a particular point in time and cover your individual requirements for energy, protein, fluid, vitamins and minerals, which may vary throughout your journey. You may need to make some small adjustments to what you eat and drink, such as adding or removing things from your diet based on your general health, the type and stage of your NET, or your treatment. When foods are reintroduced into your diet, it should be done carefully and adding only one new food per day, as this will allow foods which are not well tolerated to be easily identified.

Some patients with NETs may need to seek professional advice about the right foods. In particular, patients with pancreatic NETs may have more complex needs and should seek guidance from an experienced dietitian. Make a list of questions for your meeting with the dietitian. Ask about your favorite foods and recipes and whether you can still eat them. You can download 'My NET diary' to take it to your appointment and use it for your notes.

4.3.1 Quality of life markers

After you have been prescribed a specific diet, your medical team will want to know how the diet affects your quality of life. They will want to know how the diet impacts you physically, emotionally, and socially, and whether you experience a change in NET-related symptoms such as diarrhea, loss of appetite, constipation or nausea and vomiting.

5. Managing NET-related symptoms with nutrition

NETs and the treatments you may receive can often affect how your body processes food. The key to managing the following symptoms is to identify the cause. However, not all causes can be avoided or treated, therefore you will also find some tips that may help reduce the impact of these symptoms on your daily life. Sometimes, making small adjustments to your diet may help you feel better, but you should consider that there is no specific diet that is suitable for everyone so you should always follow tailored advice from your healthcare team.

5.1 Diarrhea

Diarrhea may be caused by the NET, or it may be a side effect of treatment. It may also be due to an infection, so you should always tell your doctor if you experience diarrhea.

Whatever the origin, you may want to try:

- Eating smaller, more frequent meals and snacks throughout the day
- Drinking plenty of fluids to prevent dehydration (ideally 8 to 10 8-ounce glasses a day) – include drinks with electrolytes (e.g. sports drinks)
- Reducing insoluble fiber in your diet (such as whole grains, beans and nuts. *More information on fiber can be found in the infographic below*) (cooking, peeling and removing seeds from fruits and vegetables may also help)
- Reducing your intake of stimulants such as alcohol and caffeine, which are known to promote bowel movements
- Avoiding very hot or very cold foods and drinks
- Avoiding spicy, fatty, or very sweet foods
- Avoiding sweets, gum, mints and soft drinks containing artificial sweeteners (such as sorbitol, xylitol, and mannitol)
- Including binding foods in your diet (such as white rice, white bread, pasta, baked potatoes without the skin, bananas, and applesauce)
- A non-dairy, multi-strain probiotic containing Bifidobacterium and Lactobacillus, which are available without a prescription at many grocery and drug stores. Please discuss this with your doctor if you are receiving chemotherapy.

If the above tips do not help, your dietitian may suggest that you try a low FODMAP diet (a diet low in fermentable carbohydrates).

What is fiber?

- Dietary fiber is a group of compounds found in plants
- There are two types of fiber: soluble and insoluble fiber
- Most plants contain both soluble and insoluble fiber, but in different amounts

SOLUBLE FIBER

- Dissolves in water
- Retains water and forms a gel-like material
- Slows down digestion

Sources

Apples, Eggplant, Barley, Brussels sprout, Carrots, Citrus fruits, Oats, Peas, Psyllium, Sweet potatoe

INSOLUBLE FIBER

- Does not dissolve in water
- Promotes the passage of food through the digestive system
- Increases stool bulk

Sources

Beans, Brown rice, Cauliflower, Nuts and seeds, Potatoes, Quinoa, Wheat bran, Whole-wheat-flour

5.2 Weight loss and malnutrition: How to gain weight?

It is not recommended to weigh yourself every day, as body weight can go up and down even within a single day. However, it is important not to ignore any trend towards a loss of weight, because weight loss might be due to number of problems, including disease progression.

You should discuss this with your doctor and dietitian, but the following tips may help you increase your caloric intake:

- Eat small and frequent meals and snacks throughout the day, which may be easier for you to manage than the traditional three big meals per day
- Eat when you feel hungry rather than at set times, but avoid going long periods of time without eating
- Gentle exercise may help to stimulate appetite
- Use convenience foods (such as ready meals or frozen foods) if you are too tired to prepare meals
- If you have a loss of appetite, try using a smaller plate, which can seem less daunting than a larger plate and help food seem more manageable
- Eat foods rich in protein (such as meat, poultry, fish, eggs, dairy products, and nuts)
- Eat foods rich in energy (such as those high in fat and sugar like oils, nuts or full-fat dairy products)
- Add protein and calories to other foods. For example, use peanut butter, olive oil or avocado as toppings for your meals and snacks
- Strong tasting/high-flavor foods may help stimulate your appetite
- If you do not feel hungry or you are unable to eat a reasonable amount of solid food, it is often easier to drink rather than eat. You may try drinking over-the-counter nourishment drinks, such as full-fat milkshakes, fruit smoothies, yogurt drinks, and soups.
- If necessary, your dietitian may suggest that you get a prescription for supplement drinks.

5.3 Nausea and vomiting

You may feel nauseous or vomit for different reasons.

You can ask your doctor about anti-nausea drugs, but some general tips that may help you deal with these kinds of symptoms include:

- Avoid feeling full – eat smaller and more frequent meals throughout the day instead of three big meals
- Try not to skip meals – having an empty stomach can make nausea worse
- Do not eat or prepare food when you feel nauseous
- If possible, avoid cooking smells. Hot cooked foods usually have a stronger smell than cold food and drinks. To minimize the smell produced while cooking, you can use a microwave
- Avoid very hot or very cold foods and drinks
- Avoid greasy or fatty foods to make digestion easier
- Drink nutritions drinks in between meals instead of with meals
- Try ginger extract or papaya in foods and drinks
- Eat light, bland foods such as plain biscuits, crackers or dry toast
- Try tart flavors (such as citrus juices and sorbets) or salty and minty flavors
- Rest (sitting up, not lying down) after eating and avoid brushing your teeth straight after a meal

5.4 Constipation

Constipation may be caused by different factors, but it should be investigated by your healthcare team if it is a sudden change.

Your doctor may prescribe medications to regulate bowel movements, but it can also help to:

- Drink additional fluids to prevent dehydration (more than your normal 8 to 10 8-ounce glasses a day). Some people find that it helps to drink warm or hot liquids such as coffee, tea or soup
- Stay active / keep moving and do regular, gentle exercise (for example, go for a walk after eating)
- Eat a high-fiber diet, including whole grains, beans, lentils, peas, sweetcorn, avocados, pears, bananas, berries, grapefruit, oranges, prunes (all fresh, frozen, dried or canned vegetables and fruit with skins and seeds have some fiber)
- Take probiotics or eat yogurt, because they contain bacteria that help with digestion

5.5 Loss of appetite

Many cancer patients experience loss of appetite, which can be dangerous because it may lead to decreased food intake and progressive loss of weight.

If you are experiencing reduced appetite, the following tips may be useful for you:

- Eat smaller and more frequent meals and snacks throughout the day instead of three big meals
- Eat a small bedtime snack – doing so will give you extra calories but will not affect your appetite for the next meal
- Avoid drinking fluids during meals. Instead, drink between meals and choose drinks that add calories and other nutrients
- Avoid high-fiber foods (such as fruits and vegetables), as they tend to be more filling
- Strong tasting/high flavor foods may help stimulate your appetite
- Gentle exercise may help to stimulate appetite

5.6 Gas and bloating

Diarrhea and constipation are usually accompanied by gas and bloating.

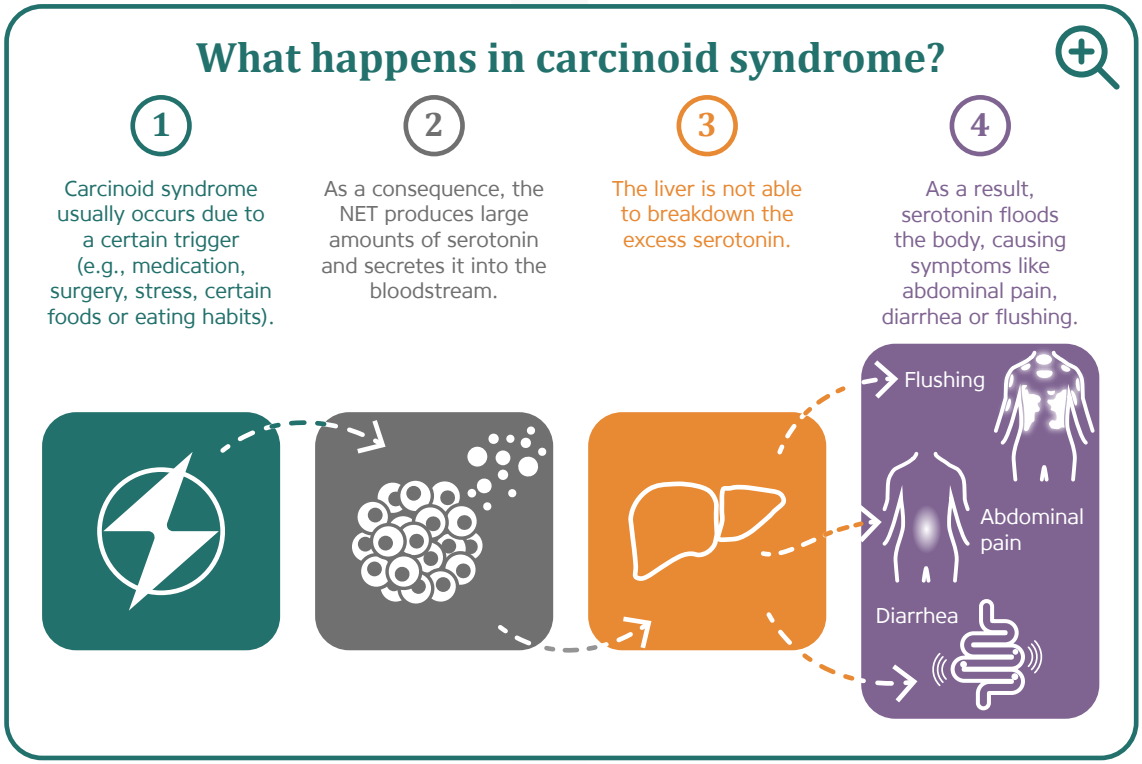
Here are some tips to help reduce or prevent any discomfort:

- Avoid gas-forming foods (such as onions, garlic, cabbage, cauliflower, broccoli, nuts, and spicy foods), as well as fizzy/carbonated drinks and chewing gum
- Try a low-fiber diet consisting of refined grains, small portions of fruits and vegetables without skins or seeds
- Eat regular meals – skipping meals is more likely to cause gas
- Chew your food well and slowly to reduce the amount of air swallowed

5.7 Carcinoid syndrome

Carcinoid syndrome can occur in patients with functioning NETs. In healthy individuals, the amino acid trypotophan is converted into the hormone serotonin and vitamin B3. However, in carcinoid syndrome, more serotonin is produced and the level of vitamin B3 is drastically reduced.

In most cases, the body, particularly the liver, is not able to break down the excessive amount of serotonin produced by the NET. As a result, the hormone floods the body, which may cause symptoms such as abdominal pain, diarrhea and/or flushing.



If you experience carcinoid syndrome, you may find it helps to:

- Eat fresh, high-protein foods which contain tryptophan (such as fish, poultry, lean meat, eggs, and low-fat dairy products)
- Eat foods low in amines (such as refined grains, cooked vegetables, and moderate amounts of most fruits)
- Avoid stimulants such as alcohol and caffeine
- Avoid fatty and spicy foods
- Pay attention to foods that might trigger your symptoms (different foods affect people differently) and reduce the amount you eat or avoid them completely
- Eat smaller and more frequent meals throughout the day
- Take a vitamin B3 supplement. Ask your doctor if a supplement is right for you.

5.8 Dumping syndrome

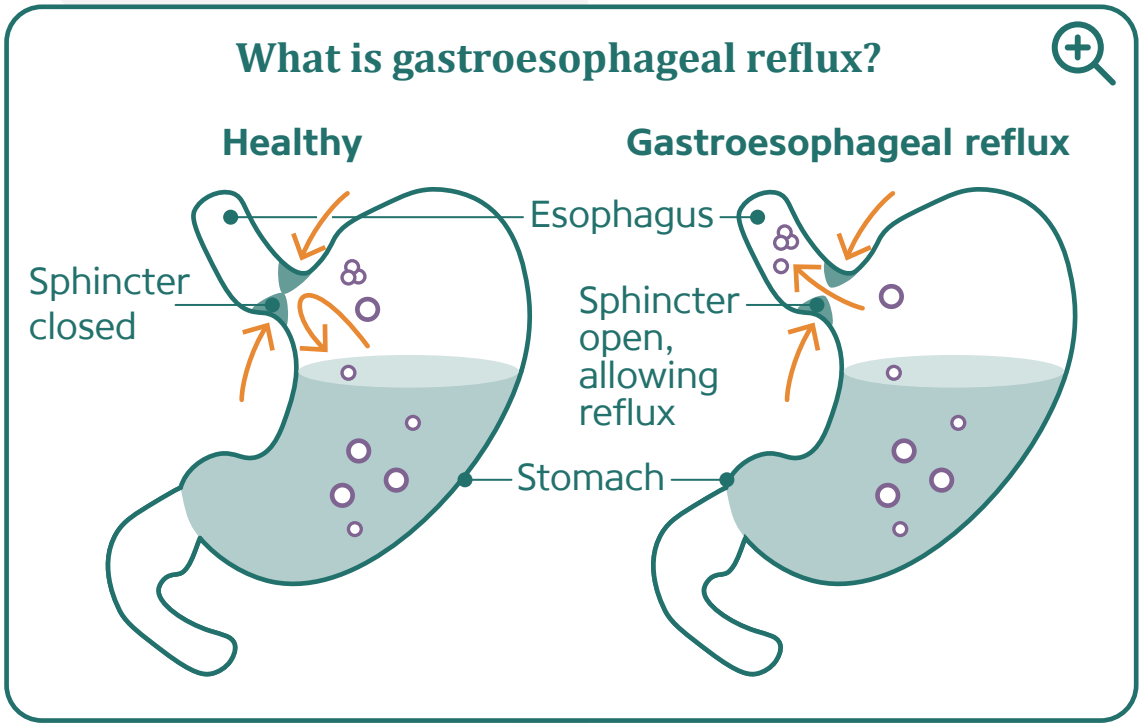
Most of the carbohydrates you eat are usually broken down by the stomach. If you have had surgery and all or parts of your stomach have been removed, food is passed on to the small bowel at a faster rate, which shortens the overall digestion process. Dumping syndrome occurs when water is drawn to the small bowel from the circulating blood to dissolve sugars. This can cause dizziness after eating, an erratic heart rate, bloating, nausea or diarrhea.

Some helpful tips to reduce these symptoms include:

- Eat small and frequent meals and snacks throughout the day
- Eat slowly and rest after eating (25-45 minutes)
- Avoid or reduce starchy and sugary foods, such as cakes and pastries
- Avoid soups and other liquid foods
- Eat a low-fiber diet and gradually increase fiber as symptoms improve

5.9 Gastroesophageal reflux disease

Gastroesophageal reflux disease (sometimes called GERD) is a condition in which stomach acid or stomach content flows back into the esophagus (food pipe).



You may experience heartburn or an unpleasant taste in your mouth.

GERD is a common symptom, but the following tips will help you relieve it:

- Eat small and more frequent meals throughout the day, but try not to eat within 3-4 hours of bedtime
- Avoid acidic foods, such as tomato-based products, citrus fruits and juices
- Avoid fatty and spicy foods
- Avoid stimulants such as alcohol and caffeine
- Try not to lie down immediately after eating, as this may intensify the feeling, and adjust your sleeping position to keep your head elevated

5.10 Fat malabsorption (steatorrhea)

If your stools appear different (for example, they are pale, oily, smelly, floating and hard to flush away) or you have diarrhea, this might indicate that your body is not absorbing fat as it should. This may be caused by different factors, including treatment and surgery.

You may want to try:

- Reducing the amount of fatty foods you eat
- Pancreatic enzyme replacement therapy (PERT) to help break down the food so it can be more easily absorbed. Your doctor will recommend the appropriate dosing of the capsules (containing enzymes normally produced by the pancreas) to control your symptoms

5.11 Feeling full

There are many reasons that may make you feel full after eating only a small amount of food, for example: abdominal tumors, stomach resection, or an enlarged liver. Gas and bloating can also have the same effect.

Here are some helpful tips to make sure you get the nutrients you need:

- Eat small and more frequent meals and snacks throughout the day
- Drink plenty of fluids but avoid them with meals or for an hour beforehand. Choose nutritious drinks and drink between meals
- Avoid rich and fatty foods, as these can make you feel fuller faster
- Avoid having dessert straight after your meal – it may be easier to eat it a couple of hours later

5.12 Sore mouth (mucositis)

A sore or painful mouth can be caused by ulcers, candida (a common fungal infection), gum disease or some systemic therapies. Mouthwashes can be useful to clean and numb your mouth (avoid over-the-counter ones which may be alcohol-based). Your doctor may also be able to prescribe some medicine to help.

In addition, you should try to avoid food that could make the pain worse, such as:

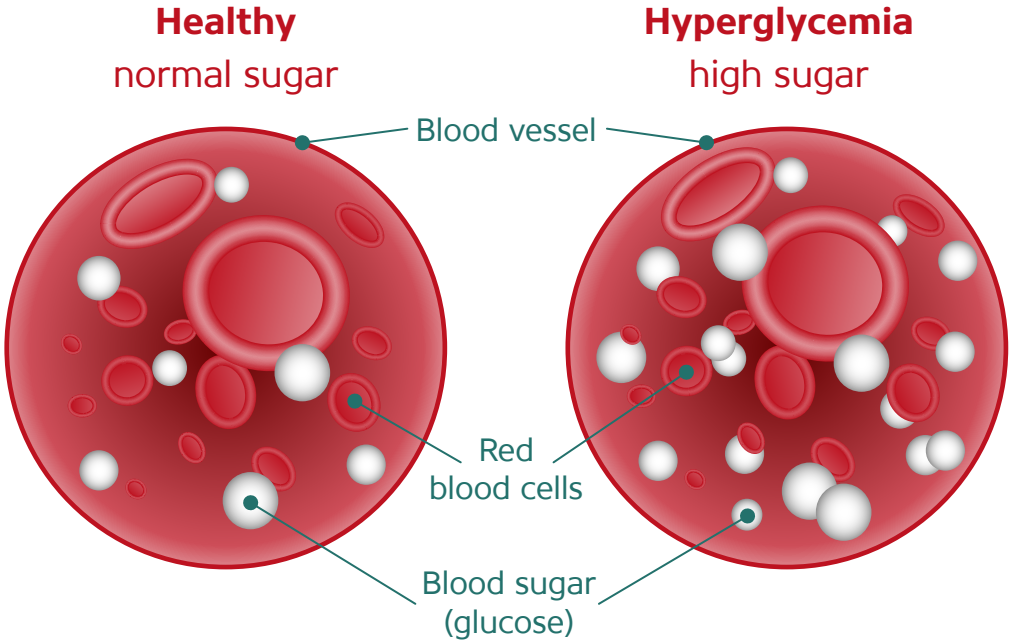
- Very hot food and drinks - cold foods and drinks can numb your mouth and be soothing (like ice cream and frozen yogurt)
- Drinks that contain alcohol
- Salty and/or spicy foods such as chips, chili, or curry
- Acidic foods such as citrus fruits and juices, tomatoes, or vinegar – you can add sugar and cream to fruit to make it less acidic, easier to swallow, and to increase the calorie content
- Sticky-textured foods such as chocolate or peanut butter
- Rough-textured, dry or crispy foods which could be abrasive (like crackers, chips, and nuts) – Try soft, moist foods (such as well-cooked pasta with sauce, stews, milk puddings, and pureed fruit and vegetables) and cut into small pieces may be easier to eat

5.13 High blood sugar (hyperglycemia)

As a result of some therapies or surgery, particularly after a resection of the pancreas, patients with NETs may develop hyperglycemia, which means that blood sugar levels are higher than normal.

What is hyperglycemia?

Hyperglycemia (also known as high blood sugar) is a condition in which the blood sugar level is higher than normal, which is above 125 mg/dL (milligrams per deciliter) after not eating or drinking for at least 8 hours or greater than 180 mg/dl two hours after a meal.



To help keep your blood sugar levels stable:

- Eat foods with a low glycemic index or 'slow-release' carbo-hydrates [such as whole grains, most vegetables, some fruits (apples or pears), potatoes with the skins, nuts and seeds, beans, and lentils]
- Eat fresh fruits and vegetables – avoid canned fruits and jams
- Eat fresh foods rich in protein (such as lean meat, poultry, fish, eggs, and low-fat dairy products)
- Avoid refined grains and sugary foods, like cakes and pastries
- Avoid soft drinks containing artificial sweeteners
- Check your blood sugar levels regularly

5.14 Anemia and vitamin deficiency

Blood tests will identify any significant deficiencies, which are quite common in patients with NETs and can be associated with additional problems such as changes in blood production or neurological disorders. Based on the test results, your doctor might recommend taking specific supplements and your dietitian may suggest changes to your diet.

Here are some ideas of foods you may want to include in your diet depending on the vitamins that you need:

Vitamins at a glance

Vitamin A
Important for
Eyes, Skin, Growth
Included in
Oily fish, Eggs, Red/orange fruits & vegetables

Vitamin B3
Important for
Sleep, Heart function, Metabolism
Included in
Meat, Oily fish, Eggs, Whole grains, Nuts & seeds, Bananas, Beans, Peas, Lentils

Vitamin B12
Important for
Nervous system, Formation of red blood cells, Cell growth and division
Included in
Meat, Poultry, Fish, Seafood, Dairy products, Eggs

Vitamin D
Important for
Healthy bones, Calcium intake, Immune system
Included in
Oily fish, Eggs, Dairy products
Sun exposure is very important for vitamin D

Vitamin E
Important for
Blood circulation, Immune system
Included in
Oils, Nuts & seeds, Green vegetables, Avocado, Mushrooms

Vitamin K
Important for
Blood clotting, Wound healing
Included in
Oils, Green vegetables, Mushrooms, Soy, Figs, Blueberries

5.15 Dry mouth

Some therapies can affect the production of saliva. Having a dry mouth can be uncomfortable and make it difficult to chew and swallow food.

If you have a dry mouth, the following tips may help you:

- Drink plenty of fluids to keep your mouth moist. To avoid filling yourself up too much, drink between meals rather than with meals
- Keep your lips moist with lip balm
- Chew on gum or suck on hard candies to stimulate your salivary glands to produce more saliva. Check with your dietitian if you also have diarrhea, as some sugar-free products can make it worse
- Eat soft, moist foods with plenty of sauce so that they are easier to swallow (for example, soups, stews, yogurt, and ice cream)
- Very sweet or acidic foods and drinks may help you make more saliva
- Avoid alcohol, as it can make your mouth even drier
- Avoid alcohol-based mouthwashes

6. Nutrition and specific NET tumors

Depending on the type of NET you have been diagnosed with, you may experience different symptoms and may need to adapt your diet accordingly.

6.1. Insulinomas

Insulinomas are a rare type of pancreatic NET which release insulin into the bloodstream. This causes a drop in blood sugar levels (hypoglycemia), which can result in feeling sweaty, faint, anxious and/or confused.

The tumor will not stop producing insulin, but there are some changes you can make to your eating habits to have more control over your blood sugar levels:

- Eat small and frequent meals throughout the day
- Consider eating in the night or having a bedtime snack to prevent low blood sugar overnight
- Eat carbohydrates with a low glycemic index (such as whole grains, nuts and other healthy fats, most vegetables, potatoes with the skin, and beans), which help maintain/stabilize blood sugar levels for a longer time by raising them slowly
- High-glycemic index carbohydrates (such as glucose or dextrose tablets, non-diet soft drinks, pure fruit juice, non-sugar-free gum, and licorice) are very useful to get your blood sugar levels back up quickly if they drop too low

6.2 Glucagonomas

Glucagonomas produce large amounts of the hormone glucagon, which increases blood sugar levels. They can lead to glucose intolerance, which can cause diabetes. Your doctor may prescribe medication to help lower your blood glucose levels and reduce the need to change your carbohydrate intake.

Glucagonomas can also cause diarrhea, sore mouth and weight loss. Please see **Section 5** for tips on how to manage each of these symptoms.

6.3 Gastrinomas

Gastrinomas produce the hormone gastrin, which stimulates the secretion of gastric acid. This can cause indigestion, sickness, diarrhea and weight loss. Too much gastrin can lead to stomach and/or intestinal irritation, as well as ulcers and/or bleeding, which in turn can result in iron-deficiency anemia. You may be prescribed medications to reduce or block the production of acid and to help correct anemia.

If you're diagnosed with a gastrinoma, you may also want to avoid:

- Eating large meals
- Spicy food
- Citrus fruits and juices
- High-fat and high-fiber foods
- Pickled foods and vinegar

6.4 Vasoactive intestinal polypeptide (VIP)omas

Vasoactive intestinal polypeptide (VIP)omas are a rare type of NET which produce vasoactive intestinal polypeptide (VIP). The overproduction of VIP can cause severe and frequent watery diarrhea, which may result in dehydration, numbness, muscle aches and weakness due to loss of fluid, potassium and bicarbonate.

To ease these symptoms, it may help to:

- Drink 10-12 glasses (8-ounces each) of non-alcoholic, caffeine-free fluids every day
- Include high-potassium foods and drinks in your diet (such as bananas, avocados, tomatoes, dried fruit, nuts and seeds, potatoes, and beans)
- Drink electrolyte rehydration solutions and/or take supplements

6.5 Somatostatinomas

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

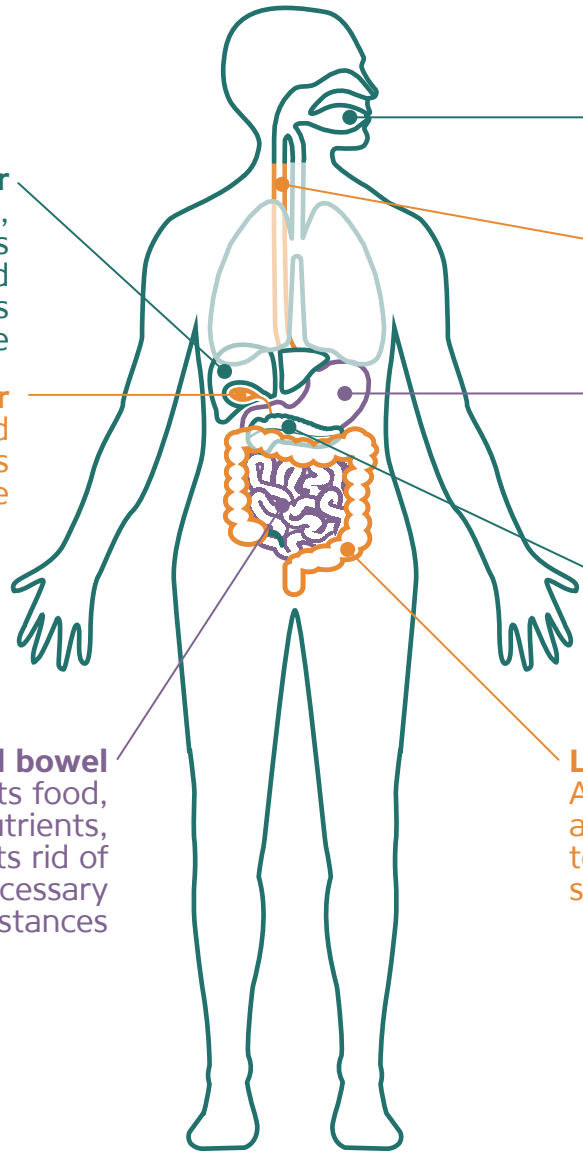
Some people with a somatostatinoma may experience steatorrhea (see Section 5.10) and require pancreatic enzyme replacement therapy.

7. Nutrition and surgery

7.1 Overview of the digestive system

Each segment of the gastrointestinal tract plays a unique role in digesting and absorbing various food components. Therefore, it is important to consider these digestive functions in addition to diet to prevent deficiencies and/or digestive issues after undergoing surgical removal of specific sections of the gastrointestinal tract.

The digestive system



Mouth
Chews and mixes food with saliva

Esophagus
Carries food from the mouth to the stomach

Stomach
Mixes food with gastric juices that contain digestive enzymes

Pancreas
Releases digestive enzymes and produces the hormone insulin

Large bowel
Absorbs water and electrolytes to form a solid stool

Small bowel
Digests food, absorbs nutrients, and gets rid of unnecessary substances

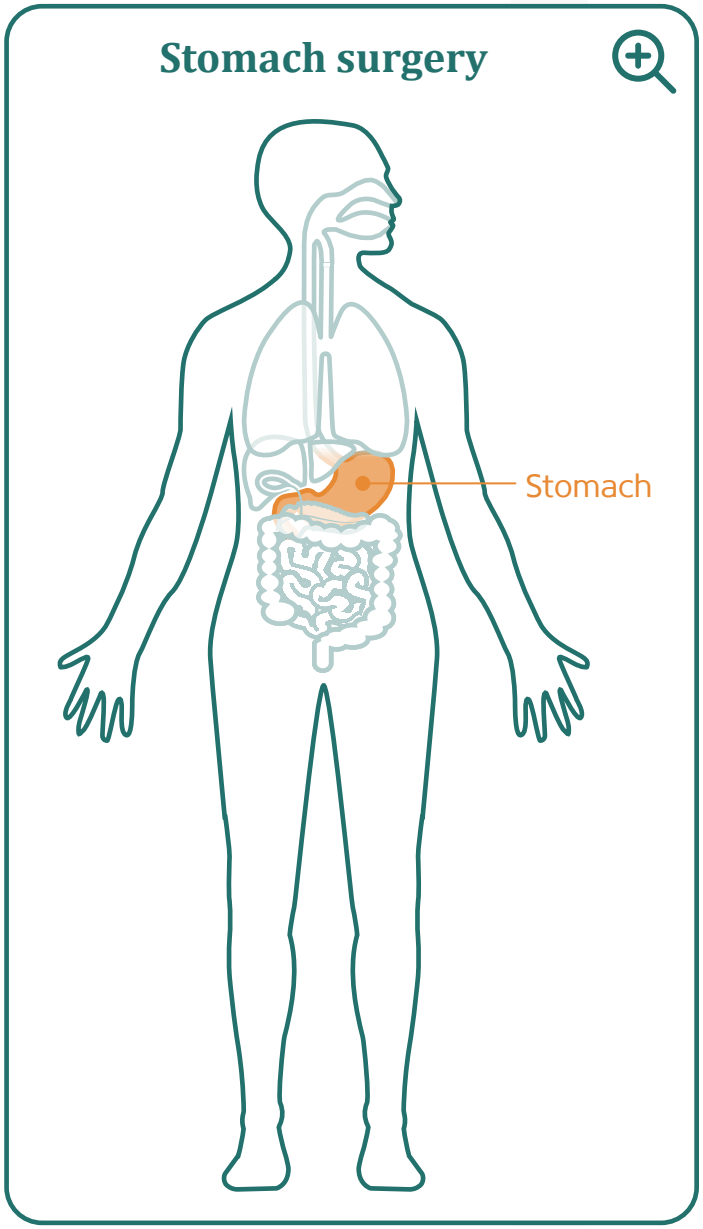
Liver
Filters blood, removes toxins and produces bile

Gallbladder
Stores and concentrates bile

7.2 Stomach surgery

The stomach is a hollow muscular organ, whose main function is the mechanical and chemical digestion of food before it is passed on to the intestine. In addition, the stomach also serves as a reservoir and ensures that the food does not reach the other sections of the intestine too quickly.

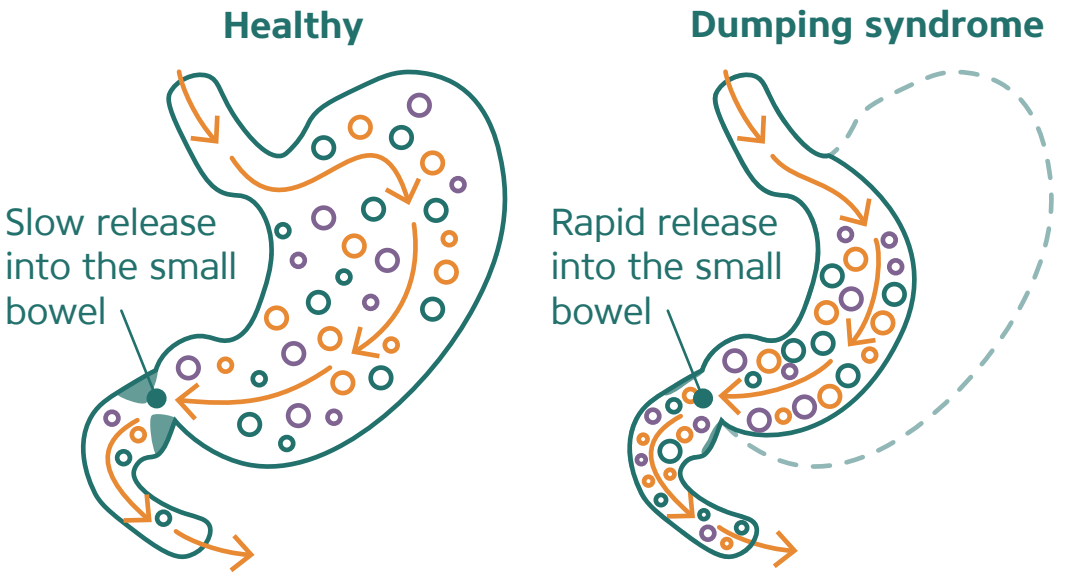
After partial or total removal of the stomach due to a NET, you may feel full after a very small amount of food. This is known as “early satiety”. You will likely need to adjust your eating patterns and consult with a professional dietitian to avoid losing too much weight.



Dumping syndrome

People who have had a stomach surgery can develop dumping syndrome, which is when the stomach empties food into the small bowel at a faster rate than normal.

What is dumping syndrome?



Dumping syndrome can be classified as either early or late.

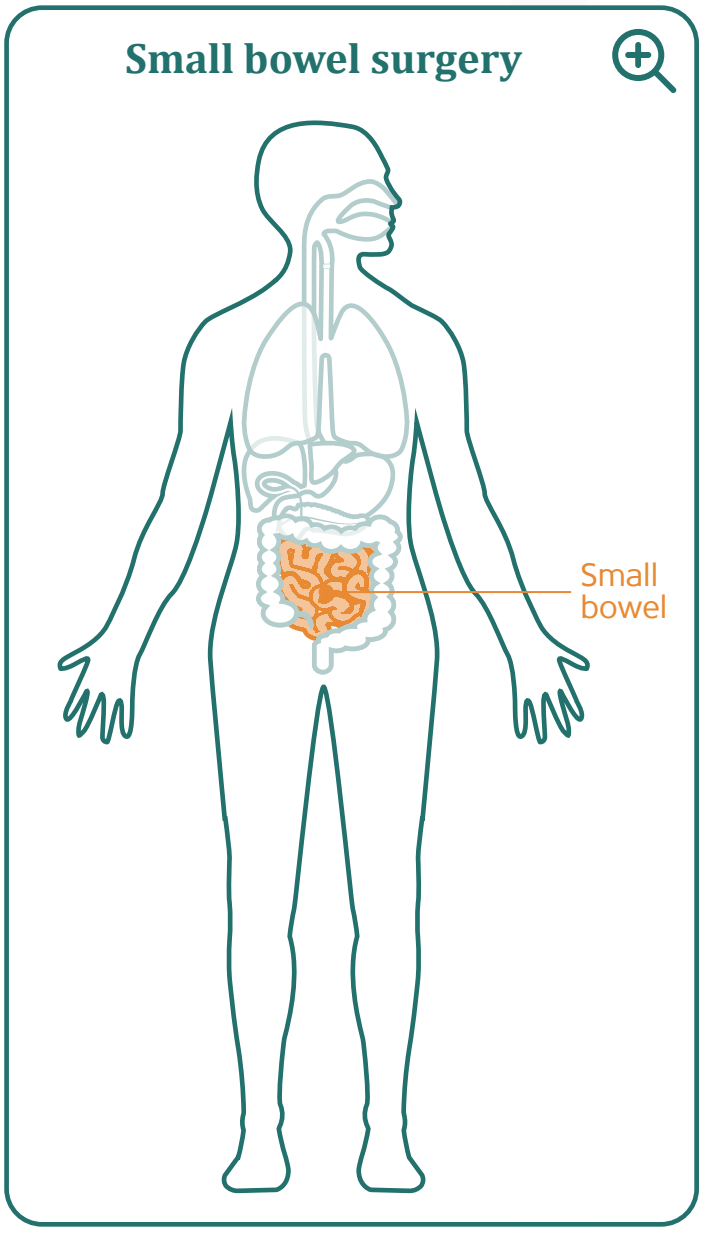
Early dumping syndrome usually starts minutes after eating and results in symptoms like upper abdominal cramping, nausea, vomiting, fullness, and tiredness. In these cases, it may be helpful to eat smaller meals at a moderate temperature, chew thoroughly and avoid drinking directly after the meal.

Late dumping syndrome generally occurs between 1 to 3 hours after eating a meal. It results in low blood sugar and causes symptoms similar to early dumping with the addition of restlessness, sweating or dizziness. Please see section 5.8 for specific tips on how to manage symptoms related to a dumping syndrome.

7.3 Small bowel surgery

As the longest segment of the digestive system, the small intestine breaks down food, absorbs nutrients, and gets rid of unnecessary substances.

If parts of the small intestine are surgically removed, the remaining sections generally try to adapt and compensate for the loss by absorbing nutrients and liquids that would have normally been handled by the removed segment. However, it is very important to ensure an adequate intake of all necessary vitamins and minerals by consuming small, easily digestible, and calorie-rich meals. If you have any concerns about whether you are not getting all the vitamins, minerals and calories you need, ask for advice and support from your healthcare team. In some cases, it might be necessary to supplement certain nutrients.

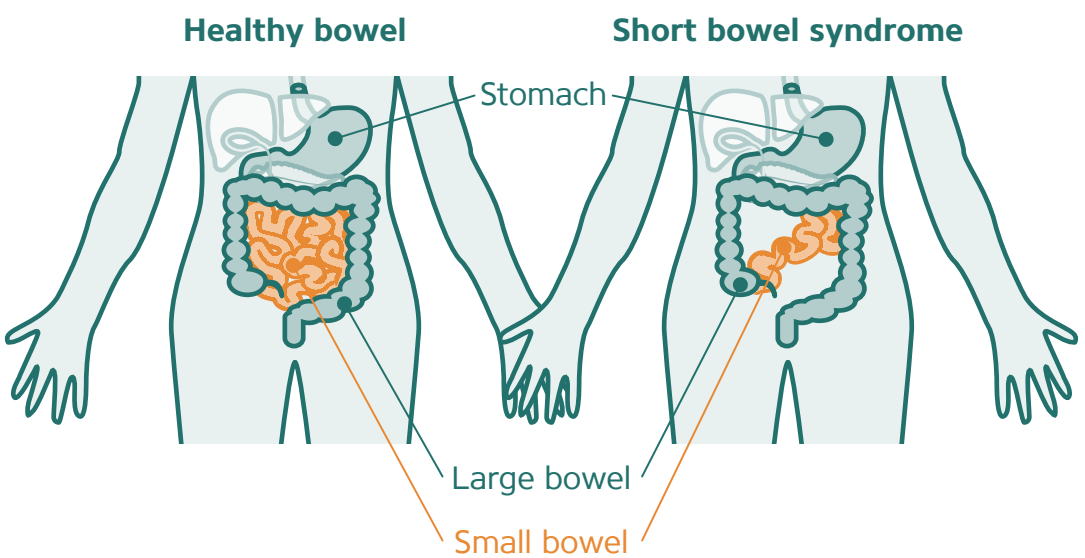


Short bowel syndrome

If the removed part of the small intestine is too large or its function cannot be replaced by the remaining segments, you may be at risk for developing short bowel syndrome. Short bowel syndrome is a condition in which your body is unable to absorb enough nutrients from the foods you eat. This may result in diarrhea and dehydration, but in general, symptoms and nutritional consequences may vary depending on the extent and location of the removal and how well the remaining parts of the intestine function.

If you think you might have short bowel syndrome, do not hesitate to talk to your healthcare team. People with small bowel syndrome will need to follow a special diet and take nutritional supplements.

What is short bowel syndrome?

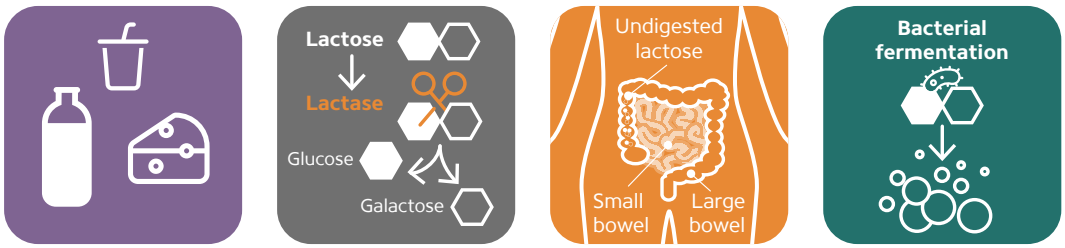


Lactose intolerance

Lactose is a milk sugar that is broken down into glucose and galactose by the enzyme lactase, which is found in the small intestine. If lactose cannot be broken down in the small intestine due to small bowel surgery, it reaches the large bowel, where it may cause symptoms like gas, cramps, and diarrhea after eating or drinking dairy products.

What happens in lactose intolerance?

1. Dairy products such as milk, yogurt, or cheese naturally contain the sugar lactose.
2. Lactase, an enzyme usually found in the small bowel, splits lactose into its two components glucose and galactose, which are then absorbed into the bloodstream.
3. If the small bowel does not produce enough lactase, the undigested lactose reaches the large bowel where it is metabolized by bacteria.
4. The bacterial fermentation process in the colon may cause physical discomfort such as gas or diarrhea.



If you experience lactose intolerance after surgery, you don't have to worry: Lactose-free alternatives are available in most grocery stores. Furthermore, some foods like aged cheese or yogurt contain less lactose than other dairy products and may be more tolerable.

On the other hand, lactose can also be present where you might not necessarily expect it, like in bakery products, instant meals, or medications. Therefore, be cautious, pay attention to ingredient lists, and check package inserts.

Fructose intolerance

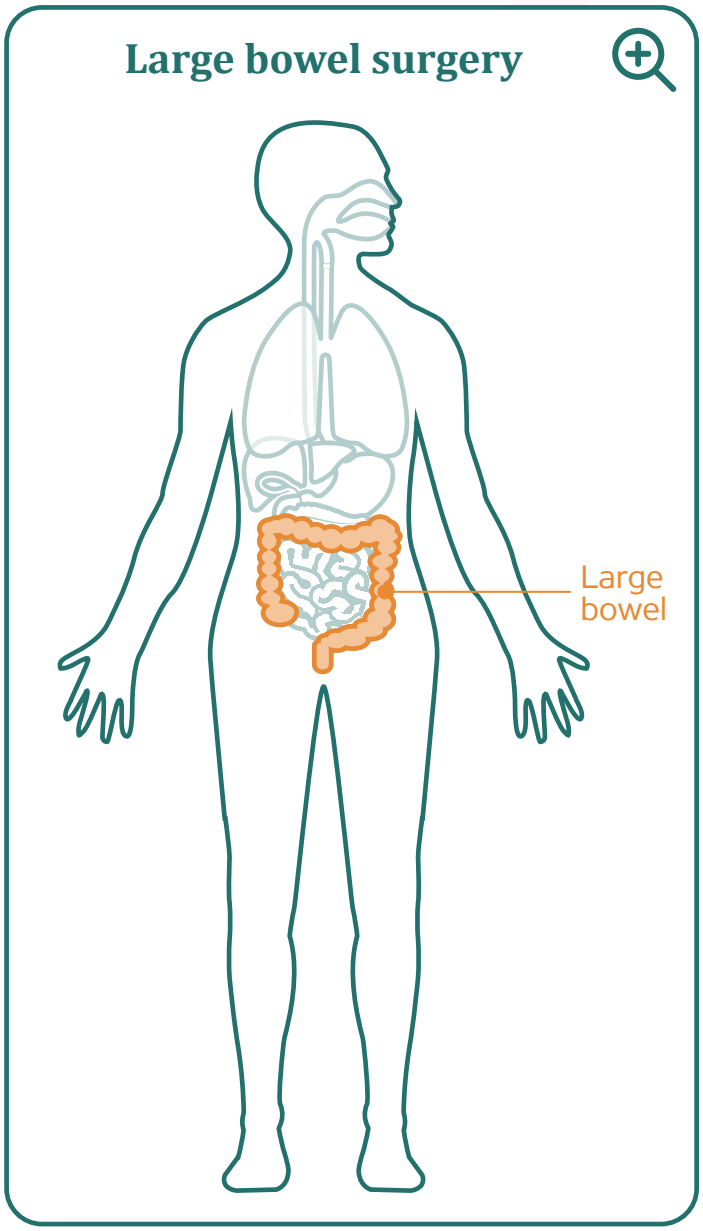
Fructose or fruit sugar is primarily absorbed in the upper part of the small intestine. If the small bowel is not able to break down enough fructose due to surgery, the sugar can cause discomfort in the large intestine.

As even small amounts of fructose can trigger symptoms in people with fructose intolerance, it might be helpful to avoid fruit preparations and pay attention to ingredient lists of foods such as cakes, ice cream, and various desserts which may also contain fructose. If you don't want to give up eating sweets completely, experiment gradually with different foods to find out what is tolerable for you as an individual.

7.4 Large bowel surgery

The large intestine absorbs water and electrolytes from partially digested food passed on from the small intestine. Thus, it changes food waste from liquid to a solid stool and stores it until it is finally excreted.

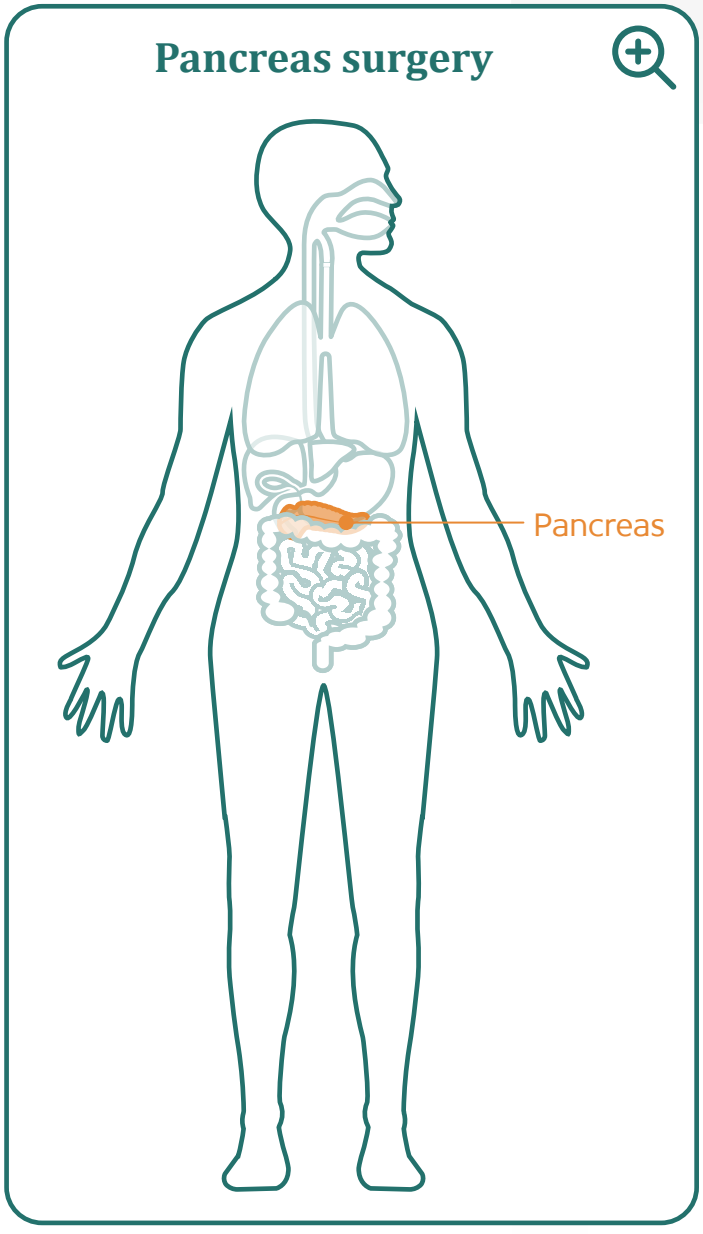
After large bowel surgery, you may experience loose bowel movements, diarrhea, or constipation. If the remaining bowel sections compensate for the removed part, symptoms might gradually improve. Hence, it's essential to monitor your symptoms and tolerance levels. Keeping a food diary, like 'My NET Diary', can be beneficial. Furthermore, talk to your doctor or a dietitian about what works best for you and how you can adapt your diet accordingly.



In general, it might be helpful to avoid spicy foods or those that cause gas/bloating. Also, some foods, such as vegetables, digest more easily when steamed, grilled, or cooked rather than raw. Eating slowly and chewing your food thoroughly makes it easier for your bowel to digest the food.

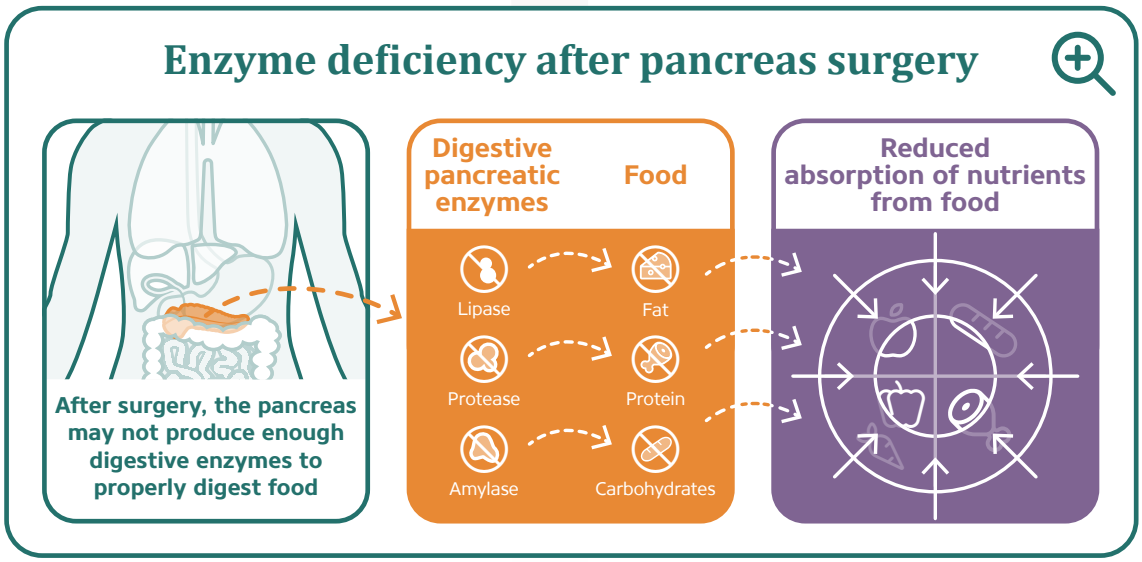
7.5 Pancreas surgery

The pancreas is a gland located behind the stomach and plays a large role in the digestive process. The pancreas head releases digestive enzymes to the small bowel, and the pancreas tail produces insulin, a hormone that regulates blood sugar. The symptoms and consequences following partial resection of the pancreas depend on the location of the removed segment.



Enzyme deficiency

If parts of the pancreas head are removed, insulin production can remain sufficient, but digestion may be affected due to the missing digestive enzymes. As a result, dietary fats are not sufficiently absorbed in the intestine and go undigested. Reducing fat intake can help minimize fatty stools. In some cases, it may be necessary to use pancreatic enzyme replacement therapy (PERT) to break down the food for better absorption by the body. Another option is to replace regular fats with MCT (medium-chain triglycerides) fats, which can be absorbed without relying on pancreatic enzymes.



Diabetes

Partial removal of the pancreas can also result in Type 3c diabetes mellitus (or pancreatogenic diabetes), a condition where the body does not produce enough insulin, causing blood sugar to be abnormally high.

While the better known Type 1 and Type 2 diabetes are associated with insulin deficiency resulting from autoimmunity and insulin resistance respectively, Type 3c diabetes usually results from an illness or condition that affects or damages the pancreas.

Types of diabetes

Type 1

- Autoimmune disease
- Often hereditary
- Develops early in life
- Immune system attacks pancreatic cells so that they can no longer produce insulin

Type 2

- Usually diagnosed in adults
- Develops over the course of many years
- Unhealthy lifestyle appears to play a role in its development
- Pancreas produces insulin, but the body is unable to use it effectively

Type 3c (Pancreatogenic Diabetes)

- Develops when the body stops producing insulin due to an illness or condition that affects or damages the pancreas

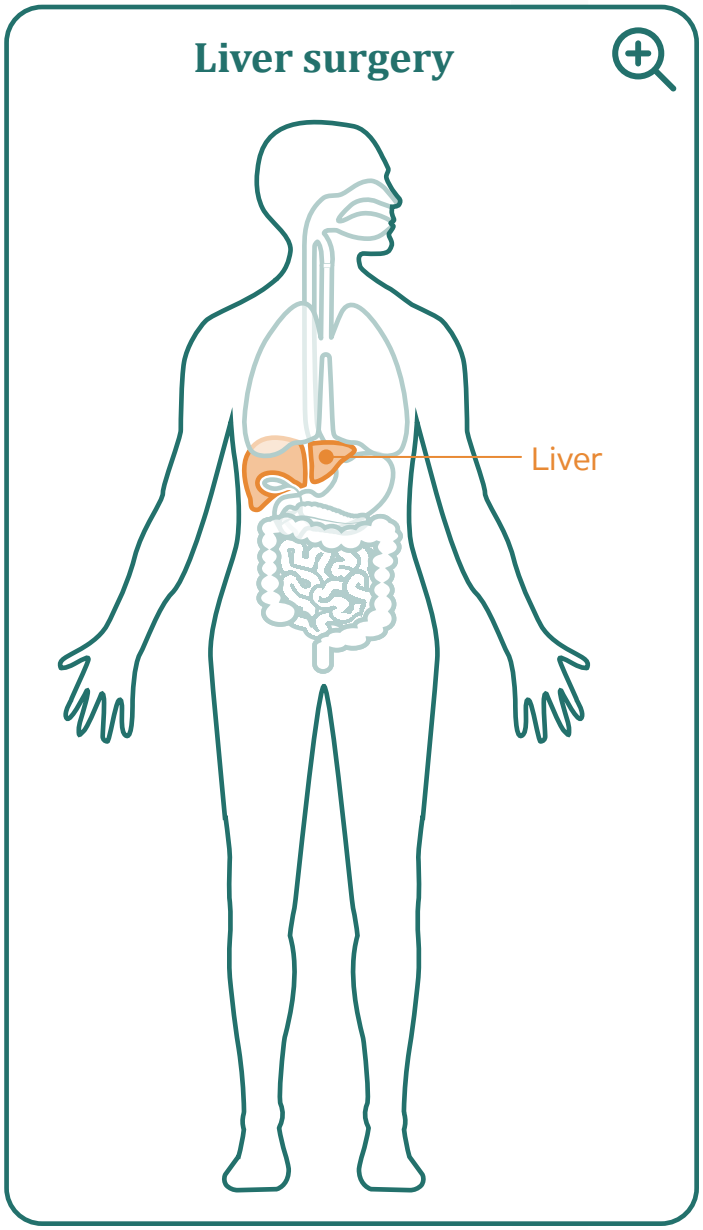
Diabetes always needs to be treated and monitored by a specialist doctor, dietitian, or a diabetes nurse. Insulin injections may be prescribed to replace the insulin your pancreas would normally produce, and you will be asked to check your blood sugar levels at home. In addition, a special diet and regular exercise may be recommended by your doctor to further control diabetes.

7.6 Liver surgery

The liver is a large organ located under the right ribcage and plays a key role in digestion and many other bodily functions. It filters the blood coming from the digestive tract, removes toxins and produces bile required to break down fat.

The liver is the only organ with the capacity to regrow. This means that after surgery it regenerates the lost tissue and can regrow until it returns to 80% of its original size within 8-12 weeks.

In most cases, those who undergo liver surgery can eat as they did before, as long as no symptoms occur. In general, you should consider eating a healthy diet and avoiding alcohol as well as greasy, fatty, or fried foods. In case of symptoms, work with your dietitian or nutritionist to tailor your diet to meet your needs.



Maintaining a food diary may help to track potential triggers for your symptoms. You can download **'My NET Diary'** to keep your notes and take to your appointments.

8. Nutrition and NET treatments

Some therapies can have side effects that may impact your nutritional status. To help prevent and treat some symptoms, you may need to eat (or avoid) specific food and drinks. Keep in mind that some symptoms may be present even after you have finished treatment. Let your healthcare team know if you are worried about your symptoms or side effects of treatment or if these persist.

8.1 Chemotherapy

Chemotherapy can be used to treat NETs. It works by stopping or slowing the growth of cancer cells. However, it can also harm healthy cells that grow and divide quickly, such as those in the lining of the digestive system. Possible side effects associated with this damage to healthy cells include weight loss, diarrhea, nausea and vomiting, constipation, loss of appetite, and sore mouth. Please see Section 5 for tips on how to manage each of these symptoms.

If you are supposed to take antioxidant supplements such as coenzyme Q10, selenium and vitamins A, C, and E during the chemotherapy period, it is important to ask your doctor whether you need to continue them as they may interfere with the treatment. The use of probiotics should be discussed with your medical team. Nutritional advice to date has been to avoid their use due to the theoretical risks posed to immunocompromised patients, but actual evidence to support this recommendation is still lacking.

8.2 Somatostatin analogs

Somatostatin analogs are used to treat some NETs. Some somatostatin analogs may reduce pancreatic enzyme release and cause steatorrhea (fat malabsorption), which in turn may result in weight loss and vitamin deficiencies. If your pancreas does not produce enough digestive enzymes, your doctor may recommend pancreatic enzyme replacement therapy (PERT).

Other possible side effects which affect nutrition are diarrhea, nausea and vomiting, constipation, and gas and bloating. For tips on how to manage each of these symptoms, please refer to Section 5.

Your doctor will also monitor your blood glucose levels. 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.

8.3 Everolimus

Everolimus is sometimes used to treat pancreatic NETs. This targeted therapy may cause inflammation of the lining of the digestive system, which may lead to symptoms such as diarrhea, constipation, or nausea and vomiting. Other possible side effects of this treatment include loss of appetite, weight loss, and dry/sore mouth. See Section 5 for tips on how to manage these symptoms.

If you develop a fever, tell your doctor. You will need to drink more fluids than your normal 8-10 glasses (8-ounces each) per day. You should also tell your doctor if your blood glucose levels have changed since starting this treatment.

Please avoid grapefruit, oranges, star fruit, and their juices, as they may interact with everolimus.

8.4 Sunitinib

Sunitinib is another targeted therapy that can be used to treat pancreatic NETs. Possible side effects of this treatment include: nausea and vomiting, diarrhea, sore mouth, loss of appetite, weight loss, constipation, anemia, and gastroesophageal reflux disease (GERD).

Tell your doctor if you are experiencing tiredness and breathlessness. These symptoms may be due to anemia and you may need iron tablets or a blood transfusion.

8.5 Interferon

Interferon is used to stimulate the immune system to fight cancer. However, it may also cause damage to healthy cells, and can lead to side effects such as nausea and vomiting, diarrhea, loss of appetite, weight loss, and sore mouth. Please refer to Section 5 for tips on how to manage these symptoms.

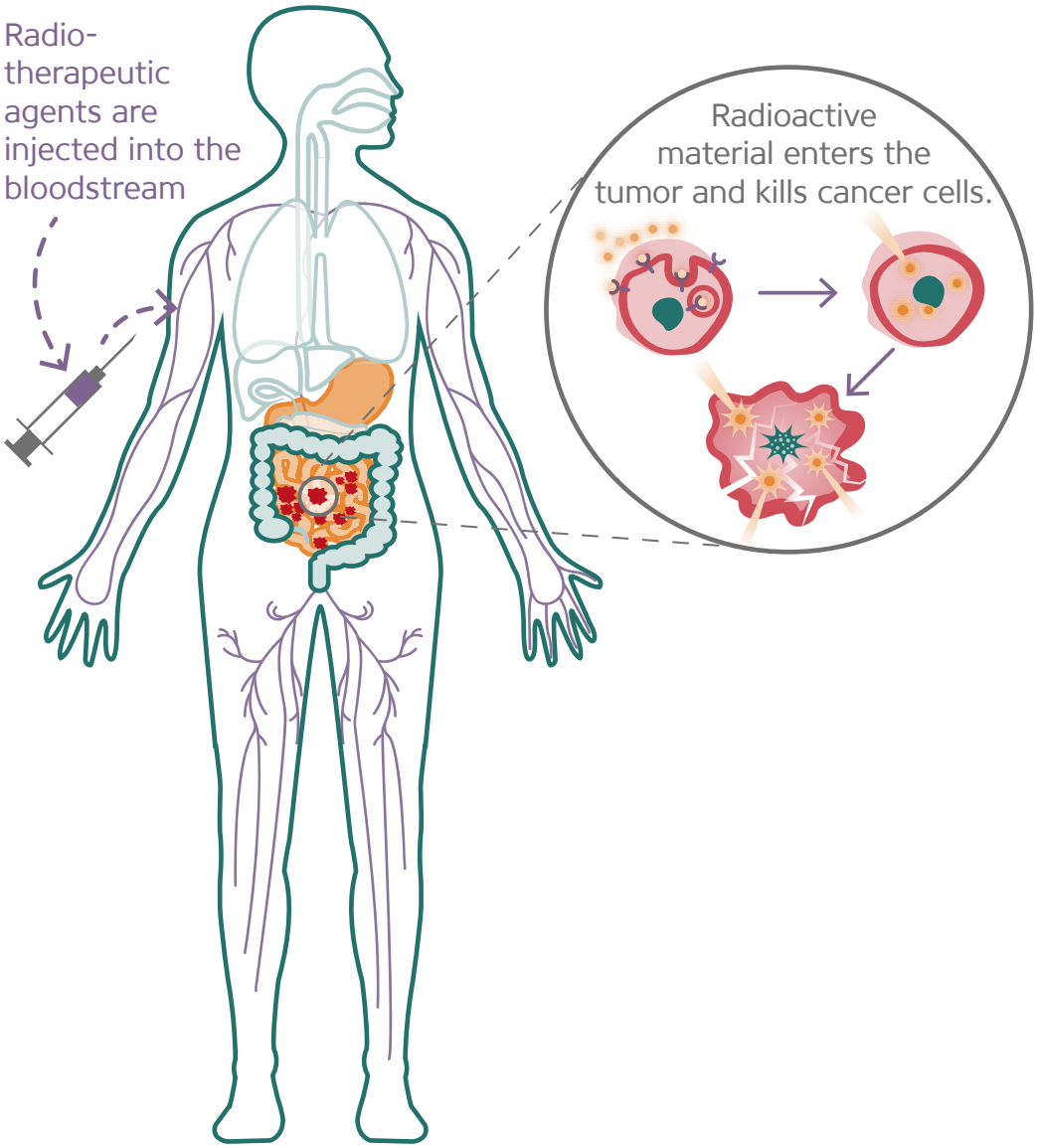
Treatment with interferon may also cause neutropenia (low levels of neutrophil white blood cells), which increases the risk of infections. You should ask your doctor or dietitian for advice on which foods to avoid, such as those that could be at high risk of causing food poisoning. Some people may also develop anemia, which may be associated with tiredness and fatigue. If necessary, your doctor may recommend iron tablets or a blood transfusion.

8.6 Radionuclide therapy

Some patients with NETs may benefit from radionuclide therapy. This treatment may cause nausea and vomiting in some patients, which can usually be managed with anti-nausea drugs. Ask your doctor for a prescription and refer to Section 5.3 for other helpful tips.

Some patients may also develop neutropenia (low levels of neutrophil white blood cells), which increases the risk of infections. Until your white blood cell counts return to a normal range, you should avoid foods with a high risk of causing food poisoning. Ask your doctor or dietitian for advice on food safety.

What is radionuclide therapy?



9. Helpful everyday tips to facilitate nutrition

9.1 Don’t put yourself under pressure

There may be times during your illness, when you don’t want to eat or really can’t. In these cases, you and the ones close to you may be concerned that you do not eat enough.

However, putting yourself under pressure, especially to eat large meals, won’t help and can actually make things worse. The same is true if family members or friends are pushing you to eat because they are worried and want to see you recover as quickly as possible.

Try to be patient and accept what you can and can’t do at the moment. It may help to set goals that you can truly achieve: Try to eat little and often, consume your preferred foods, if you tolerate them, and drink plenty of fluids.

9.2 Keep a food and symptom diary

Sometimes, you may have the feeling that you cannot tolerate any food at all. Keeping a food and symptom diary, a simple list of everything you eat and drink and any symptoms you may have throughout the day, can be a useful tool to help understand your eating habits and patterns and help monitor which food might be triggering symptoms for you.

As you learn more about what you eat by noting it down, you become more aware of your food choices and triggers. This will help you to make more informed food choices and avoid foods you do not tolerate.

It may be helpful to bring your food diary to your doctor visits and share it with your healthcare team. They can review it and help you make changes to your diet, if needed, to improve your symptoms and overall well-being.

If you want to start keeping a journal, please have a look at the free, downloadable **'My NET Diary'**, which makes it easy to log your meals and track your symptoms.

9.3 Cook in a healthy way

Many patients find that they are especially sensitive to smells caused by cooking. Frying, for example, creates a stronger odor than other forms of food preparation and it also makes foods fattier, which, in general, may be best to avoid. Therefore, it may be a good idea to stick to low-fat cooking methods such as steaming, roasting or baking.

Using the microwave is also a great and easy method to cook food in a healthy way and minimize the smell produced. The microwave can be used to cook many different types of food, from vegetables to eggs or even meat and fish. As with steaming, foods are cooked in their own juices, which means that there is no need to add any fat and the loss of vitamins ais minimized.

If you often feel too tired to cook, it may help to cook and freeze or refrigerate a batch of food during periods when you have more energy. Then, on the days when you feel really tired, you can still have a healthy meal by just turning on the microwave or oven and reheating the food you previously prepared.

9.4 Eat smaller, nicely arranged meals

If you often feel full after a meal, eating five to six smaller dishes with snacks throughout the day instead of three large meals is often easier on your digestive tract. In other words, whenever you feel the urge to eat, eat - even if it isn't mealtime.

The most important thing is that the portions you see in front of you are not too big. Otherwise, you may get the impression that it is necessary for your recovery to eat the entire portion that is served. One useful suggestion for creating smaller meals is to opt for a smaller plate when preparing your food.

Furthermore, it could help to stimulate your appetite if you arrange the food on the plate nicely or set the table beautifully to make the meal feel special.

9.5 Avoid eating your favorite food prior to treatment

Some NET treatments can have side effects that affect the digestive system, resulting in nausea, vomiting or gastrointestinal discomfort.

If you know that your NET therapy makes you feel nauseous, it might be helpful to avoid eating your favorite meals before treatment as you may start to associate these foods with feeling sick and develop a dislike for them.

9.6 If possible, try to eat your meals in a nice surrounding

Some patients may lose their appetite once they are in the hospital. This may be due to several reasons: the disease or the treatment itself, the smells of the clinic, having to stick to set mealtimes or being served foods they do not like.

If you or your loved one feel the same way and are well enough, you may find it helpful to eat outside the ward in the hospital restaurant or café or even outside the clinic on a park bench in a relaxing environment. Another benefit is that your appetite may also be increased by the movement on the way there. Make sure to discuss your “excursion” with the clinic staff first.

In any case, try to keep a positive attitude: After returning to the usual routine at home, most patients experience an improvement in appetite.

9.7 Seek advice from a dietitian

Due to the diverse nature of the disease, there is no one-size-fits-all diet that suits every individual affected by NETs. Rather than figuring out suitable food or intolerances independently, seeking professional nutritional counseling from a dietitian can help you manage your NET diet and avoid unpleasant reactions.

A dietitian can answer your questions, support you with any eating difficulties you may encounter and offer tailored recommendations for meals, snacks, and food choices. Furthermore, a dietitian can guide you on how to prepare food that makes consumption easier or create a customized diet plan to ensure you receive adequate calories and essential nutrients.

As spouses and family members are often responsible for meal preparations at home, it is highly recommended to involve them in your nutrition therapy and counseling as well.

9.8 Tips for families and friends

In many cases, family members and friends do not understand why eating is so difficult for a person with NET. However, all of us have experienced situations in the past, such as flu or gastro-intestinal infections, when even drinking is difficult. Therefore, whenever you care for someone suffering from nausea or loss of appetite, be patient and try to remember your own experiences.

Speak with your loved one and figure out what works best in terms of nutrition and which foods may cause symptoms. Ask the healthcare team about specific recommendations or restrictions as well.

Try to encourage your loved one to eat but don't be too forceful – there may be times, especially after treatment, when they may not want to eat. No matter how little they have eaten, try to praise them, this will keep you both motivated.

During hospitalization, patients sometimes prefer to eat more when they are being cared for by family members or friends. Additionally, you can prevent the tray being taken away too quickly. Nevertheless, there should be no pressure to eat in these cases either.

When caring for a person with NET, always keep in mind that many small steps lead to success, regardless of how difficult it may seem at times.

10. ‘Cancer Diets’ – Useful or harmful?

There are a lot of diets in the media that claim to cure or improve cancer. Unfortunately, there are no scientific studies that provide any evidence that a special diet, vitamins or other supplements can slow down or cure cancer. In fact, they may be unsafe for some people or even interfere with treatment.

If you have any questions concerning specific diets or if there are any supplement drinks or tablets that you would like to take, please discuss this with your dietitian and medical team before you make any changes. Do not rule anything out from your diet unless your dietitian specifically asks you to.

11. Frequently asked questions (FAQ)

11.1 How can I check my body composition?

11.2 Which markers tell me that my diet is correct?

12. Useful resources, links and additional information

Learn more about NETs on myNETjourney.com

If you are searching for NET facts online, you might get a huge and overwhelming number of results. To get a detailed overview of all important topics related to NETs, please visit myNETjourney.com.

With myNETjourney.com, we would like to support you on the journey ahead!

This site provides valuable information, tools, and advice on NETs. It connects you with resources and empowers you to engage in your disease management.

If you have a family member, friend or loved one affected by NET, these resources will also help you to better understand their condition and enable you to support them throughout their journey.

Check out myNETjourney.com – A platform for people with NET and anyone who wishes to learn more about the disease.

Track your diet and symptoms with 'My NET Diary'

'My NET Diary' is a printable diary which helps patients affected by NET keep track of their symptoms, medications, nutrition, and other relevant health information.

Maintaining a health diary may help to gain a better understanding of the condition, improve the communication with your doctor and help identify patterns and triggers.

'My NET Diary' also provides tips on how to take care of yourself, how to prepare for your next doctor's appointment, and how to stay in touch with your healthcare team.

Download the printable 'My NET Diary' for free!

Patient advocacy groups (PAGs)

Patient advocacy groups give you the opportunity to connect with others facing similar challenges and to obtain information about living with the disease, as well as support in several ways.

The International Neuroendocrine Cancer Alliance (INCA) is an umbrella organization representing 33 patient advocacy and research groups from around the world to support patients with NETs, their families and friends.

For further information, take a look at **https://incalliance.org/**

American Cancer Society Recommendations

As mentioned before, your medical team will provide nutrition advice based on consensus guidelines published by cancer societies. The American Cancer Society has developed practical guidelines on nutrition for people with cancer.

For more information, please visit:

https://www.cancer.org/cancer/survivorship/coping/nutrition.html

13. Glossary

Amylase. Digestive enzyme that catalyzes the breakdown of starch into maltose.

Anemia. Condition in which the blood has a reduced amount of red blood cells, which are responsible for carrying oxygen to the rest of your body.

Bifidobacterium. Group of bacteria called probiotics that normally live in your intestines and stomach.

Carcinoid syndrome. Condition in which a NET releases hormone-like substances into the bloodstream.

Chemotherapy. Cancer treatment using chemicals to kill fast-growing cells in the body.

Dehydration. A condition caused by the excessive loss of water from the body.

Diabetes Type 1. Chronic, metabolic disease characterized by elevated levels of blood glucose in which the pancreas produces little or no insulin by itself.

Diabetes Type 2. Chronic, metabolic disease characterized by elevated levels of blood glucose usually in adults, which occurs when the body becomes resistant to insulin or does not produce enough insulin.

Diabetes Type 3c (Pancreatogenic diabetes). Chronic, metabolic disease characterized by elevated levels of blood glucose which develops when the pancreas experiences damage that affects its ability to produce insulin.

Dumping syndrome. Condition in which the stomach empties food into the small bowel at a faster rate than normal.

Electrolytes. Minerals in the blood and other body fluids. Electrolytes are lost through sweat and urine, so they need to be replaced with electrolyte-containing foods and drinks.

ENETS. European Neuroendocrine Tumor Society.

Everolimus. Immunosuppressant drug used in the treatment of certain cancers and to prevent the rejection of transplanted organs.

Fiber. Some foods contain fiber, which adds volume to stool and helps foods move more easily through the digestive tract.

FODMAP. Diet low in fermentable carbohydrates (sugars) that the small intestine absorbs poorly.

Fructose. Sugar that naturally occurs in fruit and vegetables.

Functioning NETs. Neuroendocrine tumors that make and release hormones or other substances which can cause symptoms.

Galactose. White water-soluble sugar which is a component of lactose.

Gastrin. Hormone secreted in the stomach that contributes to digestion by stimulating the production of gastric acid, as well as bowel movements.

Gastrinoma. NET that usually occurs in the pancreas or the small intestine and produces excessive amounts of gastrin.

Gastroesophageal reflux disease (GERD). Condition in which the stomach acid or content flows back into the food pipe.

Glucagon. Hormone produced in the pancreas. It has metabolic effects which help to increase blood sugar levels.

Glucagonoma. NET of the pancreatic alpha cells that results in the excessive secretion of the hormone glucagon.

Glucose. Sugar composed of 6 carbon atoms. It is the main source of energy for cells.

Hormone. Chemical compound produced by endocrine cells and released into the bloodstream to control many body functions in different tissues and organs.

Hyperglycemia. Increased blood glucose (sugar) levels, which may cause increased thirst, blurred vision, or fatigue among other symptoms.

Hypoglycemia. Decreased blood glucose (sugar) levels, which can result in feeling sweaty, anxious and/or confused.

Immunosuppressant. Drug or substance that suppresses the immune system's response.

INCA. International Neuroendocrine Cancer Alliance, an umbrella organization representing 33 patient advocacy and research groups worldwide.

Insoluble fiber. Fiber that does not dissolve in water.

Insulin. Hormone produced in the pancreas that regulates blood glucose levels by promoting the uptake of glucose by cells in many tissues and organs.

Insulinoma. Pancreatic NET that secretes insulin.

Interferon. Protein produced by cells as a reaction to infection by a virus.

Lactobacillus. Type of lactic acid bacteria that is naturally found in the gut.

Lactose. Sugar which is typically found in milk and many dairy products.

Lipase. Digestive enzyme that catalyzes the breakdown of fat.

MCT. Medium-chain triglycerides, saturated fats that are high in calories, such as coconut or palm oil.

Mucositis. Condition in which the mouth is sore and inflamed.

NANETS. North American Neuroendocrine Tumor Society.

NET. Neuroendocrine tumor is an uncommon cancer that affects specialized cells called neuroendocrine cells which release hormones into the bloodstream.

Neutropenia. Low levels of neutrophil white blood cells

PAG. Patient advocacy groups

PERT. Pancreatic enzyme replacement therapy

Probiotics. Live microorganisms like bacteria or yeasts associated with beneficial digestive effects.

Protease. Digestive enzyme that catalyzes the breakdown of proteins.

Radionuclide therapy. Medical specialty using very small amounts of radioactive compounds, called radiopharmaceuticals, to diagnose and treat various diseases, like cancer.

Selenium. Essential trace element which is particularly important in protecting the body against oxidative damage to the cells.

Serotonin. Chemical produced naturally in the brain that carries messages between nerve cells.

Short bowel syndrome. Condition in which the body is unable to absorb enough nutrients from foods caused by a lack of functional small intestine.

Soluble fiber. Fiber that dissolves in water.

Somatostatin. Hormone produced in the pancreas and other organs. It regulates blood sugar levels by inhibiting the production of other hormones, such as glucagon and insulin.

Somatostatin analogs. Drugs that stop the body from making too many hormones.

Somatostatinoma. Pancreatic NET that produces somatostatin.

Steatorrhea (fat malabsorption). Condition in which fat not absorbed in the small intestine passes to the colon, causing fatty stools.

Sunitinib. Targeted cancer drug.

Tryptophan. Essential amino acid needed for the production of serotonin and vitamin B3.

Vasoactive intestinal polypeptide (VIP). Hormone that causes vasodilation in many tissues. In the gastrointestinal tract, it inhibits the secretion of gastrin and gastric acid, and stimulates the secretion of somatostatin.

Vasoactive intestinal polypeptide (VIP)oma. NET that typically arises from pancreatic islet cells and secrets vasoactive intestinal peptide (VIP).

Vitamins. Molecules obtained through the diet which are essential for the proper function of an organism.

14. References

Arends J, et al. ESPEN guidelines on nutrition in cancer patients. *Clin Nutr* 2017; 36(1):11-48.

Deutsche Krebshilfe, Deutsche Krebsgesellschaft (2020). Ernährung bei Krebs.
https://www.krebshilfe.de/infomaterial/Blaue_Ratgeber/Ernaehrung-bei-Krebs_BlaueRatgeber_DeutscheKrebshilfe.pdf
Accessed August 10, 2023.

Grozinsky-Glasberg S, et al. European Neuroendocrine Tumor Society (ENETS) 2022 Guidance Paper for Carcinoid Syndrome and Carcinoid Heart Disease. *J Neuroendocrinol* 2022;34(7):e13146.

Hofland J, et al. European Neuroendocrine Tumor Society (ENETS) 2023 Guidance Paper for Functioning Pancreatic Neuroendocrine Tumour Syndromes. *J Neuroendocrinol* 2023;e13318.

Mayo Clinic. Neuroendocrine tumors: symptoms & causes.
https://www.mayoclinic.org/diseases-conditions/neuroendocrine-tumors/symptoms-causes/syc-20354132
Accessed August 9, 2023.

Muscaritoli M, et al. ESPEN practical guideline: Clinical nutrition in cancer. *Clin Nutr* 2021;40(5):2898-2913.

National Cancer Institute (NCI) (2022). Eating Hints: Before, during, and after Cancer Treatment.
https://www.cancer.gov/publications/patient-education/eating-hints
Accessed August 10, 2023.

NET Patient Foundation, Royal Free London NHS Foundation Trust (2019). Gut surgery: How diet can help.
https://www.neuroendocrinecancer.org.uk/neuroendocrine-cancer/patient-information/
Accessed August 10, 2023.

World Cancer Research Fund. Our cancer prevention recommendations.
https://www.wcrf-uk.org/preventing-cancer/our-cancer-prevention-recommendations
Accessed August 9, 2023.