

Gut surgery: how diet can help



In collaboration with

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Introduction

Neuroendocrine Cancer was first described as a specific disease in the mid-1800's and yet few have heard of it. However, NET (Neuroendocrine Tumour) has been used for some time now, as an umbrella term to describe cancer of the Neuroendocrine System.

More recently, a new term has been proposed and is now being used, though mostly in medical publications – **Neuroendocrine Neoplasm** (neoplasm means new growth) – though in practice, you may still hear 'carcinoid' and NET mentioned.

Neuroendocrine Neoplasm, or NEN, has been introduced as the new umbrella term to help clarify the differences between all abnormal growths of the neuroendocrine system – benign or malignant. For example adenomas are benign but can occur in neuroendocrine cells.

More importantly, this new term was to help distinguish between the two specific types of neuroendocrine cancer: **NET** and **NEC**.

- NET or Neuroendocrine Tumour has a particular appearance under the microscope – the abnormal changes seen are called 'well-differentiated'.
- NEC or Neuroendocrine Carcinoma – these changes are called poorly differentiated.

Both have variable rates of growth, with NET more likely to show slow to moderate growth and NEC more likely to grow rapidly.

Neuroendocrine cells are present throughout our bodies and create a

network to keep us well by monitoring what is happening within our bodies and communicating with each other to release specific substances such as gut hormones to help our bodies function normally. This network is the Neuroendocrine System.

What type of hormones neuroendocrine cells release depends on what part of the body they are in, for example:

- In the digestive system they produce hormones that help to break down food in our gut and move food through the small and large bowel – helping both nutritional uptake and eliminating waste.

Cancer of the Neuroendocrine System can therefore produce a number of different symptoms or, in fact, none at all – it all depends on which neuroendocrine cells are affected - and how they are treated.

This booklet has been developed to provide reliable dietary information for those with neuroendocrine cancer who may be considering or have had surgery of the gut (digestive system). The surgery may be to remove, 'debulk' or bypass neuroendocrine cancer or for an indirectly related condition, for example, removal of the gallbladder as treatment for gallstones.

As with any treatment, surgery can have both short and long term risks/benefits and consequences. Through this booklet we will discuss the possible effects of surgery and how diet may help you both prepare for surgery by improving your nutritional uptake and manage some of the symptoms you may experience post-op.

Preparing for Surgery

Being diagnosed with a neuroendocrine cancer (be it a NET or NEC) can put you at risk of having a poor nutritional status or even malnutrition.

This may be because you have lost weight, had a reduced food intake leading up to or since diagnosis or because where your cancer is has reduced your body's ability to process food normally.

Surgery to the digestive system can increase the risk of reduced nutrition - either in the short or long term. Post-operative complications and increased length of stay in hospital have both been linked to malnutrition.

Obtaining adequate nutrition before and after surgery is therefore vitally important for a number of reasons.

Some symptoms can be managed by eating a healthy and appropriate diet.

Good nutrition can promote healing, prevent deficiencies and help you to maintain a healthy weight.

Being undernourished can weaken the immune system, which can contribute to complications such as a chest infection or prolonged wound healing.

It can also cause tiredness and/or depression, which can lead to decreased mobility and can make recovery more difficult and prolonged.

Each hospital will have its own protocols, its own way of doing things before and after surgery, this booklet provides general guidance and advice, based upon

the contributors years of experience in managing neuroendocrine cancer.

Preoperative Nutrition

Nutritional support can reduce post-operative complications and time spent in hospital.

Here are some tips that can help to improve your nutritional status before surgery:

1. Increase your carbohydrate intake

While 6 hours of fasting from solids and 2 hours fasting from clear fluids before surgery is currently recommended, longer periods of fasting beforehand can lead to problems that may make it difficult for your body to start healing afterwards.

Even as you rest after surgery, your body is burning calories to help you recover. To support your recovery, eat more complex carbohydrates before and after surgery. Examples include beans, oatmeal, whole-wheat bread, quinoa, barley, potatoes, and sweet potatoes. These foods are also naturally rich in vitamins, minerals, and phytochemicals.

For many, nausea can prevent them from eating for up to three to four days after surgery. Discussion with your pre-assessment team, dietician and ward staff can help to ensure you get enough calories and nutrients, through snacks and appropriate, timely meals during your stay.

Runners aren't the only ones to benefit from "carb-loading," with research showing that you lose more glycogen (a form of carbohydrates stored in your muscles for

energy), during surgery than while training 2½ hours for a race.

Research shows carbohydrate-loading before major surgery can help reduce:

- hunger, thirst and anxiety before a surgery
- nausea, vomiting, pain and even a patient's length of stay in the hospital following surgery.
- the short-term insulin resistance that is experienced by surgical patients who fast prior to surgery, which can lead to complications.

2. Boost Your Immune Function with Arginine and Omega-3s

The stress from surgery can trigger inflammation, which can lead to complications. This stress can continue for several weeks and weaken the immune system, making you more prone to infections.

Nutrition containing immune-enhancing ingredients, such as arginine and omega-3 fatty acids, could help.

To support immune health and recovery, try to get:

- 4-12 grams of arginine which is an amino acid naturally found in red meat, poultry, fish and dairy products.
- 1-3 grams of omega-3 fatty acids naturally found in a variety of fish and fish oils.

These nutrients also are found in immunonutrition drinks, which will be recommended in some hospitals for patients in the week leading up to and following surgery.

3. Keep up your strength with extra protein

In older adults, three days of bed rest can cause up to 10 percent of total leg muscle loss.

That's why getting up and moving as soon as possible following surgery can help patients preserve their lean muscle, and stay strong and make a faster transition back into their regular routine.

In fact, many hospitals are encouraging patients to be up and moving as soon as possible after surgery to help with recovery. Increasing your protein intake before and after surgery with for example white meat, fish and eggs can help protect your muscles.

Gastroesophageal Surgery

The oesophagus and surgery

The oesophagus is a muscular tube which takes food from the mouth into the stomach.

Oesophagectomy and endoscopic mucosal resection

If you have a neuroendocrine cancer here, you may need to have part or all of your oesophagus removed. Immediately after oesophageal surgery you can't eat or drink, but you will have fluids through a drip and then you will be able to have sips of water within 24-48 hours.

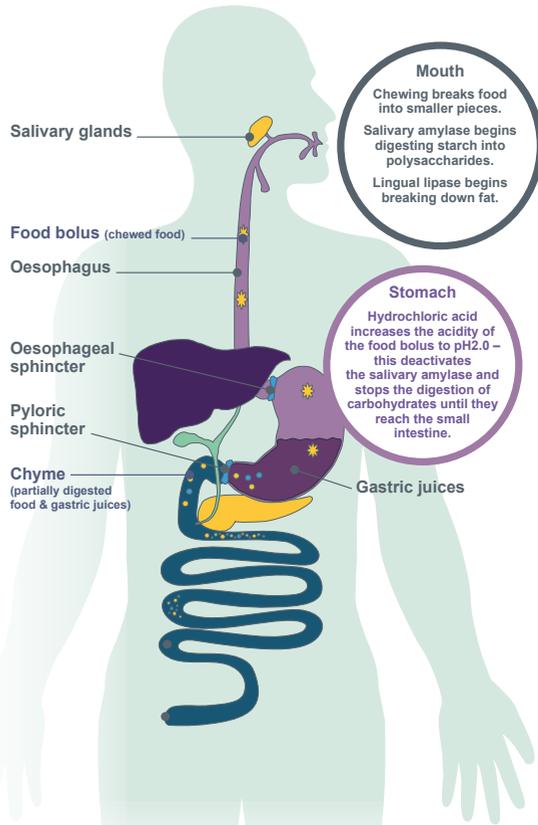
After this time, you can gradually build up what you drink and eat. Most people are able to eat regular, small, moist, soft meals within a week or so.

Some people need a feeding tube to help them maintain their nutrition.

Oesophageal Stent

If your neuroendocrine cancer cannot be removed surgically, your clinical team may suggest an oesophageal stent. A stent is a mesh tube, approximately 2cm (3/4 inch) wide, like a short section of a small hosepipe, which is put into the oesophagus to bypass the cancer, to keep your oesophagus open for food and fluid to pass through.

The stent gently expands to hold the narrowed area of the oesophagus open and should make swallowing foods and beverages easier. The stent will not be as wide or as flexible as a normal oesophagus, so you will need to take care with certain foods, and how you eat, to prevent blocking the stent.



Step 1 Fluids only – water, tea, coffee, fruit juices, milk, soft drinks or sports drinks. Start with small sips and increase the volume as you feel confident.

Once you are told you can eat, please progress onto the next step 2.

Step 2 Progress to smooth or pureed foods, including soup (without lumps), fruit puree, yogurt, ice cream, pudding or jelly.

If these are tolerated, continue to step 3.

Step 3 Increase the texture of your food to a soft consistency as you feel your swallowing

becomes easier and your confidence builds. You may try scrambled eggs, cottage cheese, steamed fish (no bones), mashed potatoes, mashed banana and pudding.

Try to include a wide variety of foods and fluids in your diet so you achieve as close to a normal diet as possible and to ensure you meet your nutritional needs. If you feel that you cannot achieve this on a soft consistency diet, ask to speak to a Dietitian.

Slipping fluid at meals and sitting upright may help prevent food sticking, but you must also avoid common obstructing foods. You will need to be careful that the stent doesn't get blocked, so try to avoid foods that may get stuck (see list below).

Foods that can cause blockages include:

- Bread and toast
- Tough gristly meat
- Hard boiled or fried egg
- Fish with bones
- Pithy fruit (e.g., orange, grapefruit, pineapple)
- Stringy vegetables (e.g., green beans, celery)
- Potato skins
- Salad items (e.g., salad leaves and lettuce)
- Raw vegetables
- Crisps
- Ice cream or yogurt with chunks of fruit, cereal or nuts

The stomach and surgery

The upper part of the stomach is joined to the oesophagus, and the lower part of the stomach is joined to the beginning of the small bowel (duodenum).

Once food has been swallowed it passes down the oesophagus and into the stomach, where it's mixed with gastric juices. The

semi-solid food then passes into the small bowel, where it's broken down further and nutrients are absorbed.

The gastric juices in the stomach help the bowel absorb some important substances from our food such as Vitamin B12, iron and calcium.

Surgery to the stomach (gastric surgery)

There are two main types of surgery for cancer of the stomach :

- Partial gastrectomy, in which only part of the stomach is removed
- Total gastrectomy, in which the whole stomach is removed.

Other types of operations on the digestive system to treat cancer of the oesophagus or the pancreas may also involve removing part or all of the stomach. This is discussed in the HPB section (p12).

Dietary problems

People can have different types of dietary problems after stomach surgery. These can be short or long term :

Short-term can include:

- feeling full after eating and drinking
- weight loss and malnutrition
- poor appetite
- indigestion and/or reflux (this can be continuous)
- dumping syndrome
- diarrhoea
- bilious vomiting

Feeling full after eating and drinking

This is a sensation of fullness after meals and sometimes even after small snacks.

The stomach acts as a storage chamber for food, and its muscle wall relaxes to accommodate a meal in response to the

sight or smell of food. This response is controlled by the vagus nerve.

If an operation has made the stomach smaller or if it is scarred, this can affect the stomach's ability to stretch and the stomach's capacity will be reduced.

The vagus nerve may also have been cut or damaged during surgery.

When the capacity is reduced, food and drink enters the stomach and puts direct pressure on the stomach wall, making it stretch (distend). This gives a feeling of fullness.

Sometimes eating smaller, more frequent meals may reduce the sensation of fullness.

It's helpful to avoid foods that are high in fibre, such as large portions of fruit, vegetables and wholegrain cereals, as these can make you feel full very quickly.

Although it's important to drink plenty of fluids, try not to drink a lot just before meals.

Weight loss and malnutrition

If you are not able to eat very much due to feeling full very quickly, you may find that you lose weight very easily and may not absorb all the nutrients that you need to keep healthy.

It is useful to build up your energy intake with small frequent meals and supplement drinks.

Your cancer specialist and Dietitian can give you further advice on how to manage this problem.

Poor appetite

A poor appetite can be due to feeling too full after meals or snacks. Eating small high energy, high protein snacks and drinks will help. For example try peanut butter on toast, tuna and mayonnaise in a buttery jacket potato and/or real ice cream. Try

to avoid skipping meals or snacks, little and often can help stimulate appetite and hunger. If you are losing weight nutritional supplements and sometimes a steroid will be prescribed to stimulate your appetite.

Indigestion

Indigestion and/or reflux (a backward flow of stomach juices into the oesophagus) can occur after any stomach surgery. Indigestion can also be caused by wind trapped in the digestive system. Wind can be helped by taking peppermint water or charcoal tablets, which are available at local chemists. Avoid fizzy drinks, alcohol and spicy foods if they make your symptoms worse.

Reflux can cause soreness and inflammation of the lining of the oesophagus, and can be reduced by antacid medicines e.g omeprazole, lansoprazole or ranitidine

Dumping syndrome

Dumping syndrome is divided into two types: early dumping syndrome and late dumping syndrome. Each of these have different processes and symptoms:

Early dumping syndrome

This usually happens within 30 minutes of eating a meal. You may feel dizzy or faint, and your heart may start to beat faster.

These symptoms may last for about 10-15 minutes. Some people may also have tummy cramps and diarrhoea.

The symptoms happen when food passes too quickly through to the small bowel.

This draws fluid into the bowel from the surrounding organs and tissues and causes a drop in blood pressure.

Early dumping syndrome often gets better on its own over a few months. It can be

reduced by eating slowly and choosing small, frequent, dry meals and having drinks between meals, rather than during them.

It can also help to avoid foods that are high in added sugars. It's important to eat some sugars as these are a good source of energy (calories), so don't cut them out of your diet completely. Try taking them as part of a mixed meal rather than as sugary drinks.

Eating meals that are high in proteins, such as fish, meat and eggs, and higher fibre starchy carbohydrates, such as whole grain pasta, and bread, brown rice and potatoes can help.

Resting for 15-30 minutes immediately after meals can also help to reduce the problem.

Late dumping syndrome

This usually occurs a couple of hours after meals or when a meal has been missed. You may feel faint, sick and shaky.

Late dumping syndrome is caused by stomach contents that are high in carbohydrate being released into the small bowel. This causes a sharp rise in the level of glucose in the blood as sugars are rapidly absorbed. Large amounts of insulin are released into the bloodstream as a response to this. The insulin levels continue to rise after the blood glucose levels have begun to fall. It is the high insulin level that causes the symptoms.

If you have this problem, follow the same advice for early dumping syndrome: take small regular meals that are low in refined white starchy carbohydrates or sugar, but do contain high fibre starchy carbohydrates, such as whole grain bread, potatoes and whole grain pasta or brown rice.

If you feel the symptoms coming on, taking glucose tablets may help you feel better.

Eating food and drinking fluid at separate times may also be useful in preventing late onset dumping syndrome.

If your symptoms continue or are severe your doctor may prescribe a medicine such as octreotide, or a similar drug.

Diarrhoea

Diarrhoea can happen after any type of stomach surgery, but it's more likely after surgery involving the vagus nerve. If the vagus nerve has been cut during surgery (vagotomy), there may be a strong sense of needing to open the bowels urgently. This can be quite upsetting.

Diarrhoea can happen in short episodes for a few days or weeks after surgery, before the bowel returns to normal.

Everyone is different, so it's difficult to predict how long it may last or how many times a day it may happen. Some people may have diarrhoea once a day, while others may have it a few times a day.

Taking an anti-diarrhoea drug called loperamide (Imodium®) regularly in the morning can sometimes help. As the diarrhoea is due to the effect of the surgery, it may not be possible to reduce it by changing the foods you eat. If you find that some foods particularly affect your bowel it may help to avoid them, but it's best not to exclude too many foods from your diet.

If severe and prolonged, taking oral rehydration sachets such as dioralyte may help you prevent dehydration.

Bilious vomiting

This can occur first thing in the morning. People find that they have stomach pain and a feeling of fullness when they wake up. This is relieved by vomiting clear fluid, which has some dark brown fluid (bile) in it.

Vomiting in this way can be very distressing for some people, but it only lasts for a short time.

The cause is quite complex and it usually happens after removal of part of the stomach (partial gastrectomy). Some drugs that act on the digestive system may help control bilious vomiting.

Many of the problems mentioned above improve gradually over a period of time.

You may need to make long-term changes to your daily eating patterns, such as eating smaller meals, more regularly.

A very small number of people will find it difficult to eat enough food and may need to be fed artificially via a tube (enteral feeding).

Tube feeding is usually only needed for a short time. Your doctor will discuss tube feeding with you if necessary.

Long term can include:

- Calcium malabsorption
- Anaemia, caused by iron and vitamin B12 deficiency
- Narrowing of the join (anastomosis) after surgery, which can make it difficult to swallow food.

Your surgeon will monitor you after your treatment, this is because late side-effects can occur months or even years after treatment.

Calcium malabsorption

Following surgery to remove the stomach (gastrectomy) it can be difficult for people to absorb enough calcium after eating.

This can cause a condition known as osteomalacia, which is a weakening of the bones.

Osteomalacia can be prevented or reduced by taking vitamin D and calcium supplements, as prescribed by your doctor.

Anaemia

Anaemia means that the blood is not carrying enough oxygen, and this can occur for several reasons.

Iron-deficiency anaemia, the most common form, occurs if you do not have enough iron in your diet or if you are not able to absorb iron sufficiently from the foods that you eat.

Iron is the main component of haemoglobin (Hb) which carries the oxygen in the blood.

There can be several reasons for an iron deficiency after stomach surgery.

These are:

- Changes in the way iron is converted from food - this is due to a reduction of stomach juices
- Food moves more quickly through the bowel, reducing the time for iron to be absorbed.
- If a small bowel (duodenal) bypass has been done, it reduces the normal surface area of the bowel so that less iron is absorbed.

Anaemia that is due to these reasons can be treated with iron supplements.

A lack of vitamin B12, which is needed to make red blood cells, can be another cause of anaemia.

This can happen if part or all of the stomach has been removed, because the stomach produces a protein known as the 'intrinsic factor', which is needed for the absorption of vitamin B12.

After stomach surgery, the body is no longer able to produce intrinsic factor, which leads to a reduction in the amount of vitamin B12 and folic acid absorbed.

If you've had all of your stomach removed you will need to have vitamin B12 injections for the rest of your life. These will be given to

you every 3 months by your GP.

If only part of your stomach is removed, your doctor will do a blood test to check your levels of B12 from time to time in case you need injections.

Narrowing of the anastomosis-stricture

When the whole stomach is removed, the lower end of the oesophagus is joined to the upper end of the small bowel. This join is called an anastomosis. Occasionally the anastomosis can become narrowed, which can make it difficult to swallow food. This is known as a stricture.

If you find it is getting difficult to swallow food, you may need an endoscopy to look into your oesophagus.

If you have a stricture, the doctor may be able to stretch it (called a dilatation), making it easier for you to eat.

Alternatively it may be possible to place a tube (stent) into the narrowing to keep it open (see oesophageal stent).

If you are having problems swallowing, you may find that you begin to lose weight quite quickly.

It can be helpful to try eating soft or puréed foods and to have nourishing drinks.

Rarely, you may need to be fed artificially via a tube (enteral feeding) for a short time.

Digestive enzymes

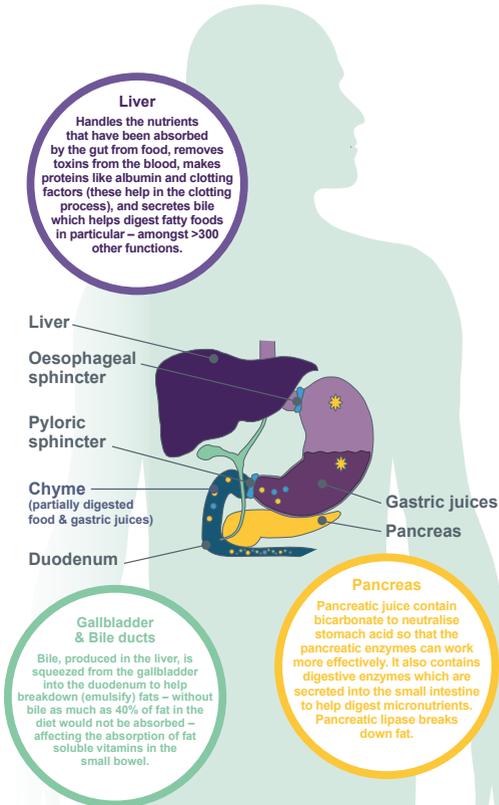
Some patients who have a total gastrectomy require pancreatic enzyme replacement therapy (PERT).

This is because the part of the stomach which is involved in stimulating pancreatic enzyme release has been affected.

See page 14 for further information.

HPB Surgery

HPB surgery includes liver (hepatic), pancreatic and biliary organs. There are several types of operations which are undertaken, depending on where your neuroendocrine cancer is situated.



The liver and surgery

The liver sits above the intestines on your right hand side, just under your right ribcage. The liver works to filter the blood coming from the digestive tract, before passing it to the rest of the body. The liver

also detoxifies chemicals and metabolizes drugs. As it does so, the liver secretes bile, which helps break down fats, bile salts are reabsorbed at the end of the small bowel, where the large bowel starts (ileo-caecal junction). The liver also makes proteins important for blood clotting and has many other functions.

Liver resection

Liver resection refers to the removal of the segment or lobe of the liver where the cancer is - this could be a primary or secondary cancer. The principal aim of performing a liver resection is to completely remove the cancer. The success of liver resection depends upon the location of the tumour, the number of tumours, the amount of liver left after removal of the tumour, and the biology of the tumour (grading – or how the tumour behaves).

The liver is the only organ in the body that is able to regenerate (regrow). This means that when part of the liver is removed, the volume of the remaining liver increases (hypertrophies) until it returns to about 80% of its original size. Bile ducts and blood vessels do not re-grow, rather the remnant liver increases in size. This normally takes up to 8 – 12 weeks following a major liver resection. Up to 70% of a healthy liver can be removed. However, in the presence of chronic liver disease or chemotherapy, a larger remnant is required, reducing the amount of liver that can be removed.

Nutrition after resection

After the operation you will be monitored very closely. You will be able to have fluids

as soon as you have woken up from the anaesthetic. Once you are able to manage fluids you will be able to eat as soon as you feel able to. Anaesthetic and pain relieving medications can often make you feel sick, so we will offer you anti-sickness tablets or an injection to make you feel better. If you do not feel like having a meal, you can have a supplement drink to give you some nutrition and energy.

The gallbladder and surgery

The main role of the gallbladder is to store bile which is produced in the liver. Bile is one part of digestion which helps to break down food.

Sometimes you will have surgery because you have gallstones or because it is part of a larger operation in nearby organs - such as liver resection.

Problems after a cholecystectomy

Most people don't need to follow a special diet after having surgery to remove their gallbladder, as although useful, the gallbladder isn't essential for digestion.

You can usually start eating normally a few hours after your operation, although you'll probably prefer to eat small meals to start with.

You may have been advised to follow a low-fat diet for several weeks before surgery, as moderate to high fat foods can increase the symptoms associated with gallstones, but this doesn't need to be continued afterwards. Instead, you should follow a diet that is healthy, moderate in fat, or appropriate for your NET/NEC diagnosis. Instead of being stored in the gallbladder, bile will drip into the small intestine all day long, because of this you may experience:

- indigestion,
- bloating,

- flatulence
- diarrhoea

therefore it may help to:

- Limit drinks containing caffeine – such as coffee and tea
- Avoid foods that make the problems worse – such as some spicy or very fatty foods.
- Gradually increase your intake of fibre – good sources of fibre include fresh fruit and vegetables, brown rice, whole grain wheat pasta and bread, seeds, nuts and oats.

Your GP can also recommend medications which bind the bile salts if you have diarrhoea.

Side effects of gallbladder surgery usually only last a few weeks, although diarrhoea can be a more persistent problem for a small number of people.

The pancreas and surgery

The pancreas has a variety of roles, including hormone production to raise and lower blood glucose, and to make digestive enzymes which break down food. Patients with neuroendocrine cancer of the pancreas such as glucagonomas, VIPomas, gastrinomas, somatostatinomas, non-functioning pancreatic tumours and some insulinomas may be offered pancreatic surgery.

Pancreatic surgery

The different forms of pancreatic surgery are below:

- Distal Pancreatectomy (tail of pancreas)
- Sub-total pancreatectomy (central/ tail)
- Classic Whipples or a modified Whipples (Pylorus preserving pancreaticoduodenectomy - PPPD) - head and / or neck of pancreas.
- Total pancreatectomy (removing all the

pancreas)

- Enucleation (essentially scooping out the tumour without having to remove too much surrounding pancreatic tissue)

After pancreatic surgery

Immediately after the operation you may not be allowed to eat or drink, for a day or two, this is to allow your intestinal tract and pancreas to heal.

The doctors will assess this on a daily basis, introducing sips of fluids and subsequently diet gradually.

During your surgery you may have a feeding tube. This tube allows the delivery of nutrition directly into your small bowel.

This will be removed after you have fully recovered from your surgery and are eating and drinking well.

When parts of the pancreas are removed, patients may have significant adaptations to make.

Problems after pancreatic surgery

Dumping syndrome

With all of the above surgery types, you may suffer with dumping syndrome because of removal of some of the stomach, so please see the section on stomach surgery on page 10.

B12 Deficiency

Patients having a total pancreatectomy may need Vitamin B12 injections every 3 months - please check with your medical team that this has been arranged, before you leave hospital.

Fat Malabsorption (steatorrhoea)

This can be caused by a few factors, for example: the somatostatin analogue or octreotide injections you are having, or due to surgery.

Steatorrhoea has a certain appearance – your stools may look pale or even

putty-coloured. They may be floating, foul smelling, greasy and frothy looking.

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

Your doctors may prescribe pancreatic enzyme replacement therapy (PERT) to help break down the food so that it can be more easily absorbed into the body.

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

Some people benefit from taking antacid medication 30 minutes before taking the enzymes.

- Take with a cold drink before your first mouthful.
- Suggested starting dose:
 - One x 22,000/25,000 units of lipase capsule with all snacks/drinks (except carbohydrate/protein/fat free drinks).
 - Two x 22,000/25,000 units of lipase capsule with all main meals.
- The dose can then be titrated upwards by one capsule. Sometimes 66,000 to 80,000 units of lipase per main meal is enough, but some people may need more than this.
- They last 30-60 minutes before they stop working so you may need to take more for a multi-course meal.
- It is possible that alcohol intake may negatively affect both your own enzymes and any additional enzymes too.

Fat malabsorption and vitamin deficiency

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

Since we live in a colder climate we are at higher risk of vitamin D deficiency

regardless of a neuroendocrine cancer diagnosis. The best source of vitamin D is a little sunshine, but dietary sources of vitamin D include dairy, oily fish, fortified foods or supplements.

Diabetes

Some people develop diabetes following pancreatic surgery. You may be started on insulin injections to replace the insulin your pancreas would have normally produced.

A diabetes nurse specialist can provide information to help you to manage your insulin injections.

If you are at home following surgery and have the symptoms of diabetes including thirst, rapid weight loss and passing a lot of urine and you are not on insulin then you should contact your G.P.

A good diet will help you to control your diabetes in combination with regular insulin injections.

- Eat regular meals. Have a breakfast, lunch, evening meal and supper.
Depending on your regime you may also be advised to have a bedtime snack.
- Have starchy food such as bread, potatoes, rice, pasta or cereals at every meal. Try to choose wholemeal or wholegrain varieties if possible.
- Include meat, chicken, fish, well-cooked eggs, milk, yogurt, cheese or pulses, such as lentils or baked beans, at least three times a day.
- Avoid adding sugar and honey to foods and sugar coated cereals.
- If you are feeling unwell or run down you must still try to eat and drink regularly.
Enriched drinks (such as ensure plus or build up) can be useful if you do not feel able to cook. Keep a supply handy in the cupboard.

- Never stop taking your insulin. Consult your GP or diabetes specialist nurse if you are concerned about your blood sugar levels.

Hypoglycaemia (Hypo) Treatment

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

When treating a hypo, first have a high GI snack (below) :

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

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

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

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

If over 4mmol/l, eat some starchy carbohydrate (Low-Medium GI):

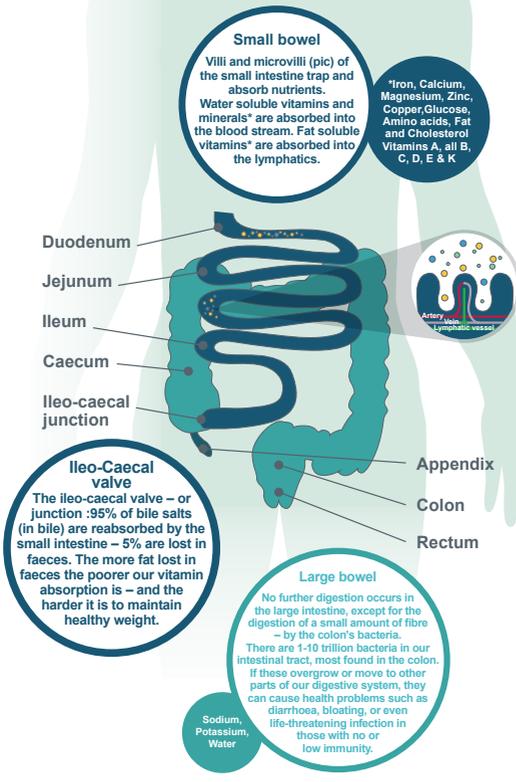
- 1 unripe banana
- 1 thick slice of toast / half a sandwich
- Small bowl of cereal
- Whole-wheat / oat biscuits and milk
- Eat the next meal if due

Some people gain weight if they have frequent hypos as they exceed the amount of high GI products they need to treat each hypo episode.

Any excess glucose in the body is stored as fat so you may need to be careful if you are already overweight - ask your medical team or dietician for advice.

The small bowel and surgery

The duodenum is attached to the bottom of the stomach and is the first part of the small bowel. The middle part is called the jejunum and the final part is called the ileum. The ileum is the most common site of small bowel neuroendocrine cancer and, therefore, the most common site for surgery.



Small bowel resections

When a part of your bowel is removed, the part that is left adapts to this change. It does this by absorbing the nutrients and liquids that would have normally been handled by the part that was removed.

Parts of your bowel can be removed without having a major impact on your nutritional health, but it can take up to 2 years for your remaining bowel to adapt to these changes.

Your body may not absorb nutrients, liquids, vitamins, and minerals as well as before your surgery.

Speak with your surgeon or Dietitian if you think you may be at risk of deficiency.

Lactose intolerance

Many people will be lactose intolerant for a few weeks after small bowel surgery, but as the small bowel adapts, you can start to reintroduce lactose.

Follow a low-lactose diet long-term only if you have a positive lactose intolerance test. Lactose is a sugar that is found in dairy products. It can cause gas, cramps, and diarrhoea in some people who cannot digest it well. These symptoms usually begin within the first 30 minutes of taking a dairy product.

To see if you can tolerate lactose, start by drinking 1/2 cup of milk.

If you have any symptoms, try lactose-free dairy products such as LactoFree milk and yoghurt.

- Some foods have less lactose than others. Try cultured yogurt and aged

cheeses (e.g., hard cheeses such as cheddar and Swiss). If you can eat those, try soft cheeses (e.g., cream cheese and cottage cheese). If you are still having symptoms, you may want to avoid all dairy products for 1 or 2 months and then try them again.

- Make sure any dairy free alternatives you buy are fortified with calcium to avoid you becoming deficient.

Fibre

After your surgery, you may find that fibre, particularly insoluble fibre, is hard to digest. Insoluble fibre is found mainly in whole-grain and bran products.

It can't be broken down by the body and increases the bulk of stool (faeces).

Soluble fibre is usually tolerated better because it helps slow digestion.

Foods with soluble fibre include oatmeal, oat bran, barley, soy, peeled apples and plums, fruit pectin, and psyllium (fibre supplement).

Check with your doctor before taking any fibre supplements.

Duodenal Stents

The duodenum is the first part of the small bowel. When food leaves the stomach as a thick lumpy liquid it enters the duodenum.

When your duodenum becomes blocked by scar tissue or cancer, food cannot pass so easily.

When it is completely blocked this can cause vomiting. In this case you may have a tube (stent) placed to open up the gap inside your duodenum again.

It takes about 3 days for the stent to settle and so it may take 3 days to get back to your normal appetite.

The following dietary stages are to be

followed:

1. Following the stent placement you will be allowed only liquids. These can be sweet or savoury eg soups without lumps or milkshakes and ice cream etc.
2. If you can manage the liquid diet without having nausea and vomiting, you will be able to try a soft and moist diet.

Breakfast

- Cereals which become soft and moist easily. Eg rice krispies, cornflakes, Weetabix, Ready Brek.
- Plain / natural yoghurt and fruit puree, scrambled egg
- Tea, coffee, milk, fruit juice, smoothie

Lunch and evening meal

- Tender meat, minced / Quorn mince, made into shepherd's pie / cottage pie / spaghetti bolognaise
- Filled pasta with tomato sauce and parmesan
- Well-cooked and peeled carrot, squash, courgette, swede, marrow, broccoli and cauliflower florets, tinned chopped tomatoes
- Cream of Chicken Soup
- Vegetable soup with conchigliette or noodles
- Mashed potato/sweet potato/carrot/swede topped with cream cheese & chive
- Very tender meat stew made from gravy, skinless potato, carrots, swede
- White fish potato topped pie
- Tuna and mayonnaise / small soft prawns in marie rose dressing / bolognaise with jacket potato (throw away the skin)

Snacks

- Seasoned scrambled eggs, poached eggs (no bread)
- Houmous / Tzatziki with peeled

cucumber / cooked and cooled carrot batons

- Yoghurts
- Jelly
- Mousse
- Crème caramel
- Banana and custard
- Rice pudding
- Banana
- Instant whip
- Milk chocolate
- Egg custard

Foods you need to avoid include:

- Bread
- Unpeeled fruit and vegetables
- Fish with bones
- Pithy fruit (e.g., orange, grapefruit, pineapple)
- Stringy vegetables (e.g., green beans, celery)
- Tough gristly meat
- Any hard, crispy, dry foods.
- Seeds and nuts (smooth peanut butter ok)

Most people will tolerate a soft moist diet, but if you do not tolerate this then you must see a Dietitian to work out how to get a nutritionally complete diet without solid foods.

This may involve being prescribed some supplement juices / milkshakes and powders in addition to a liquid diet so that you can manage your diet at home.

Rarely, some may need to be fed with a tube long term.

Normal Diet

Some people who tolerate this soft moist diet well, who have a wide opening in the duodenum will be able to try a normal diet.

It is best to introduce 'normal' foods slowly. If you are losing weight you will need to see

a Dietitian.

Short bowel syndrome

Short bowel syndrome occurs when there is less than 200cm of viable small bowel left after surgery. It is signified by malabsorption, (diarrhoea, steatorrhoea), fluid and salts loss, and malnutrition.

Your symptoms and nutritional consequences depend on the site of surgery, how much was taken out, how healthy your remaining small bowel is and how well it adapts.

You should be told if you are diagnosed with this and you will need to liaise closely with a gastrointestinal specialist Dietitian.

You may have to try a variety of methods to get the right nutrition, including; adapting solid meals, supplement drinks, tube feeds and parenteral nutrition.

The aims of short bowel treatment are:

- To prevent thirst and dehydration
- Reduce stoma stool output to under 2L a day or reduce diarrhoea if no stoma
- Prevent electrolyte, micronutrient and essential fatty acid deficiency

In the early stages after surgery the small bowel needs nutrient contact to allow it to adapt. Long periods of 'nil by mouth' are not helpful.

- Eating small, frequent meals will put less stress on your shortened bowel. Small meals help control your symptoms, and will result in better digestion and absorption.
- Eat slowly and chew your food well.
- Only drink 1/2 cup of liquids during each meal. Drinking large amounts of liquids with meals pushes your food through your bowel at a faster rate. This means that you may not digest or absorb

enough nutrients.

- You can slow down this process by drinking most of your liquids between meals, at least 1 hour before or after a meal. Take advice on what fluid and how much, from your Dietitian.
- Include more than enough nutrients in your meals to help you heal and to cover those which will not be absorbed.

Your meals should be:

High in proteins, such as:

- Fish
- Poultry (chicken, turkey)
- Meat (beef, pork)
- Eggs
- Tofu
- Dairy products
- Smooth peanut butter and other nut butters, such as almond butter

High in refined or low-fibre complex carbohydrates (starches), such as:

- White bread
- Cereals such as Rice Krispies® and corn flakes
- Potatoes without skin
- White rice
- Pasta

Moderate in fats, such as:

- Oils
- Butter
- Margarine
- Mayonnaise
- Gravies
- Cream sauces
- Regular salad dressings

If you had a large section of your ileum (the last section of your small intestine) removed, you may tolerate larger amounts of fat at breakfast time rather than later on in the day.

You can use small amounts of artificial sweeteners like Splenda®, however, limit your intake of mannitol, sorbitol or xylitol, as taking large amounts may have a laxative effect (make you have a bowel movement).

Nutrient deficiencies and short bowel syndrome

Deficiencies of vitamins and minerals will occur in short bowel syndrome. This is because large sections where they are normally absorbed have been removed.

Speak with your Dietitian and arrange suitable micronutrient tests before supplementing your diet.

For those on oral diets only and suffering fat malabsorption, there is a risk of developing essential fatty acid deficiency and this can be supplemented subcutaneously, under the care of the Dietitian.

Jejunostomies

A jejunostomy is the surgical creation of an opening (stoma) through the skin at the front of the abdomen and the wall of the jejunum (the middle part of the small intestine).

A stoma bag is attached to the end of the jejunum to collect partially formed stools.

It can take a lot of trial and error to learn what foods suit you. Because food does not travel through the entire bowel, food transit can be much quicker, and fluids and electrolytes can be lost easily with diarrhea. Vitamins A, B12, D, E, K, bile acids and fat are not properly absorbed.

This leads to weight loss and deficiencies.

There are two ways of managing a jejunostomy and this is dependent on how much jejunum you have left:

- If you have over 100cm of jejunum left in perfect condition you may be managed on foods and micronutrient

supplements. You may also need to have special oral rehydration solutions which contain a very high sodium (salt) dose of 120mmol/L e.g Double strength Dioralyte®, Glucodrate®.

- If you have under 100cm of your jejunum, or 100-150cm that is not in good condition, you may have to have parenteral nutrition (nutrition into your vein), in addition to an adapted diet.

Ileostomies

An ileostomy is a small opening where the ileum (last part of the small bowel) is diverted to the abdominal wall after surgery.

Stools will not be solid and formed, but should not just consist of liquid.

Stool output should be under 2000mls / 24 hrs. If it goes over this, Dietitian advice will include:

- The higher your stool output, the higher your sodium chloride (salt) losses are. You may need to have 1L of a prescribed high sodium drink per day and limit yourself to 1L of normal drinks per day.
- Try jelly babies, marshmallows and eat salty snacks to thicken stools.
- Chew food well to avoid blockages, large bits of insoluble fibre in fruit and vegetables or tough meat/fish bones are to be avoided. Certain foods may benefit from blending.

Jejuno-colic anastomosis and kidney stones

Patients who have had an operation joining the jejunum to the colon are at risk of oxalate based kidney stones because the large bowel starts absorbing more oxalate.

The following foods are rich in oxalates – aim to limit your intake to no more than one item from this list per day:

- Some fruits, including blackberries, blueberries, raspberries, strawberries, currants, kiwifruit, concord (purple) grapes, figs, tangerines, and plums.
- Some vegetables, such as okra, parsley and leeks.
- Nuts and seeds.
- Cocoa and chocolate.
- Soy products, including soy milk, soy cheese, tofu and soy ice creams.

Tea and coffee have a moderate oxalate content, aim to have no more than two to three cups per day.

But plenty of non- alcoholic, non-caffeinated fluids to prevent dehydration is encouraged.

Your diet should also be calcium rich and moderate in fat content

Small Intestinal Bacterial Overgrowth

When you have had any form of gastrointestinal and/or HPB surgery, as well as some other cancer treatments, you are at increased risk from something called small intestinal bacterial overgrowth (SIBO).

The small bowel is supposed to have small numbers of protective bacteria living inside it, but sometimes a few strains of bacteria can move upwards from the large bowel, and multiply into high numbers, causing digestion problems.

Some people do not notice they have it, but others have a change in bowel habit, becoming constipated, have flatulence or diarrhoea.

A hydrogen and methane breath test will be booked for you if your Doctor suspects this problem and you may need to see a Dietitian to review and possibly alter your diet.

The large bowel and surgery

The large bowel is about 5 feet long in adults and absorbs water and any remaining nutrients from partially digested food passed from the small intestine. The large intestine then changes waste from liquid to a solid stool. Neuroendocrine cancers which grow in the large bowel or rectum can sometimes require surgery to remove or bypass the tumour and help maintain the passage of stools.

Types of large bowel surgery include:

- Right Hemicolectomy
- Left hemicolectomy
- Transverse colectomy
- Sigmoid colectomy
- Anterior Resection

After surgery it is common for your bowel habit to be erratic initially. You may experience loose motions or diarrhoea that may be quite frequent, or you may become constipated (unable to pass your bowel motions). See diarrhoea advice mentioned previously, but also combine this with dietary advice if you have a type of NET or NEC where diarrhoea is common.

Colostomies

Eating a balanced diet is important for us all and you should continue to follow a balanced diet for good health if you are a healthy weight. Everyone's tolerance to different foods varies, so monitor your reactions to foods to understand your tolerance. Follow the advice below to help you enjoy the foods you eat.

- Eat at regular times and avoid long gaps between meals.
- Enjoy your meals in a relaxed atmosphere.
- Sit down, preferably at a table.

- To prevent wind, do not drink and eat at the same time.
- If you wear dentures, make sure they fit properly.
- Chew food thoroughly to help digestion and to prevent wind.
- Once your colostomy has established your 'normal' output, include high fibre foods one at a time as some people will get gas.

Dealing with common stoma issues

Wind/gas

Some foods may cause wind through your stoma, these may be similar to the foods that caused wind before you had your surgery (see list below). Avoid these foods for the first 1-2 weeks following your surgery, then only include them in small quantities, or avoid them completely if they continue to cause problems.

- Pulses such as lentils, peas and beans.
- Brussels sprouts and cabbage, broccoli, cauliflower, and all brassica vegetables.
- Chewing gum and mints that contain sweeteners such as sorbitol, mannitol or xylitol.
- Beer and fizzy drinks (stir these drinks then allow them stand for about 10 minutes to reduce the fizz before drinking).

Odours / smells

If your stoma bag is correctly applied you should not experience any smells. However, some foods may increase the smell from your output – if they affect you, just avoid them. Higher-risk foods include:

- Onions (particularly raw).
- Garlic.
- Cauliflower, cabbage and sprouts.

- Spicy foods.
- Eggs.

A few drops of vanilla essence, deodorant powders or sprays in your stoma bag may help with odour. Discuss this with your stoma nurse who can recommend where you can buy these.

Constipation

Constipation can affect all of us. A colostomy may not work every day, but should produce an output most days. If you have had no output from your colostomy for 3 days and/ or you feel unwell, contact your GP or stoma care nurse.

To prevent constipation, drink more fluids, such as water, milk, tea, fruit juices. Include more wholemeal bread/cereals, fruit and vegetables to increase your fibre intake.

If you are able, be more active, for example walk more and take the stairs rather than the escalator or lift, as your normal mobility allows.

Colostomy diarrhoea

If your stoma is producing loose output, your body will be losing more water and salt. This increases your risk of dehydration. If this happens, it is important to drink plenty of fluids such as water, tea and still isotonic sports drinks. Adding salt to your meals will also help replace any lost salts.

To avoid diarrhoea:

- Have no more than 5 pieces of fruit and vegetables a day.
- Have no more than 150mls of fruit juice in a day.
- Limit your alcohol intake.
- Limit your caffeine intake – have no more than 3-4 cups tea/coffee per day.
- Limit your intake of sweeteners such as those found in diet fizzy drinks, no-added-sugar squash and sugar-free sweets/ chewing gum.

- Reduce high-fibre foods such as whole grain cereals or bread.

If you feel the increase in your output is due to a change in your food/fluids or daily routine, including the following foods may help:

- Under ripe bananas.
- White rice, pasta, noodles and bread.
- Low-fibre breakfast cereal such as cornflakes or Rice Krispies®.
- Porridge.
- Foods that contain gelatine, for example marshmallows or jelly babies.

If you think the high output is a result of an illness, stomach upset or food poisoning, or if it continues for more than 24 hours contact your doctor, stoma care nurse or local chemotherapy unit, if applicable.

Colostomy and blockages

While it is very rare, your colostomy may become blocked. The best way to avoid this is to chew your food well. Take time to eat your food slowly and drink plenty of fluid after you have eaten. Be aware of high-risk foods from the list below, so you can be cautious or avoid them. Keeping a diary of the food you eat and any symptoms you experience can help you to identify any foods that cause you problems.

- Sweetcorn and peas, all pulses and legumes.
- Orange/grapefruit pith.
- Dried fruit.
- Celery.
- Salad vegetables.
- Pineapple.
- Mushrooms.
- Raw or desiccated coconut (coconut milk is ok).
- Tomato skins and pips. Nuts and seeds.

Supplements and probiotics

Patients suffering from carcinoid syndrome should already be taking a niacin containing supplement, however there are additional deficiencies to be aware of, which are a result of surgery.

This may be due to food running through the digestive system too quickly for absorption to occur or because the place where something is normally absorbed has been taken away.

These micronutrients are discussed in each relevant section and the levels should be tested before a supplement is taken because high doses can lead to toxicity.

Patients commonly ask if there is something we would recommend to help with their neuroendocrine cancer and immune system.

Apart from the hop extract, xanthohumol, there have not been any trials using botanical compounds to treat NETs or NECs. Xanthohumol was successful in treating neuroendocrine cancer cells, but research is in its very early stages.

As previously mentioned, omega 3 oil and arginine (or a prescribed supplement drink containing these nutrients) may be useful when preparing for surgery.

High doses of vitamin C or any other antioxidant are not recommended (unless deficiency is proven), as it may do more harm than good.

Curcumin is an extract from turmeric and this has not been tested specifically after surgery in neuroendocrine cancer, but it has been used to treat inflammation and irritable bowel syndrome with some success. Choose a strong, high absorbing formulation as it is

a very difficult compound for the body to absorb.

Probiotics are 'good' bacteria found in functional food products or supplements that can beneficially affect our health by improving the balance of the gut bacteria. They are found in many different forms such as yoghurts, tablets, capsules and sachets. Although there are no studies in neuroendocrine Cancer specifically, some people find that they help with diarrhoea, immunity and protecting against the side-effects during or after antibiotics.

If you are taking with antibiotics, leave a 2 hour gap between taking them. As long as your immune system does not have too few white blood cells (neutropenia), probiotics are considered safe.

A high strength multi-strain probiotic is the best option. By this we mean those with at least 8 strains of bacteria, including some *lactobacillus* and *bifidobacteria* species.

We would strongly recommend that you have your vitamin and micronutrient levels checked BEFORE taking supplements - as high levels (excess) can cause toxicity and as many problems as levels that are too low (deficiency).

Discuss dietary concerns with your medical team and dietician.

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