

THE NET HANDBOOK



**Your Guide to Life with a
Neuroendocrine Tumour**



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A FEW BASICS



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**YOU DON'T
NEED TO GO IT
ALONE**

HELLO AND WELCOME...

... to your personal guide to living with neuroendocrine tumours, or NETs. No doubt you'd rather you weren't reading this - we would too. But as you are, we hope it'll give you a lot of useful and straightforward information about a subject it can be hard to find out about.

This isn't a book that's intended to be read cover to cover. Instead, we hope you'll dip in and out when you want more information about tests, time in hospital, talking about cancer, living with a NET or whatever else is on your mind.

We've designed it so you can pull out pages and take them to appointments, and you can store extra information in the flap at the back, too. So, carry parts of the guide or the whole thing with you; write in it, stick reminders in it and get people to read it, especially if you get tired of explaining what NETs are. We'd love to see copies of this handbook looking dog-eared and well used.

We're here for you

At the NET Patient Foundation, we've been supporting people who are diagnosed with NETs since 2006. We have put this guide together based on what people have told us; to include what will be most useful - after diagnosis, through treatment and living with NETs.

You'll find plenty of medical information - because our charity is run by a variety of medical specialists in NETs - explaining what's happening inside your body in clear, simple language is a big part of what we do.

But this guide goes well beyond that, because a cancer diagnosis doesn't only affect your body. It can have a big impact on your emotions, your relationships, your job, your bank balance and many other parts of your life. So we cover all of that and more too - guided by people who've been in your position and told us what they wished they'd known.

We really hope you'll find a lot that's useful here. Getting diagnosed with a NET can leave you feeling confused and alone, but we've written this book to help cut through the confusion and to make it very clear that you're certainly not on your own.

Cathy Bouvier
CEO NET Patient Foundation

HEARING THE NEWS

People react in all kinds of ways when they are told they have cancer.

Maybe you fell silent or couldn't stop asking questions. Maybe you wanted to be alone or wanted your whole family around you. Maybe you felt numb or overwhelmed by emotion. Maybe you even felt relief.

However you reacted is completely normal. There's no wrong or right way. The situation with NETs can be even more complicated because these types of tumours are often misdiagnosed initially or can take a long time to be correctly identified.

It's not unusual at all to feel unwell for years before a NET is diagnosed, or to be wrongly told that you have another condition, like irritable bowel syndrome, Crohn's disease, gastritis, asthma or problems linked to the menopause or blood pressure.

On the other hand you may not have felt unwell at all and have received your diagnosis as a result of a routine health check.

Not all NETs produce symptoms.

When the diagnosis is made, you may find it difficult to get your head around the fact that not only do you have cancer, but you have a type of cancer you, and those around you, may never have heard of.

You don't need to go it alone

The main thing to try and remember at this stage is that you really aren't alone. It's easy to feel isolated when you find out you have an uncommon condition, but getting the correct diagnosis means you should now have access to the right expert care team who understand your condition and can help.

So if you have questions, ask them and keep asking until you understand the answer. We hope a lot of issues that might come up are answered in this book, but don't be afraid to ask your care team anything that isn't - or to give us a call. There really is no such thing as a stupid question.

And while we know it can often be difficult, talking to family and friends can help - though it may be hard to decide how and when. Bottling things up can often make things seem worse.

Many people find our online forums and support groups are a helpful way to talk to others, who really do understand what being diagnosed and living with NETs is all about. You can find out more about these on our website. Our contact details are below:

Adviceline number
0800 434 6476
Office number
01926 883487
nurses@netpatientfoundation.org
www.netpatientfoundation.org

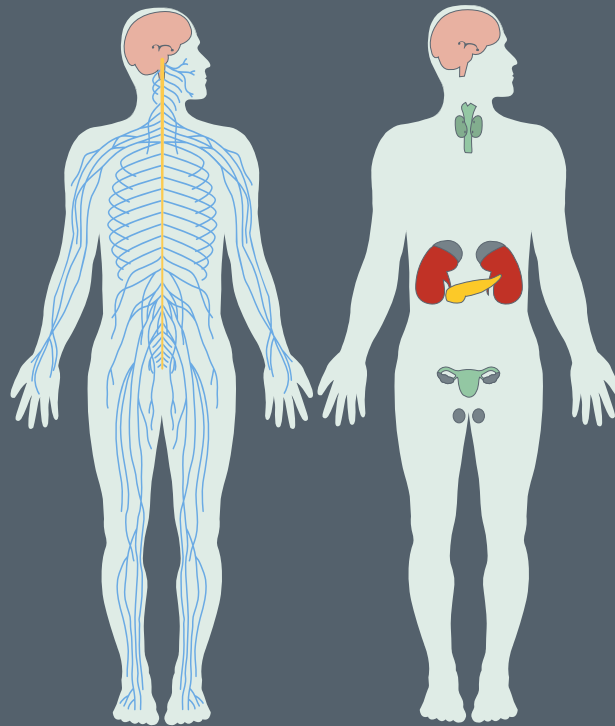
SO WHAT ARE NETs?

It can be hard enough coming to terms with the fact you have cancer, let alone trying to understand what the neuroendocrine system is or how neuroendocrine cells can cause a tumour.

So if you're struggling to get your head around this, hopefully this section will make things a little clearer.

The Neuroendocrine System

- the endocrine and nervous systems working together



Neuroendocrine cells help our bodies to function

Our bodies are made up of billions of cells - from blood cells to brain cells. **Neuroendocrine cells** are found in many parts of the body, throughout a network called the **neuroendocrine system**.

These specialised cells produce hormones (endocrine action), usually in response to signals from other cells, or the nervous system (neurological stimulus).

Neurological stimulus for an **endocrine function** = Neuroendocrine. These cells have different functions depending on where they are, but they all release hormones and other chemicals into the blood to help our bodies work normally. For example:

- Neuroendocrine cells in the **digestive system** produce hormones that move food through your intestines and help to break down food in your gut
- Neuroendocrine cells in the **respiratory system** produce hormones that help with the development of the lungs and regulate breathing

- Neuroendocrine cells in your brain produce hormones including oxytocin, which plays a role in everything from social bonding to breastfeeding
- Other neuroendocrine cells help to control things like **blood pressure** and **heart rate**.

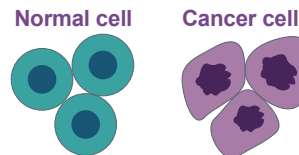
You can think of the neuroendocrine system as a bit like a bicycle inner tube. It's essential to keep things running smoothly - but you're hardly aware it's there.

All neuroendocrine cells release hormones and other chemicals that help our bodies work normally.

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Cancer is caused by cells acting strangely

When neuroendocrine cells work well, our bodies work well. But, as in all cancers, problems start when abnormalities occur and the cells start growing and behaving abnormally.

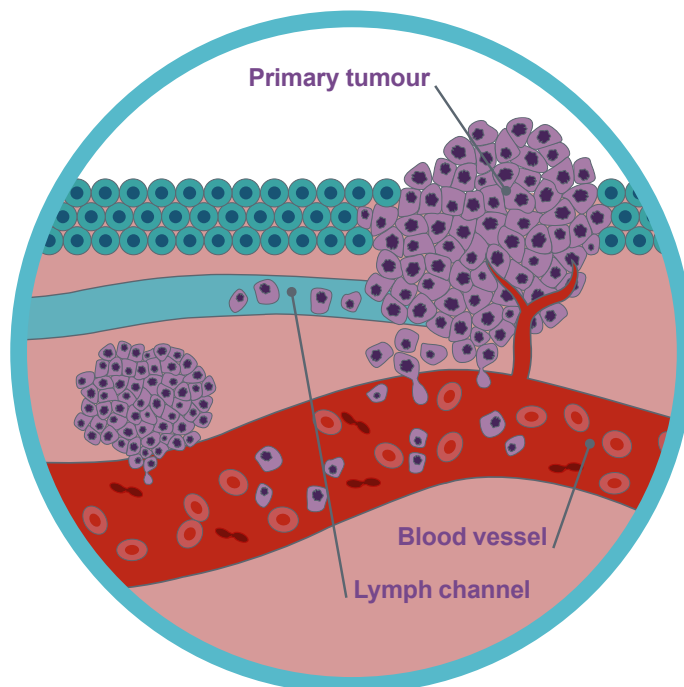


A normal cell:

- Exists in a specific place in the body
- Divides and replicates itself only when necessary
- Has a life cycle, so does its job then dies off
- Repairs or destroys itself if it gets damaged
- Doesn't cause damage to neighbouring cells by growing too large or invading them.

A cancer cell:

- Can detach from the tumour (collection of cancer cells) and travel to other parts of the body
- Keeps dividing and growing - as it doesn't know to stop
- Often grows abnormally, so can't perform a function properly
- Doesn't destroy itself if it gets damaged
- Ignores warnings from neighbouring cells to stop growing and can invade them.



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So how do NETs differ from other cancers ?

In more common cancers like carcinomas (which includes most lung, breast, prostate and bowel cancers), between 20% and 100% of cells in a tumour will be actively replicating and growing.

In NETs, however, the percentage of cells that are active can be lower. This can be described using a grading system:

- In Grade 1 NETs, fewer than 3% of tumour cells are actively dividing
- In Grade 2 NETs, between 3% and 20% of tumour cells are actively dividing
- In Grade 3 NETs (known as NECs - neuroendocrine carcinomas), more than 20% of tumour cells are actively dividing.

In lower grade NETs, the relatively small percentage of cells dividing means that tumours grow slowly, which is one of the reasons it can take years to develop and be diagnosed. Grade 1 NETs are sometimes described as being like 'cancer in slow motion'.

Higher grade NETs (NECs) often grow more rapidly and can behave more like the more common cancers. The highest-grade NETs are actually called neuroendocrine carcinomas (NECs), rather than neuroendocrine tumours. You can read more about this in section 2.

In 2015, more than 4500 people (about 12 people a day), in England, were newly diagnosed with NETs and the incidence is rising

For NETs explained turn to section 2, page 13.

Malignant vs benign NETs (cancer vs not cancer)

Not all NETs are malignant, a small percentage are truly benign.

Your tumour may be described as benign but it is important to be absolutely clear as to whether it is truly benign or just behaving benignly (that is very slowly growing).

This guide is for those diagnosed with a malignant NET - whatever the rate of growth.

THE NETs MYTHBUSTER

To help overcome common misconceptions related to NETs, we asked people we support about the issues that confused or concerned them after diagnosis. These are some of the myths they wanted us to put right...

Myth #1

Incurable and terminal are the same thing

Not true

If a condition is incurable it can't be cured, which is not the same as being terminal. A terminal illness is when it can reasonably be expected to shorten a person's life to a limited amount of time (for example less than 6 months). But a condition that's incurable isn't necessarily terminal - for example, diabetes, asthma, hypertension and NETs.

That's an important distinction, because at the time of diagnosis NETs may well be incurable* but are rarely terminal. Many people can live well for years with a NET.

Myth #2

You don't have cancer

Not true

This is one that can really upset or confuse people, and rightly so. Because some NETs develop much more slowly than other cancers, you might meet people - including medical staff - who downplay their significance, or mistakenly refer to them as benign - which is massively unhelpful. Cancerous NETs may behave differently to some cancers, and may grow significantly slower - but they are, unfortunately, most definitely still a form of cancer.

Myth #3

NETs always grow slowly

Not true

Most low-grade NETs do grow slowly, but other moderate to high-grade NETs can grow as quickly as more common cancers. The rate of growth of even low-grade tumours can change over time, too - their behaviour can be unpredictable. If someone tells you that NETs are always slow to develop, they don't understand NETs.

*Just to be totally clear, a small number of NETs may be considered cured if they're caught early enough and have been completely removed by surgery - before they've spread or infiltrated nearby cells. Even in that situation, close follow-up care may still be needed.

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Myth #4

NETs are always in the bowel

Not true

Strange one this, but it's certainly out there. Whilst the small bowel is one of the most common sites for NETs to start, others include the lungs, appendix and pancreas. It can be frustrating when, looking for information, many publications and articles focus solely on bowel NETs.

If you read section 2 of this book you'll see the many parts of the body in which NETs might start.

Myth #5

The stage of your tumour defines how serious it is

Not true

This is another myth it's important to tackle upfront, because NETs are not only defined by the stage they are at. The stage of a tumour can give important information about the primary site, and whether it has spread. However, other factors such as how active it is (grading), what the tumour cells look like under a microscope (differentiation) and your overall health, alongside tumour staging, will determine how serious it is.

So please make sure you always chat to your care team to get the full picture about your condition.

We explain more about how NETs are classified in section 2

Myth #6

Treatment is something that happens to you

Though it may at times feel like it - not true

This one isn't specific to NETs, but it is something vitally important to be clear on. In short, treatment shouldn't be something that just happens to you - it should be something you're constantly involved in.

Treatment cannot happen without your consent - your informed consent. If you don't feel you have received enough information to make a decision or don't feel like all options for treatment have been fully discussed - ask for more, and more, again and again if need be, until you feel certain and confident in making a decision that's right for you.

Myth #7

Everyone responds to treatment in the same way

Not true

Absolutely not. You are unique - you were unique before you were diagnosed with a NET, and that's still true now. So don't let your experience be filtered through other people's, there will be similarities and shared experiences, however please remember that your condition and your reaction and response to treatment will never be exactly the same as anyone else's.

Not only are you unique, so is your NET, so even if someone else has the same type - how you or your tumour responds may be different.

GETTING THE RIGHT CARE

As soon as you're diagnosed with a NET, it's vital to get the best possible advice and treatment from the right team of people - and across the UK there are procedures in place to ensure this happens.

If you're diagnosed with a NET, a specialist, accredited, NET specific Multi-Disciplinary Team (NET MDT) should review your case on an ongoing basis.

That team will be made up of a range of clinical experts who specialise in NETs. We talk more about MDTs in section 3.

Getting referred to a specialist NET team

Referrals to specialist NET services work slightly differently across the UK. They can also vary slightly depending on who refers you - for example your GP, A&E staff or a specialist in another area of medicine. NB most NET specialist centres have specific NET referral forms that can be used.

This doesn't necessarily mean that you need to travel to and keep travelling to your nearest specialist centre, but it does mean that information about your situation, including the results of any scans and other tests, should be

looked at by the NET MDT. This team can also advise on or arrange the most appropriate tests and treatment for you.

So wherever you are and whoever is caring for you, it is vital to get support from a specialist NET MDT as soon as possible.

You should be referred to one automatically, but if that doesn't happen you can ask for a referral to be made.

At the NET Patient Foundation we work with all of the UK's specialist NET services either directly or through UKI NETS. UKI NETS - The UK and Ireland Neuroendocrine Tumour Society - is a professional organisation made up of the UK and Ireland's experts and other clinicians and nurses who work in the field of NETs. The society maintains an up-to-date list of NET experts, clinics and accredited Centres of Excellence - along with a current list of research projects and clinical trials.

For a current list of experts, clinics and Centres of Excellence please visit the clinical practice page on the UKI NETS website: www.ukinets.org

TREAD CAREFULLY ONLINE

It's natural to want to have more information about your condition, and understanding what's happening definitely puts you in a position of power. But do remember to click carefully, because...



The 4am surf is not your friend

We've all been there. Can't sleep. Can't get comfortable. Thinking the worst. So you reach for your phone, tablet, laptop or pc . . . and half an hour later you're still reading something that's only making you more worried.

Trust us - the 4am surf is usually a bad idea. So if you can't sleep and think of a question you want answered, write it down - with or without some of the concerns you have, then try to rest. You can revisit it in the morning instead when things may seem clearer and you can pick up the phone and talk it through with a friend, your GP, a member of your care team or us.

Balance matters

It's easy to be affected more by negative stories or by articles that seem to promise miraculous cures. So it's always worth checking how reliable that information is, for example, for any information on treatments - has it been published and reviewed in a reputable medical journal such as the British Medical Journal or New England Journal of Medicine? Are the claims supported by evidence and references? Have initial results been reproduced and reliably proven?

It's also worth preparing yourself for reading things that you might not like, so try to look for a balance of information if you do hunt for answers online.

Some sites are more reliable than others

Your care team will be able to recommend websites you can trust to find out more about your condition.

Apart from our own pages, we cannot comment on or guarantee the content of websites, however you may find the following useful:

www.netpatientfoundation.org

Our online hub, where you can find further information including our support groups, events and resources for people who have NETs

www.taect.scot

The website of Scottish NETs charity the Ann Edgar Charitable Trust

www.ukinets.org

The website of the UK and Ireland Neuroendocrine Tumour Society

www.amend.org.uk

The Association for Multiple Endocrine Neoplasia Disorders

www.enets.org

The website of the European Neuroendocrine Tumour Society

www.cancer52.org.uk

An alliance of 80 organisations that support people who have rare cancers

www.cancerresearch.org

For general information on cancer and cancer research

www.incalliance.org

The International Neuroendocrine Cancer Alliance (INCA)

www.nhs.uk

The National Health Service (NHS) website

www.accsupport.uk

Adrenocortical cancer support and information

www.merkelcell.org

Merkel Cell Carcinoma information

There are also online forums - these tend to be self-regulated or rarely censored - and so you may occasionally find some of the information contradictory or questionable - however they can be incredibly good for sharing experiences, discussions, information and making supportive friendships.

Facebook pages:

NET Patient Foundation

Friends of NET Patient Foundation (Global group)

NET Natter UK online (UK NPF Patient group)

Next2NETs

(NPF Family and friends - supporters page)

NETs Scotland:

The Ann Edgar Charitable Trust

Welsh NET Natter Group/ Grwp Natter NET Cymraeg

NI NET Natter-ers (Northern Ireland)

Others you may find helpful:

NET Whippersnappers

(for those under 50 years young)

Parenting with NETs

NETs PALs : NET Cancer Support Group

AMEND (Multiple Endocrine Neoplasia)

Lovable lungnoids

(Carcinoid/NET Lung Cancer Support)

High Grade (Aggressive) Neuroendocrine Cancer Support

Phaeochromocytoma and

Paraganglioma Support Group for UK

Merkel Cell Carcinoma Support Group (Skin NET)

Insulinoma

THE POWER OF BEING PREPARED

Whether you want to know every detail of what a NET can mean or would rather your care team just got on with it, there's a lot to be said for being prepared.

Everyone deals with illness differently. Some people want to know exactly what's happening, others prefer doctors to keep things as general as possible - and it's completely up to you how you approach your life with a NET.

However, trying to prepare for what is to come can help. This doesn't mean you suddenly need to spend hours reading medical textbooks or scouring websites about the neuroendocrine system. But it does mean that getting your head around some of the facts and potential implications of a NET diagnosis can put you in a stronger and maybe less stressful position.

Being prepared for treatments, for instance, can help you know what to expect, what is usual and what's not - for example what side effects could happen and how to deal with them, if they occur.

Being prepared for appointments and conversations with your medical team can help you to get the best out of your consultation - think of the questions you may want to ask - that may help you to get the information you need, write them down to take with you. (We've included some handy tips and questions you might want to ask in the next section Understanding NETs)

We talk about the emotional impact and relationships in section 6.

But being aware of the effect your diagnosis may have on those around you may help you to prepare for those who might act or treat you differently: some may carry on as normal, others may offer help in a variety of ways, some may drift away or not know what to do. This may be helpful, annoying, upsetting or uplifting. Whilst we may not be able to change how others react or behave, we can alter how we respond to them.

Any type of cancer can cause your life to change in all kinds of ways, and NETs are no different. So being prepared for those changes, and spending a little time thinking about how you want to respond, is usually a very good idea - and it's one we'll keep coming back to throughout this book...

UNDERSTANDING NETs



**IF YOU HAVE
ANY QUESTIONS
OR CONCERNS,
ASK!**

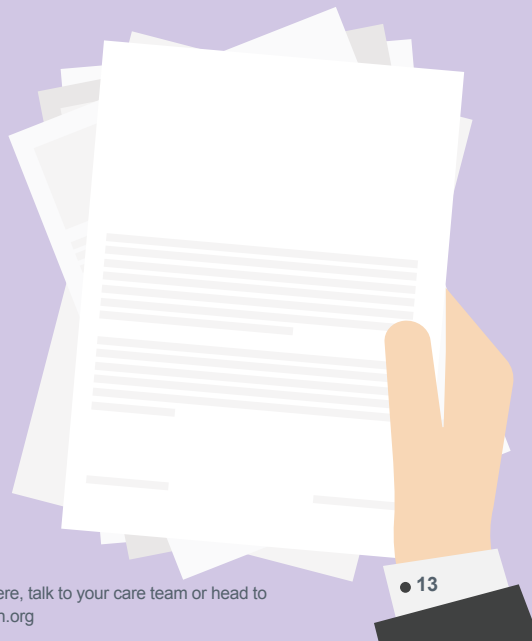
THE DIFFERENT TYPES OF NETs

As we have said, NETs (neuroendocrine tumours) occur when neuroendocrine cells stop working normally and start to grow and/or behave abnormally.

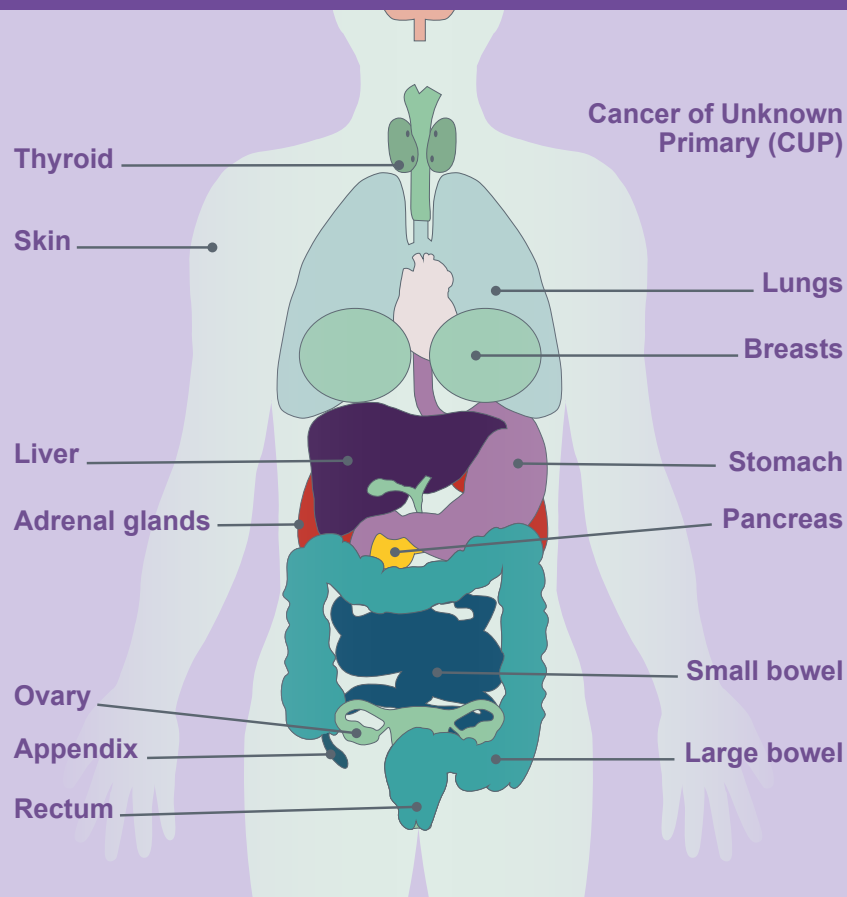
They can grow in many places throughout the body and, like all cancers, NETs are named after the place where they first form - so if you have a NET that starts in your lung, you'll be diagnosed with a lung NET. Your lung is then known as the primary site of your cancer, and if the cancer spreads to other parts of your body these are known as secondary sites, secondaries or metastases.

We publish detailed individual factsheets on the most common NETs and these are available for free at www.netpatientfoundation.org or by calling NET Patient Foundation on **01926 883487**.

The information overleaf should begin to explain the different types of NET.



WHERE NETs ARE FOUND



The place where your cancer starts is called the **primary cancer site**.

If it spreads to other parts of your body, these are known as **secondary sites**. Or in medical terms **metastasis or metastases**.

Functioning vs non-functioning NETs

Your care team will almost certainly talk about 'functioning' and 'non-functioning' NETs. So what's the difference?

Functioning NETs produce a specific set of symptoms, known as a syndrome.

More information on syndromes starts on page 25.

Non-functioning NETs generally don't produce a specific set of symptoms. In fact they often don't cause any symptoms, which is why they can be hard to diagnose.

Symptoms that do occur with nonfunctioning NETs are usually linked to where the NET is in your body and how big it is. They can include pain, a cough, jaundice (which gives your skin and eyes a yellowy tinge) and/or tiredness. Weight loss can also be a sign of a non-functioning NET.

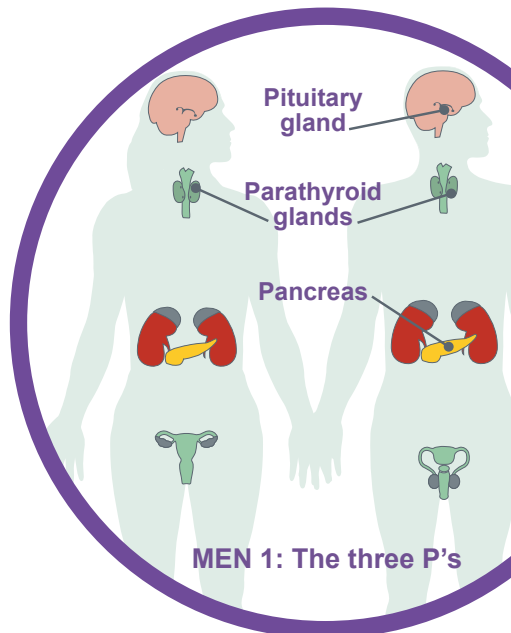
Cancer of unknown primary (CUP)

It's usually possible to work out where a cancer started based on your symptoms and by looking at test results. But if this isn't possible your doctors may call your NET a cancer of unknown primary. This doesn't usually affect treatment options, and research is constantly happening to help find and identify primary tumours more effectively.

Multiple Endocrine Neoplasia 1 (MEN1)

MEN1 is an inherited condition that causes tumours to develop in more than one place - usually the pancreas, parathyroid gland and pituitary gland, which you might hear called the 'three p's'. These tumours can be cancerous or benign, and can produce excessive amounts of hormones and other chemicals that are then released into your body.

Further information about MEN conditions can be found at www.amend.org.uk

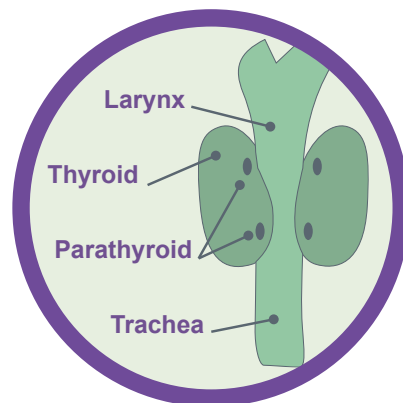


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Thyroid NETs (aka Medullary Thyroid Cancer or MTC)

The thyroid is a gland in the neck that produces hormones involved in blood pressure, body temperature, heart rate and metabolism. MTC is a rare type of NET that begins in the thyroid, with one in four cases caused by a rare hereditary disorder.

Further information about MTC can be found at www.amend.org.uk



Lung NETs

Lung NETs account for up to 6% of all lung cancers. You might also hear them referred to as bronchial or pulmonary NETs, and there are five different types: DIPNECH, typical lung NETs, atypical lung NETs, small cell neuroendocrine carcinoma and large cell neuroendocrine carcinoma.

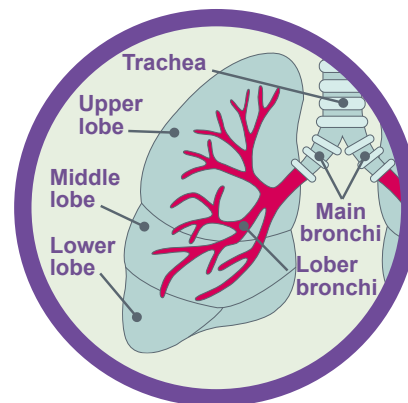
DIPNECH is a very rare condition that can cause neuroendocrine cells in your lungs to get too big - these can sometimes become very small tumours.

Affected cells usually don't change significantly or quickly, but DIPNECH may sometimes be considered a pre-cancerous condition as it can develop into a typical or atypical lung NET.

Around 90% of cases involve typical lung NETs (also called TCs - typical carcinoids). These grow slowly and rarely spread beyond the lungs (less than 15%). A second type - atypical lung NETs (or ACs - atypical carcinoids) - tend to grow more quickly.

Together, typical and atypical lung NETs account for 40% of all NETs. Hormone related symptoms are not common for lung NETs, but a small number of patients may experience "Carcinoid Syndrome" (see page 25 for more information on this)

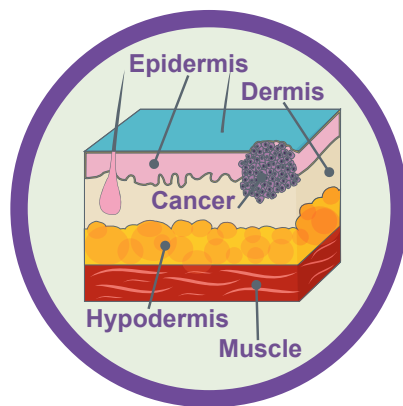
Small cell neuroendocrine carcinoma and large cell neuroendocrine carcinoma are the rarest lung NETs - but also the most active. They grow at a similar rate to more common lung cancers.



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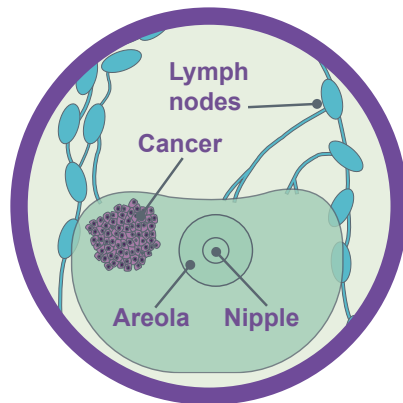
Skin NETs

Merkel Cell Carcinoma (MCC) is a rare type of skin cancer thought to start in neuroendocrine cells called Merkel cells. It's an aggressive form of skin NET and can occur on or just underneath the surface of the skin.



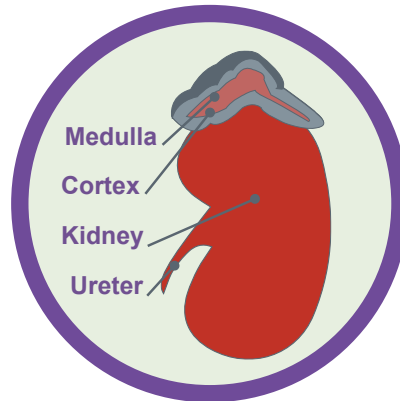
Breast NETs

Breast NETs are extremely rare. They are usually diagnosed after a biopsy, when tissue is studied for more common types of breast cancer.



Adrenal NETs

There are three types of neuroendocrine tumour that can start in or near these glands: adrenocortical carcinoma, pheochromocytomas and paragangliomas.



Adrenocortical Carcinoma (ACC)

ACC is a cancer of the outer layer of the adrenal gland. It can cause excessive amounts of hormones to be released, including adrenaline, noradrenaline and steroids, such as cortisol, which help the body to maintain blood pressure as well as salt and sugar levels.

Further information about ACC can be found at www.accsupport.org.uk

Pheochromocytomas (phaeos) and paragangliomas (PPGL)

Pheochromocytomas, often known as 'phaeos' ('fee-ohs'), are rare tumours of the adrenal gland arising from the inner section of the gland called the medulla. Similar tumours can arise from sites outside of the adrenal gland and these are called (extra-adrenal) paragangliomas.

Further information about pheochromocytomas and paragangliomas can be found at www.amend.org.uk

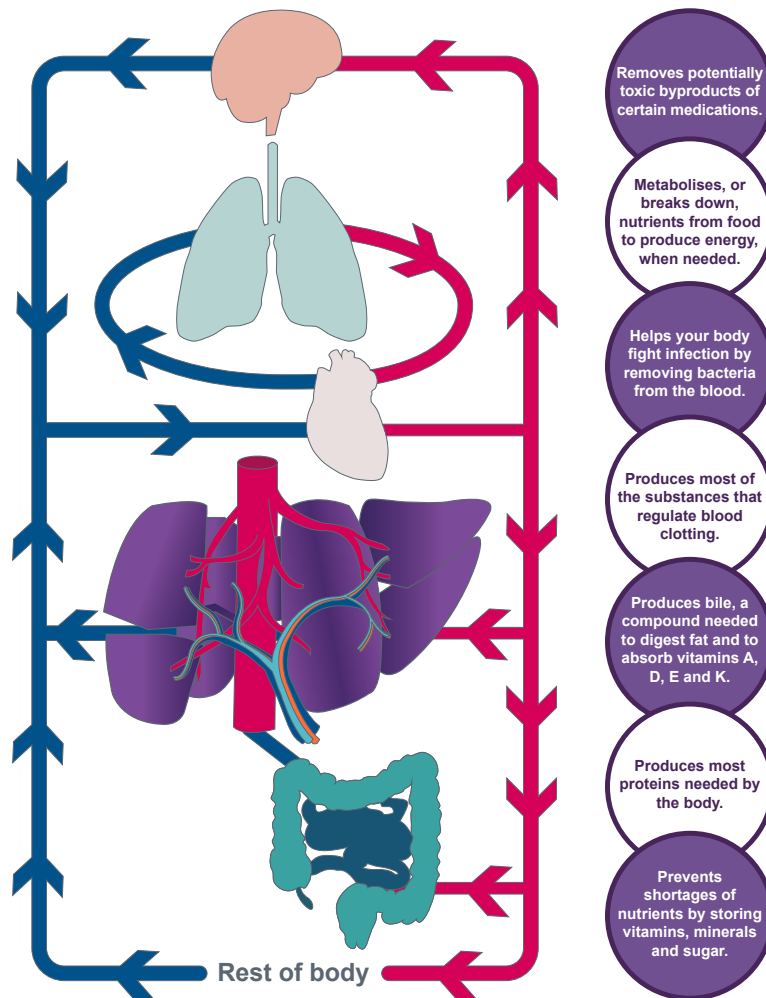
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Liver NETs

It's very rare for NETs to start in the liver. If you have a NET in your liver, it's much more likely to have spread from a primary site elsewhere in your body. NETs in the liver can be associated with certain symptoms including carcinoid syndrome - even if the primary site did not (see page 25 for more information on syndromes).

The liver is the most common place for secondary NETs (which have spread from elsewhere), partly because of the way blood flows through the body and partly because of the role it plays in almost all body functions.

As this image shows, it's a very fertile place for cancer cells to develop and grow.



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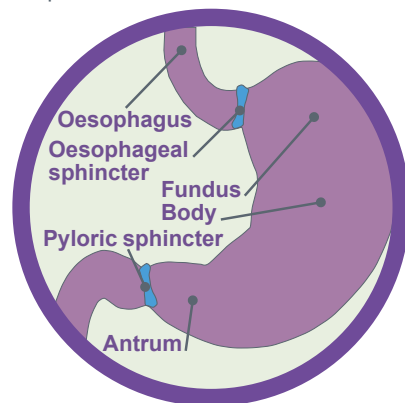
Stomach NETs

Also known as gastric NETs, there are three different types of stomach NETs. Together, they account for less than 1% of all stomach cancers.

Type 1 stomach NETs are small and the least aggressive stomach NETs, often causing multiple tumours.

Type 2 stomach NETs tend to be larger and can spread.

Type 3 stomach NETs are the largest stomach NETs and are more likely to spread.



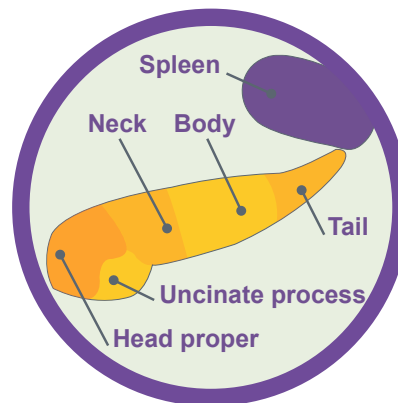
Pancreatic NETs

The pancreas is a large gland that produces insulin and other hormones. Pancreatic NETs can be described as **-functioning** and **non-functioning**.

Functioning pancreatic NETs cause a specific set of symptoms (also known as a syndrome).

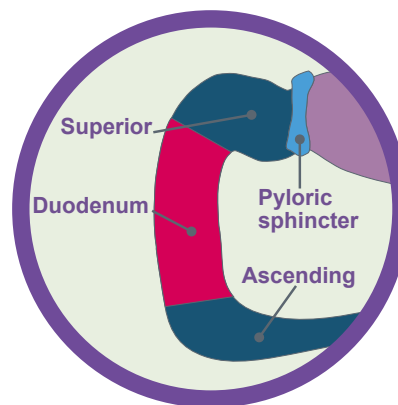
NETs in this category include insulinomas, gastrinomas, VIPomas, somatostatinomas and glucagonomas. (See page 27-28 for more information on syndromes.)

Non-functioning pancreatic NETs don't cause a syndrome, but common symptoms include back pain, jaundice, stomach pain and weight loss.



Duodenal NETs

The duodenum is the first part of the small bowel, where food from the stomach begins to be broken down.

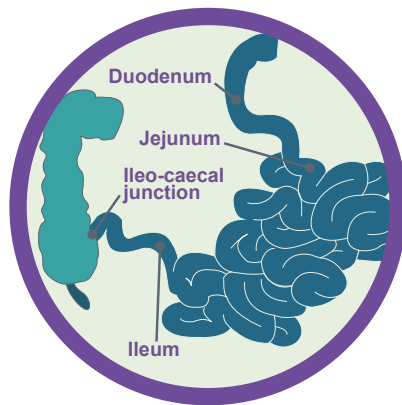


Duodenal NETs may cause symptoms similar to either some pancreatic or small bowel NETs. You can read more about these syndromes in Syndromes explained on page 27-28.

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Small bowel NETs

Also called jejunal, ileal or ileo-caecal NETs, these are the most common bowel NETs.

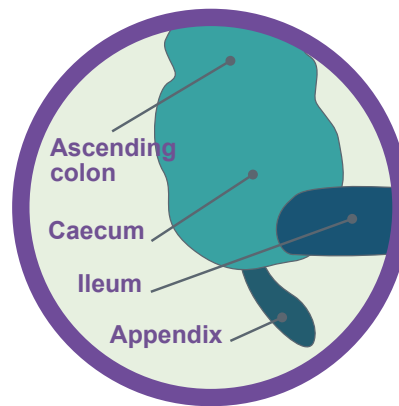


They tend to grow slowly and may cause symptoms - that are similar to irritable bowel syndrome or carcinoid symptoms - or not.

As such, early diagnosis can be difficult and unfortunately small bowel tumours have often spread by the time a NET is diagnosed. (See page 25 for more information on syndromes.)

Appendiceal NETs

Although considered rare, NET is the most common tumour of all appendiceal tumours. They are usually discovered during tests or treatments for other conditions, such as surgery for suspected appendicitis.



Appendiceal tumours less than 1cm in size are often removed and cured using surgery. However, if you have a larger tumour or if your appendix has burst or you are told it is a Goblet Cell Carcinoma (GCC)* you may need further investigations, further surgery or other treatments.

Goblet Cell Carcinoma (GCC)*

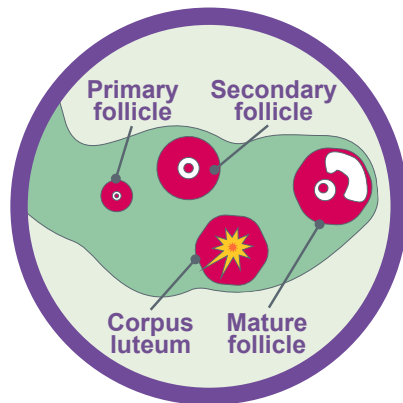
Goblet cell carcinomas are very rare - they start in the appendix and get their name because the cells look goblet shaped under a microscope. They have both neuroendocrine and adenocarcinoma features, making them more aggressive than appendiceal NETs, and more likely to spread. Treatment strategies tend to follow bowel or peritoneal cancer recommendations rather than NET guidelines.

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Ovarian NETs

Ovarian NETs are usually secondary NETs that have spread from a primary site in the bowel or appendix.

Primary ovarian NETs are extremely rare, with only around 30 women in the UK diagnosed each year. Due to this rarity detailed information is limited.

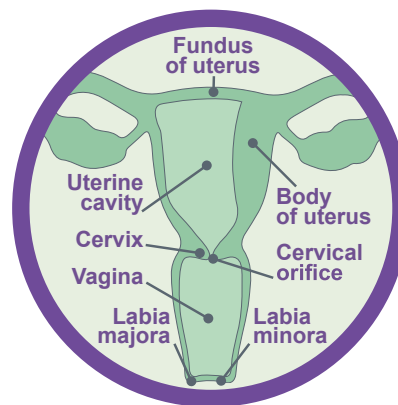


However two main types have been identified - Ovarian neuroendocrine tumour (NET) and neuroendocrine carcinoma (NEC) of the ovary.

Neuroendocrine tumours tend to be low to moderate grade - that is slow growth, whereas neuroendocrine carcinomas tend to be high grade and behave more like ovarian cancer. Some ovarian NETs can cause carcinoid syndrome (see page 25 for more information on syndromes).

Other gynaecological primary NET sites

Cervical, uterine, vaginal and vulval NETs are amongst the rarest of all NETs, with only a handful of cases reported worldwide. They are rarely suspected before surgery and usually only diagnosed by biopsy or post surgical tissue examination (histopathology). As with primary ovarian NET, two main types exist: Neuroendocrine Tumour and Neuroendocrine Carcinoma.



Neuroendocrine Tumours (NETs) tend to be low to moderate grade - that is slow growth, whereas Neuroendocrine Carcinomas (NECs) tend to be high grade and behave more like common cancers.

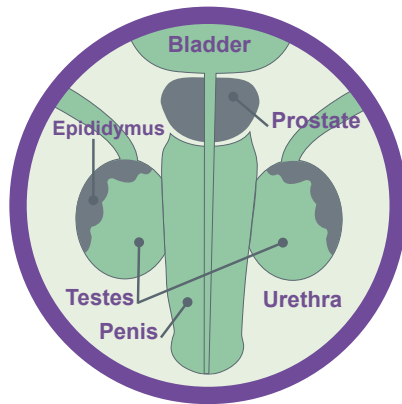
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Testicular and prostate NETs

NETs in the testes and prostate are usually only found during tests for more common cancers.

As with NETs of the female system, testicular and prostatic NETs can be classified as carcinomas or tumours, depending on how cells look under a microscope.

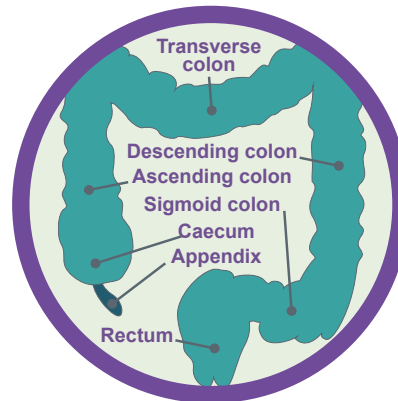
True NET of the prostate is rare. A more common finding is prostate cancer with neuroendocrine differentiation (under a microscope the tumour has neuroendocrine features): this does not make it a NET. Prostate cancer with neuroendocrine differentiation tends to be very aggressive and may be resistant to standard prostate cancer treatment.



Large bowel NETs

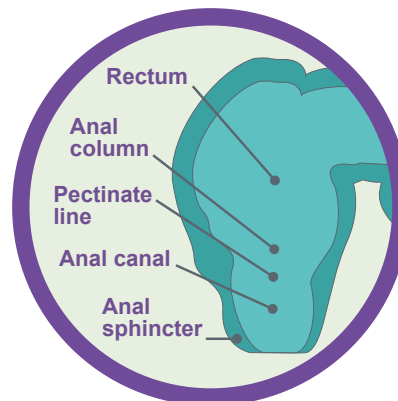
Also known as colonic NETs, these are rare and can cause symptoms such as altered bowel habit (e.g. diarrhoea and/or constipation), stomach or abdominal pain, weight loss and bleeding - similar to symptoms of the more common bowel cancer.

Large bowel NETs can be aggressive and often spread.



Rectal NETs

Rectal NETs are amongst the most common intestinal NET, approximately 14%, and the most uncommon colorectal cancer, less than 1%. Around half of cases are diagnosed during tests or treatments for other conditions. Rectal NETs can cause bleeding, constipation, or pain on defecation (opening your bowels), but they may cause no symptoms at all - which may delay diagnosis.



NET JARGON EXPLAINED

There are plenty of acronyms used to describe different types of NETs. Here are some that you might hear your care team use:

pNETs are pancreatic neuroendocrine tumours, or NETs found in the pancreas.

F-pNETs are functioning pancreatic neuroendocrine tumours, or NETs in the pancreas that produce a specific set of symptoms.

NF-pNETs are non-functioning pancreatic neuroendocrine tumours, or NETs that aren't producing a specific set of symptoms.

CUP NETs are Cancers of Unknown Primary, which means that the investigations you have had, have not shown where your NET started.

GEP NETs are gastroenteropancreatic NETs, or tumours in the gut or pancreas.

GI NETs are gastrointestinal neuroendocrine tumours, or NETs in the oesophagus, stomach or intestine (bowel).

NENs are neuroendocrine neoplasms, which is another way of saying NETs (neoplasm means "new growth" or tumour).

SiNENs are neuroendocrine tumours in the small intestine.

gNENs are gastric neuroendocrine tumours, or stomach NETs.

dNENs are duodenal neuroendocrine tumours.

MANEC are tumours that contain both neuroendocrine and adenocarcinoma cells.

MiNEN Mixed Neuroendocrine-Nonneuroendocrine Neoplasm - a combination of both neuroendocrine and non-neuroendocrine (usually adenocarcinoma) cancer cells.

NECs are neuroendocrine carcinomas, NET cells that behave more aggressively and are most likely to spread. They behave more like common cancer.

WDNET well-differentiated NETs

PDNEC poorly-differentiated NECs (We talk about differentiation on page 30)

NETs IN CHILDREN

Unfortunately, as with the more common cancers, NETs can also affect children, however, most NETs that do occur in children are usually low grade or benign.

NETs in children are rare, but amongst those that do occur are those with a familial or genetic link - that is a small proportion of specific NETs that do appear to run in families.

NETs that may have a genetic component include MEN 1, 2 and 3 Neurofibromatosis, Familial Pheochromocytomas, Familial Paragangliomas, Medullary Thyroid Cancer and Von Hippel-Lindau syndrome.

If you have a NET that may have a genetic component, for example MEN1, your endocrinologist, alongside an expert geneticist and paediatrician, will usually plan the best way, and time (age of child), to screen your children - and/or other family members.

This involves tests to identify a specific gene that may show whether they are at risk - and if so, from what.

Further clinical screening, including annual CT and MRI scans, blood tests and urine tests, may follow - these can highlight any cause for concern and ensure treatment starts as quickly as needed.

Identifying the relevant gene early is necessary to plan appropriate care and treatment where necessary. Early identification of risk may also help to prevent potential complications for the future.

Specific guidance is in place to ensure doctors follow the correct process and the right Multi-Disciplinary Team (MDT) is in place to support children and their families. Genetic counselling before and after genetic testing for familial neuroendocrine tumour syndromes is vital.

Further information can be found at www.amend.org.uk

SYNDROMES EXPLAINED

A syndrome is a collection of specific symptoms. On page 15 we mentioned functioning vs non-functioning NETs. Functioning NETs often have a specific syndrome (set of symptoms) associated with them, for example, functioning small bowel NETs and Carcinoid Syndrome. Here we will talk through the most common.

Carcinoid syndrome

Carcinoid syndrome is caused when NETs release excessive amounts of certain substances such as hormones and peptides into your bloodstream. The most common substance is serotonin, others include histamine, tachykinins and vasoactive peptides. You're more likely to experience symptoms of Carcinoid Syndrome if you have a primary bowel, lung or ovarian NET or secondary NET in the liver.

Typical symptoms of carcinoid syndrome include:

- Flushing: reddening, usually of the chest and face - though some people may experience a whole body flush. It is usually "dry"- so not usually associated with sweating (as seen in menopausal flushing)
- Abdominal cramps, bloating and "wind"
- Diarrhoea
- Loss or reduction of appetite

- A fast heart rate or "palpitations" - often accompany a flush
- Wheezing
- Stomach and /or abdominal pain
- Tiredness
- Inflammation or irritation of your skin
- Carcinoid heart disease. (See overleaf.)

Managing flushing

Identifying and avoiding the triggers that cause flushing can help to control and reduce the problem. Triggers can include:

- Drinking alcohol and/or caffeine
- Eating large meals and highly spiced foods
- Eating food that contain a substance called tyramine or any foods high in amines. This includes mature, aged or blue cheeses (but not fresh or young cheese such as ricotta, cottage cheese or cream cheese), salted and pickled meats and fish, pickled beans, and certain fruits and vegetables. (More information about food and nutrition can be found in section 5)
- Stress

Some people find that strenuous exercise or the simple act of bending over to pick something up can trigger a flush, others may be unaware that they are flushing until a family member or friend notices and comments on it. Noting when and how often a flush occurs can be helpful in symptom monitoring and treatment.

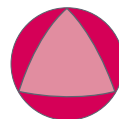
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Carcinoid heart disease (aka Hedinger syndrome or CHD)

Carcinoid heart disease is a syndrome thought to be caused by the hormone serotonin. It affects up to 80% of people diagnosed with carcinoid syndrome.

When NET causes excessive amounts of serotonin to be released, fibrous deposits sometimes build up and engulf the heart valves. This can stop the valves from opening and closing normally, disrupting blood flow and potentially causing breathlessness and severe tiredness. In this situation, heart surgery may be required to replace damaged valves.

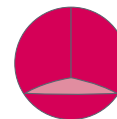
Assessment for the presence or risk of carcinoid heart disease includes checking your serotonin levels - through either a urine collection or blood sample. A further blood test called NT-proBNP is also recommended. You may also have an ECG and echocardiogram at the same time or later depending on results and symptoms. You can find out more about tests starting on page 38.



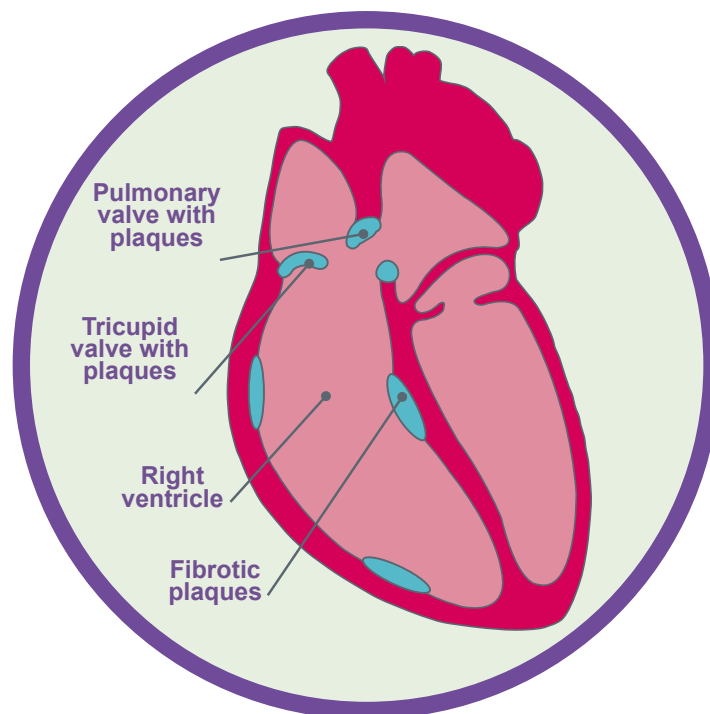
Open valve



Closed valve



Partially open valve



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Clinical hypoglycaemia (aka low blood sugars) - the Whipples Triad

The Whipples Triad: low blood sugar level with low blood sugar symptoms that are easily alleviated by eating sugar or high sugar foods.

This syndrome is usually caused by insulinomas - tumours in the pancreas that cause the hormone insulin to be over-released. Insulin lowers blood sugar levels, and excessive insulin can cause blood sugars to drop too low - resulting in a range of problems.

Symptoms of lowered blood sugars include sweating, hunger, dizziness, looking unusually pale, confusion and irritability. If sugar levels drop too quickly and too low, you can also lose consciousness or have a fit.

It is not uncommon for those with an insulinoma to gain weight - because they've been experiencing symptoms, like hunger and dizziness, and eating more in response (sometimes every other hour to alleviate these symptoms).

Zollinger-Ellison Syndrome (ZES)

ZES can occur when NETs in the pancreas and duodenum release excessive amounts of the hormone gastrin into the bloodstream. Gastrin helps control stomach acid release - this helps to break down starch in food. Symptoms may include acid reflux, heartburn, stomach, or even chest pain, burping, diarrhoea and anaemia (low iron levels).

Excess of gastrin may also cause stomach and/or duodenal ulcers and bleeding. Gastrin levels can be checked using a blood test.

If you're taking drugs called PPIs for problems like heartburn and acid reflux, you might be asked to take an alternative medication or to stop taking PPIs before the test to make sure the results are accurate.

ALERT: You should always talk to your care team before stopping medications.

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WDHA (aka Werner-Morrison Syndrome)

WDHA can be caused by VIPomas, a type of NET found in the pancreas. Symptoms include very watery, frequent and high volume diarrhoea, low levels of potassium in your blood and low levels of hydrochloric acid in your stomach.

It can occur when VIPomas release too much of a chemical called Vasoactive Intestinal Polypeptide into the bloodstream.

Necrotising Migratory Erythema (NME)

Experienced by 80 per cent of people with a pancreatic NET called a glucagonoma. Symptoms of NME include a skin rash that spreads across the body - particularly the face, belly, buttocks and feet. It can crust over and cause blisters, so it's sometimes confused with eczema.

Other symptoms of a glucagonoma include weight loss, diabetes-like symptoms (high blood sugars, excessive thirst and hunger, frequency of urine at night), diarrhoea, blood clots and changes to the skin, nails and hair.

Other syndromes: sites and symptoms

Your NET team will let you know if you have a NET related syndrome and advise you on symptoms and appropriate care. Less common syndromes include:

Somatostatinoma - caused by NETs in the duodenum - symptoms include gallstones, steatorrhoea (pale, greasy, loose stools), anaemia, abdominal pain, high blood sugars and jaundice (yellowing of skin and whites of the eyes).

ACTHoma - caused by NETs in the pancreas - symptoms of Cushing's disease which include weight gain, easy bruising, anaemia, depression, increased risk of infection and darkened skin.

GRHoma - caused by NETs in the lungs or pancreas - may involve symptoms of acromegaly (abnormal growth hormone release causing abnormal growth of bone and cartilage such as enlarged hands and feet).

PTHrPoma - caused by NETs in the pancreas - includes symptoms of hyperparathyroidism - raised calcium levels, abdominal pain, nausea/vomiting, constipation, bone pain, osteoporosis, fatigue, altered mental state and confusion.

Ppoma - caused by NETs in the pancreas - symptoms may include diarrhoea, abdominal pain and weight loss.

STAGING AND GRADING

If you've been diagnosed with a NET, these are two words you'll hear a lot to describe the status of your tumour. So what's the difference between them?

Staging

If a doctor discusses the stage of a tumour, they're talking about where it is and whether it's spread.

The different stages of a NET are classified differently in different countries, and different types of NET have different stages of development - so the stages for a pancreas NET are not the same as those for a lung NET,

But the World Health Organisation's guidelines provide a useful benchmark, using a system of four stages to classify NETs.

Here's an example of the WHO stages for a small bowel NET. All NETs are classified on a similar scale:

Stage I	A solitary NET that's less than 1cm in diameter and hasn't spread to surrounding tissues or anywhere else.
Stage II	A NET [usually more than 1cm in diameter] that has started to spread to nearby tissues or structures, but hasn't spread to other areas of the body or to any lymph nodes (the tiny glands that help to fight infection).
Stage III	A NET of any size that's spread to nearby tissues and structures and to one lymph node.
Stage IV	A NET of any size that's spread to distant areas of the body, like the liver, and to one or more lymph nodes.

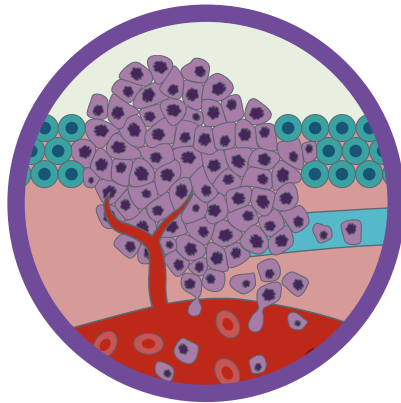
Looking at the staging, grading and function of your NET together enables your care team to understand your particular NET and to recommend the best type of treatment for you.

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Grading

The grading of a NET is based on how cells look under a microscope (differentiation) and how quickly they are dividing to form new, cancerous cells. Your care team will want to grade your NET so they can plan the best treatment for you. To understand grading, you need to know about another important part of classifying NETs - differentiation.

Differentiation refers to what NET cells look like compared to healthy cells. Cells that are well differentiated have some similarities to normal neuroendocrine cells but have started to change in size and shape. They have begun to appear irregular in how they are arranged. Cells that are poorly differentiated have become more abnormal in size and shape, and have a very irregular arrangement.



In general, low-grade tumours have well-differentiated cells and the highest-grade tumours have poorly differentiated cells.

Here's how the World Health Organisation grades NETs:

Grade 1	A NET with well-differentiated cells, less than 3% of which are dividing.
Grade 2	A NET with well-differentiated cells, between 3% and 20% of which are dividing.
Grade 3A*	A NET with well-differentiated cells, more than 20% of which are dividing.
Grade 3B*	A tumour that's called a neuroendocrine carcinoma (NEC) rather than a NET, which has poorly-differentiated cells, more than 20% of which are dividing.

* The latest evidence and guidelines suggests that Grade 3 tumours might soon be divided further - with one category for those with 20-55% of cells dividing and another for those with 55% or more cells dividing. This could play a vital part in helping your care team recommend treatments, so they'll keep you up to date with any new developments.

What's Ki67? Or Mitotic Index?

You might see Ki67 or Mitotic Index mentioned in your clinic letters or medical reports. They are the most common ways of describing how quickly cells in your NET are dividing. So, for example, Ki67<2% or mitotic index of 2/10HPF means less than 2% of cells are dividing, both would be Grade 1.

NET COMPLICATIONS

In medicine, a complication means an additional problem that occurs as a disease develops. There are serious complications that may occur as a result of NETs - these require urgent medical attention.

Carcinoid crisis

This is a very rare escalation of carcinoid syndrome (which is explained on page 25). Carcinoid crisis can be life threatening, and can happen either for no obvious reason or, more usually, as a result of an anaesthetic, tests - such as a biopsy, or surgery or other treatment.

These triggers can cause an excess of hormones and chemicals to be released into your blood. This can affect your blood pressure (usually causing it to drop), your heart rate (usually causing it to get quicker), and cause flushing, wheezing and potentially loss of consciousness. Those who have experienced a "crisis" liken it to a severe allergic reaction and panic attack / collapse combined.

Your care team should be aware of the risks and symptoms of carcinoid crisis.

Depending on the type of NET you have, your symptoms and the potential risks of any procedure you're having, you might be given "Carcinoid Crisis Prophylaxis". This is usually an infusion (IV drip) of a drug called Octreotide given according to expert recommendation. (UKINETs bitesize guidance: www.ukinets.org)



If you have carcinoid syndrome or have been told you are at risk of carcinoid crisis you can obtain one of these wallet cards by contacting the NET Patient Foundation by phone 01926 883487 or email hello@netpatientfoundation.org

Heart valve fibrosis or Carcinoid Heart Syndrome

As previously described on page 26 - carcinoid heart disease is where fibrous deposits can affect the heart valves.

Fibrosis

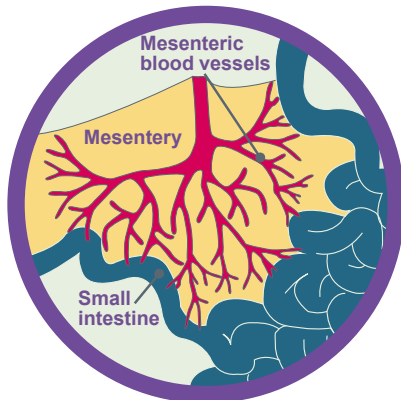
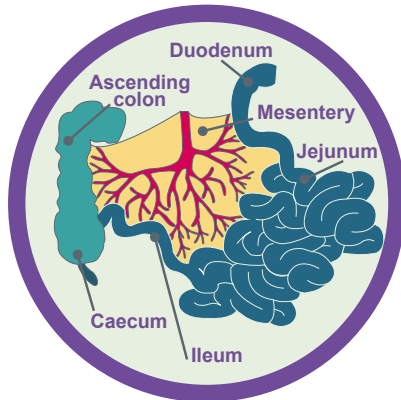
Fibrosis describes the process of connective tissues repairing themselves after they've been injured or damaged. If too much of this tissue builds up it can cause problems by blocking blood vessels and other structures in your body.

With NETs, fibrosis is more likely to occur due to the hormone serotonin being released by a NET and how this is broken down in your body.

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Mesenteric fibrosis (aka Desmoplasia)

The mesentery is a fold of tissue that attaches organs to the body wall. The small bowel mesentery, anchors the small intestines to the back of the abdominal wall. Blood vessels, nerves, and lymphatics branch through the mesentery to supply the intestine.



Fibrosis can cause bands attached to the small bowel to gather up – much like pulling a loose thread can cause material to gather up – causing twists and kinks in the small bowel. This fibrous matting of tissue (medical term is desmoplasia) can cause a partial or complete blockage of the small bowel.

Other parts of your abdomen - including blood vessels and the tubes that link the kidney to the bladder - can also be affected. This can affect blood flow, in severe cases causing healthy small bowel cells to become damaged or die. If your NET started in your small bowel or duodenum, you might also develop mesenteric masses (these are usually clumps of NET affected lymph nodes). This can happen even if your primary tumour is very small.

In fact, these mesenteric masses might be more noticeable on scans than the primary tumour - that's often because of the tethering effect or desmoplastic reaction around them.

Symptoms of mesenteric fibrosis can be similar to those of complete or partial bowel obstruction and include:

- Abdominal pain
- Nausea/vomiting
- Bloating
- Loss of appetite
- Diarrhoea or constipation
- Blockage of the tubes that connect your kidneys to your bladder (ureters).

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Treating mesenteric fibrosis

Preventing mesenteric fibrosis can be difficult, because it's often already a problem by the time a NET is diagnosed.

Treatment might focus more on helping you cope with any symptoms you are experiencing, rather than intervention - surgery is often not possible, or effective.

Insertion of a stent to alleviate a blockage, caused by fibrosis compressing either your ureters or bowel, may help. However, ureteric stents will need regular review and replacing, and bowel stents can be difficult to insert, stay in place and can be less effective than other stents.

Medications including somatostatin analogues (see section on Treatments) can help to control the amount of serotonin released into your blood, to help prevent or delay further fibrosis developing. Other medications can be used to help maintain the blood flow in your small bowel. Pain relief, anti-sickness treatments may also be used, along with other medications and dietary adjustments to minimise the risk of bowel obstruction.

Never ignore acute abdominal pain. Make sure you mention it to your care team - even if the symptoms ease off.

If you have a small bowel NET and are experiencing pain with nausea and vomiting, it could be sign that your bowel may be blocked. Bowel obstruction is a medical emergency and requires urgent medical attention.

If you have a small bowel NET or have been told you are at risk of bowel obstruction you can obtain one of these wallet cards by contacting the NET Patient Foundation by phone – **01926 883487** or email – **hello@netpatientfoundation.org**



TELLING YOUR DOCTORS ABOUT YOUR HEALTH

After a while your medical appointments might start to feel like Groundhog Day: The same questions: The same faces: And confusion over who you've told what.

But letting your care team know about your overall and long-term health, along with how you're feeling now, is a vital part of getting the right diagnosis and care. It helps to ensure the right tests are done, and can guide decisions not only about which treatments are right for you, but also about whether you need treatment at a particular time.

It's really important that you tell your doctors as much information as possible about your health - especially if anything changes. And that's where this section comes in.

On the following fold out page there are two parts - one with space to describe any problems you're currently having and another to note down information about your general health.

It can be easy to forget things or to feel nervous during an appointment, so it might help to write things here beforehand and take this section with you.

1. If you have an issue you'd like to discuss:

What's the problem, in detail?	Don't be embarrassed – something like diarrhoea can have all kind of causes, and knowing what colour or consistency it is can help doctors to make the right diagnosis.
How bad is it? How sharp is any pain?	How severe is it? Again, detail is good.
Has it spread or moved?	This can be useful for pain or rashes.
Is it linked to other issues?	For instance, does diarrhoea lead to flushing? This can be a sign of carcinoid syndrome.
When does the problem happen?	Is it constant or intermittent? Does it happen at certain times of day?
What makes it better or worse?	Think about anything you've been doing to manage the problem.

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Information about your health and lifestyle - having this written down (or typed up) and photocopied can help alleviate the need for you to have to repeat this information over and over again - you can simply hand over the photocopy! NB make sure you update it if details such as medications change.

2. Medical history

Have you had any health problems? Do you still have them? How long for? How have they affected you? Are you able to manage them? Do you have any conditions that could affect tests or treatments - for instance do you have a pacemaker or any metal pins in your body or have you had previous surgery?

3. Family history

Think first about your parents, brothers and sisters and children, and then about your aunts, uncles and cousins. Are they all alive and well? Do any illnesses run through your family? If family members have died - do you know whether they had a similar illness to you or something else? If so what? How old were they?

4. Medications

Are you taking any medicines - from aspirin to prescription drugs to herbal remedies, homoeopathy, Chinese medicines to supplements? How long have you taken them for? What dosage do you take and how often?

5. Your lifestyle

Do you smoke, drink or take drugs (prescribed, over-the-counter, illicit, herbal remedies and / or supplements)? Do you have tattoos? Do you exercise - How active and mobile are you? Do you eat healthily? What's your job - are you self-employed? Have you got friends or family who can help during a hospital stay? Are you a parent, a carer or do you have pets who will need to be looked after should you need to come into to hospital for even a short time or need time after treatment to recover?

6. Anything else

Do you have concerns or questions about anything at all? Write them down to avoid forgetting them.

NB Doctors often use a systematic approach in assessing their patients - if you write down a list, in order of what's important to you or which symptoms affect you most - and share this with them, it can help make the most of your consultation

If you're in a busy clinic, it can be easy to worry about taking up a doctor's time. Try not to!

That appointment time is yours to make the most of.

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WHICH TEST IS THAT?

Before and after you're diagnosed with a NET, tests become a regular part of your life. Here's what's likely to happen and why.

Identifying NETs isn't straightforward. The tumours are often small, starting out the size of a grain of sand and often not visible to the most accurate scans until they get to about half a centimetre across or the size of a pea.

They can occur in various parts of your body and spread to different places too, so finding them and identifying where they started can, on occasion, be difficult.

Because of this, you may well have a number of tests before your NET diagnosis is confirmed - including specialist tests to ensure the evidence is conclusive.

Once you have a diagnosis, some of the tests you have undergone will be used to monitor your health and the effects of your treatment.

Common NETs tests explained

In this section we've listed the main tests used for diagnosing and monitoring NETs. You may have other tests as well, either to prepare you for treatments or to investigate the cause of an unexpected problem. Whilst many of these tests will be available at your local hospital - some blood and urine samples might need to be sent to a specialist lab or you might need to travel to a specialist centre to undergo others - such as certain scans.

The most important thing to remember is that if you have any questions or concerns about tests, ASK!

It's important to chat to your care team about anything that's on your mind.

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Types of tests

Laboratory tests

Blood tests

Various blood tests are used to help diagnose NETs and to see how you're responding to treatment. Some can be done at GP's surgeries, others need to be done in hospitals or specialist treatment centres.

Your care team will let you know what to expect before any blood test.

Fasting gut hormone profile

This is a blood test to help diagnose NETs, and in particular to find out if excess gut hormones and chemicals are being released into your bloodstream. It can help to confirm if you have a NET and identify where it might be.

You'll need to drink only water and avoid food for six hours beforehand. You can keep taking most medications as normal and do everything you usually do afterwards, but please check for any exceptions with your care team.

Chromogranin A and B

Chromogranin A and B are proteins, often released by NETs. Doctors can test for them using the same sample that's taken for a gut hormone profile, but there's also a separate test for chromogranins alone, for those who do not need a gut hormone test, that doesn't involve fasting beforehand.

High levels of chromogranins in your blood can indicate a NET, but they can be caused by other conditions too.

Results typically take a few weeks to come through, and you may need to have a follow-up chromogranin A and B test to help your care team gain a clearer picture of exactly what your situation is.

NB It is not unusual for chromogranins to alter slightly - rise or fall by about 10% - between checks. This does not necessarily indicate a change in your NET - and could be due to something as simple as the time of day the blood sample was taken.

Please note that the laboratory tests for NETs are not 100% - there are other conditions that may cause unusual results or alterations - also your NET may not cause any irregularities in your blood or urine, so a normal result may not mean you don't have a NET.

However, they are incredibly useful, in combination with other tests, to lead to an accurate diagnosis - and, if abnormal - can be useful as a monitoring tool over time and during/after treatment.

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Other, including common blood tests, you may have are:

Full blood count, which measures the red blood cells, white blood cells and platelets in your blood, and can help your care team measure your general health and check for problems like anaemia.

Iron, B12, ferritin and folate, which can check for and monitor certain types of anaemia.

Kidney function test, which measures waste products, salts and potassium in your blood to show how well your kidneys are working.

Calcium, corrected calcium and vitamin D, which can measure your bone health, monitor calcium levels and identify causes for some symptoms related to NETs.

Liver function test, which measures enzymes and proteins produced by the liver to check how well your liver is working.

Pituitary hormone screen, which measures levels of hormones to show how your pituitary gland is functioning.

PTH and blood calcium, which can be used a screening test for MEN-1 syndrome (see page 15 for more about MEN).

Calcitonin, which checks for a hormone that can be released by thyroid NETs.

NT-proBNP, which checks for signs of carcinoid heart disease (there's more about carcinoid heart disease on page 31).

Thyroid function test, which assesses the condition of your thyroid by measuring levels of various hormones. Identifying if an overactive or underactive thyroid is related to a NET can help to determine the best treatment.

This isn't an exhaustive list. Your care team can let you know about any other blood tests you might need and answer any questions you've got.



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Urine test

If your doctors suspect you have a NET or want to assess the growth or development of a NET, you'll be asked to do a urine test to check for an acid called 5HiAA.

Why is it done?

Bowel NETs, atypical lung NETs, Ovarian NETs and NETs in your liver can all produce high levels of the hormone serotonin, and 5HiAA is produced when serotonin is broken down in your body.

So by testing for 5HiAA, doctors can work out the level of serotonin in your body and help to identify and find out about NETs. The test can also be used to identify if you have carcinoid syndrome (which is explained on page 25).

NB as with blood tests, Urinary 5HiAA on it's own, is not completely diagnostic - and levels can be altered by other conditions or even certain foods!

What's involved?

The test involves collecting your urine over a 24-hour period in a bottle that contains a powdered acid, so keep the bottle safe beforehand and handle it carefully.

To avoid skewing the result, you'll need to avoid eating and drinking certain foods for 24 - 48 hours beforehand and during the 24 hour collection - mostly things that contain serotonin or amines.

The most common ones are:

- Alcohol
- Aubergine
- Avocado
- Bananas
- Brazil nuts
- Cashew nuts
- Chocolate
- Coffee
- Kiwi fruit
- Olives
- Pineapple and pineapple juice
- Plums
- Seville oranges
- Tea
- Tomatoes
- Walnuts

You'll also be asked to avoid taking some cough, cold and flu medicines for up to a week beforehand. Your care team will let you know more about that.

You don't need to avoid these foods and drinks permanently - just before and during the 5HiAA test.

Some NET centres are now using a quicker way of measuring 5HiAA, which doesn't involve collecting urine over 24 hours.

They can use a random urine or blood sample, which can be done on the day of your appointment - which doesn't need you to avoid any foods, drinks or medications.

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Checking on the heart

Electrocardiogram (ECG)

Why is it done?

An ECG is used to gather information about your heart. It's often used if you have a history of heart problems or to check your health before treatments such as surgery.

What's involved?

An ECG is a simple test that might be carried out in hospital, at a clinic or at your GP surgery.

Sticky sensors called electrodes are stuck to your chest, arms and legs and attached to an ECG machine that records your heart's rate, rhythm and electrical activity (the signals the heart uses for each heartbeat).

Echocardiogram

Why is it done?

Often shortened to 'echo,' an echocardiogram is an ultrasound of the heart.

It enables doctors to look in detail at the structure of the heart, and in particular at the heart valves. It can also measure how well the heart is pumping.

Doctors often recommend an echo if they suspect you might have carcinoid heart disease (which you can read about on page 26), or if you or someone in your family has a history of heart problems.

If problems with heart valves are identified early enough, action can be taken in response - such as discussing with you the use of somatostatin analogues or the possibility of needing heart surgery to replace damaged valves. If you do have damaged valves you may need these treated before it is safe to go ahead with some of the treatments for your NET.

What's involved?

There are several ways to carry out an echo, but the most common is to first have sticky sensors called electrodes attached to your chest as you do in an ECG. These measure your heart rhythm during the test.

An ultrasound probe is then moved across your chest to create a picture of your heart using sound waves. A gel is used, either on your chest or on the probe, to create the clearest possible images. The test usually lasts between 15 and 60 minutes.

Cardiopulmonary Exercise Test (CPEX or CPET)

If you are being considered for surgery and there are concerns about your heart and/or lungs you may be asked to undergo CPEX or CPET. This test measures the response of the heart and lungs to exercise, on a stationary bicycle. Exercise capacity has a big influence on the need for support of the major body systems during and after an operation. The results will guide the anaesthetist, surgeon and other doctors in how to best support you,

Scans (aka Imaging)

Scans are done to create 2D and 3D images of NETs and the areas around them. Some are done in radiology departments, others in nuclear medicine departments.

Radiology scans

Ultrasound scan

Why is it done?

An ultrasound scan is a painless test that uses sound waves to create images of organs and structures inside your body. It is a very commonly used test. As it uses sound waves and not radiation, it is thought to be very safe. Certain US scans are used to look at blood or fluids flowing through the body.

An ultrasound might also be used to check for gallstones, which can be a risk if you're given somatostatin analogues as a treatment (see page 70 for more about those).

What's involved?

You'll usually be asked not to eat or drink anything for six hours before an ultrasound to make sure the picture is as clear as possible. NB you may not need to do this if you have had your gallbladder removed OR if you are diabetic - please check with the department beforehand.

Before the scan, a gel is spread on the area to be scanned. A hand-held ultrasound scanner is then gently pressed on the area, creating high-frequency sound waves that help to build a real-time picture of your internal organs on a nearby screen.

CT scan

Why is it done?

By taking pictures of the inside of your body from a variety of angles, a CT scan (also called a CAT scan) can build up a very detailed picture of the location and size of your organs and the structures around it. They are used to check for abnormalities such as a tumour or enlarged lymph nodes.

Regular scans can also help to track whether a tumour is growing or not, whether new tumours are developing and how well your body is recovering after treatment for example after surgery.

What's involved?

During the scan you lie on flat bed that slides slowly backwards and forwards through a large circular machine. The scan usually takes around 15-30 minutes, and you'll need to lie still for that time. The technician running the scan will be in a separate room, but you'll be able to speak to them through an intercom.

Depending on which area of your body is being scanned, you may need to drink a liquid or have an injection beforehand to help increase the contrast of the scan. And you may need to avoid eating and drinking for a set time in preparation - check beforehand if you haven't been given any information.

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MRI scan

Why is it done?

Like a CT scan, an MRI scan builds up a detailed picture of the organs and structures of the body using a series of cross-sectional images. The difference is that an MRI uses magnetic fields and radio waves to take pictures and a CT scan uses X-rays.

ALERT: the scan uses magnets so please tell your care team BEFORE an MRI is asked for if you have a pacemaker or any metal pins or plates in your body - an alternative form of imaging may be required for you.

For some tumours and some parts of the body, a CT scan produces clearer results. For others, an MRI scan is the preferred option. An MRI is particularly good at showing the liver, brain and spine.

What's involved?

An MRI scanner is a large tube, and throughout the scan you lie on a flat bed that's moved inside the tube - lying either head first or feet first, depending on which part of you is being scanned.

The scan usually lasts between 15 and 90 minutes. The scanner is operated by a radiographer in a separate room, who you'll be able to talk to throughout the scan. They can see you through a TV screen too.

It can be noisy, so you'll probably be given headphones or earplugs to block out the banging and tapping sounds.

Some people do find being inside an MRI scanner claustrophobic. If you're worried, make sure you chat to your care team beforehand and let the radiographer know how you're feeling. There's nothing to be embarrassed about and people can only help if they know of your concerns.

NB You may be able to go in feet first regardless of which part of you is being scanned, which can help minimise claustrophobia. Unfortunately only a few centres have open MRI scanners, so you could ask about that too.

Nuclear medicine scans

You might also hear these called 'functional' scans. Substances, called radioactive labelled tracers or isotopes are used, that have attractions to certain tumour cells, to create images that can help diagnose and monitor NETs. Although a radioactive tracer is used during functional scans, the amount of radiation that you are exposed to is low and it is usually short-lived. It is not enough to affect the normal body processes. However, there are risks due to the tracer:

- The radioactive substance may expose radiation to the foetus of a pregnant woman or to the infant of a woman who is breastfeeding. If you are pregnant or breastfeeding, please tell your doctor
- There is a very small risk of an allergic reaction to the tracer.

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Octreotide scan

Why is it done?

NET cells sometimes have receptors, on their surface, that attract a substance called octreotide. By injecting you with a radioactive octreotide 'tracer' and using a scanner that detects this tracer, doctors can follow the path of the octreotide and see if it gathers in a particular place. If it does, it means that the octreotide has latched onto the receptors of a NET.

However, they won't show up every NET, because not all NETs, especially the high-grade poorly differentiated ones have the receptors needed to attract octreotide.

What's involved?

An octreotide scan takes place over two days. On the first day you're given a small injection of the radioactive octreotide tracer. Around four hours later, once the tracer has spread through your body, you have a scan lying down for around 90 minutes. The following day you have another scan.

You'll need to lie as still as possible during the scans, and might be asked to lie with your arms above your head or at your sides to get the clearest picture.

After the scans, make sure you drink plenty of water to help flush the tracer out of your system.

mIBG scan

Why is it done?

mIBG scans are similar to the octreotide scan described above but use a different radioactive tracer "mIBG" (iodine-123-meta-iodobenzylguanidine). Although it can be used for all NETs, it is best reserved for the diagnosis and monitoring of pheochromocytomas and paragangliomas due to the mIBG tracer attraction to these particular tumours.

What's involved?

Just as you do with an octreotide scan, you have an injection of a tracer (in this case mIBG) and then two scans - one later that day and one the next day.

The main difference with an mIBG scan is that because some of this tracer can be absorbed by your thyroid gland you'll also need to take a substance called Lugol's iodine on the day before the injection, the day of the injection and the next day, to stop this happening.

PET scans

There are two main types of PET scan used to investigate and monitor NETs - FDG-PET and Gallium-PET. Currently, many PET scanners also include a conventional computed tomography (CT) scanner. This allows images of both anatomy (CT) and function (PET) to be taken during the same examination. Not all UK hospitals have PET scanners, so your nearest one may not be close to home.

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FDG-PET

Why is it done?

A PET scan uses a small amount of a radioactive drug, or tracer, to show differences between healthy tissue and diseased tissue. The most commonly used tracer is called FDG (fluorodeoxyglucose), so the test is sometimes called an FDG-PET scan. Before the PET scan, a small amount of FDG is injected and because cancer grows at a faster rate than most healthy tissue, cancer cells absorb more of the FDG. The PET scanner detects the radiation given off by the FDG and produces colour-coded images of the body that show both normal and cancerous tissue.

What's involved?

You will be given detailed instructions on how to prepare for your scan. As a rule you will be advised not to eat anything for 6 hours prior to your scan but you should continue to drink water. It is advisable to wear loose comfortable clothing.

Before your scan, you will be given an injection of the radioactive tracer drug. The tracer takes around an hour to spread through your body. Once that's happened, you'll be asked to lie on a scanner. The scan takes around an hour, and you'll need to lie as still as possible during that time.

68Ga-DOTATATE PET/CT

Why is it done?

68Ga-DOTATATE PET/CT scans use the radioactive tracer Gallium-68, rather than the FDG-18 previously described. Scans with Gallium-68 take less time, than Octreotide scans, require less tracer, produce results more quickly and create a more detailed picture of how a NET is developing and what it looks like.

68Ga-DOTATATE PET/CT has been reviewed and evaluated as the most sensitive exam to detect well-differentiated NETs. It is rapidly replacing Octreotide scans in specialist NET centres due to its improved accuracy, sensitivity, shortened time, less tracer and lower allergy risk.

What's involved?

Having a Gallium-68 scan is similar to having an FDG-PET scan. The main difference between the PET scans is the uptake according to tumour activity - FDG is more sensitive for high grade NETs, Gallium68 is better for low to moderate, and well differentiated NETs.

You will be given detailed instructions on how to prepare for your scan. A general rule is to not eat anything for at least 4 hours before the scan. You will be encouraged to drink water. If you are receiving somatostatin analogues you may be advised to alter the day (or time if on short-acting) you have this injection.

You will receive the tracer injection prior to your scan, this tracer can take up to an hour to spread through your body. Once that's happened, you'll be asked to lie on a flat bed, which is moved into a circular scanner. The scan takes up to an hour, and you'll need to lie as still as possible during that time.

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Bone scan

Why is it done?

Bone scans are used to check on your bone health. It's not a routine test for NETs, and will only usually be done if you've had a history of bone problems such as osteoporosis, or if your care team suspects a NET may have spread to your bones.

What's involved?

Before having a bone scan, you're injected with a very small amount of a radioactive substance called a radionuclide. This tends to collect in areas where there is a lot of activity in the bone, and this activity shows up on a bone scanner. It can suggest that bones are damaged or repairing themselves, for example a healing fracture, as well as helping to assess bone density (a measure for assessing osteoporosis).

After the injection, you'll then need to wait for a few hours while it works its way through your body and into your bones. Having plenty to drink during this time will help, and taking an iPad, magazine or book with you is a good idea to help you pass the time.

Once the radionuclide has spread, you'll need to lie on a flat bed while a scanner called a gamma camera takes pictures of the whole of your skeleton. Your body goes through the scanner, so let your radiographer know if you feel claustrophobic. The scan can take up to an hour.

If the radionuclide does gather in one place, that doesn't always mean a NET has spread to your bones. It could suggest osteoporosis, a new fracture (or break in the bone) or an old fracture that is either repairing itself or has healed.

Endoscopy

Why is it done?

Scans take pictures of your insides from outside your body. As detailed as they are, they don't always give a full view of what's happening inside the hollow organs of the body - for example if doctors want to see inside your airways, stomach or bowel.

In situations like that, endoscopies and endoscopic ultrasounds can be very useful. They can pick up problems - in places like the stomach and duodenum - that can be difficult to assess accurately on an MRI or CAT scan. And they mean your care team may be able to take tissue samples through the endoscope.

What's involved?

During an endoscopy, a long, thin, flexible tube with a light and a video camera at one end (the endoscope) is used to transmit footage of the inside of your body to a TV screen. (In an endoscopic ultrasound the tube includes a small ultrasound probe). The endoscope, can be fed into your body through your mouth or nose (to look at your oesophagus, stomach and duodenum or to look at your lungs) or via your rectum (to look at your large bowel)

The test can take up to an hour, and while it might sound unpleasant, it's usually only slightly uncomfortable, rather than painful. You might be given a local anaesthetic to ease any pain or a sedative to help you relax, and your care team will let you know if there's anything you need to do to prepare for the test, like not eating for a while for the upper scope or taking a preparation to help clear your bowels for the lower scope.

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As with any test, if you're worried, don't keep it to yourself. Your care team will have a lot of experience of helping people cope with anxieties, and will have ideas that could help - like visiting the relevant department beforehand so you know what to expect.

Which endoscopy is that?

Bronchoscope looks inside the lungs and airways.

Endobronchial ultrasound (EBUS) looks inside the lungs and airways. (See picture below.)

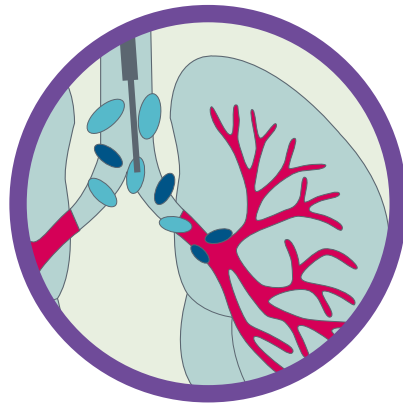
Endoscopic ultrasound (EUS) looks at the duodenum and pancreas.

Gastroscope looks inside the oesophagus, stomach and duodenum.

Colonoscope looks inside the large intestine.

Sigmoidoscopy looks inside the lower large intestine.

Rectal endoscopic ultrasound looks at the lower part of the large bowel.



Wireless capsule endoscopy or Video capsule endoscopy (WCE or VCE)

Why is it done?

Capsule endoscopies give doctors a detailed, end-to-end look at your small bowel, which is one of the most difficult parts of the gastrointestinal tract to examine because of where it is, its length and complex shape. As such, WCEs/VCEs are particularly valuable for diagnosing small bowel NETs.

What's involved?

It might sound like science fiction, but if your doctor recommends this test you'll swallow a capsule the size of a large vitamin pill that contains a colour camera, battery, light source and transmitter.

The camera then takes photos every second for eight hours and sends them wirelessly to a data recorder that you wear attached to a belt. The information from the recorder is uploaded to a computer for analysis.

You might be asked not to eat for a specific period before the test. Afterwards, the capsule comes out naturally when you open your bowels, and does not need to be retrieved.

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Tissue sampling (aka biopsy or histology)

To monitor your treatment or a suspected NET, your care team might want to take a small piece of tissue, a collection of cells or some fluid from your body so it can be studied for the presence of cancer cells under a microscope.

Why is it done?

Studying tissue under a microscope is often the only way to be absolutely sure of a cancer diagnosis. It can give clues about where a cancer started, what kind of cancer cells exist and how quickly they are multiplying. This knowledge can help doctors to recommend the best treatment.

What's involved?

There are various ways of taking tissue samples. The most common ones for NETs include biopsies, VATS, FNAs and BALs.

A biopsy is a medical procedure that involves taking a small sample of body tissue so it can be examined under a microscope. A tissue sample can be taken from almost anywhere on or in your body, including the skin, organs and other structures.

The term "biopsy" is often used to refer to both the act of taking the sample and the tissue sample itself.

A **VATS (video-assisted thoroscopic surgery)** is a surgical procedure used in the chest and lungs. VATS uses a special instrument called a thoracoscope.

This is a thin, tube-like instrument which shines light from the end inserted into the patient. It also transmit's images

back to an eyepiece or video display so the surgeon can see into the chest cavity. It is a type of 'keyhole' surgery where only very small cuts (incisions) are made in the chest wall near the ribs. The surgeon inserts the thoracoscope through one incision and special surgical instruments into the other incisions. These instruments can be used to remove a sample of the tissue to be examined. Once the surgery has finished, the instruments are removed and the incisions are closed, usually with stitches. These samples can then be looked at under a microscope.

A **FNA (fine-needle aspiration)** is another type of biopsy but may involve fewer cells being taken. A very thin, hollow needle is gently inserted through the skin into the lump or affected organ below. Often there is a syringe attached to the needle. The doctor can use the syringe to help 'suck' some of the cells into the needle by gently pulling on the plunger. Usually, the test can be done without the need to make a cut in the skin or via an endoscope.

If the lump being tested is very small it might be necessary to use a scanning machine to help guide the needle to the right place. This may be done by an ultrasound scan, endoscope or CT scan.

A **BAL (bronchoalveolar lavage)** is used to try to obtain cells from your lungs. It's done via a bronchoscopy (an endoscopy to look inside your lungs). Fluid is squirted into the specific part of the lung to be assessed and then recollected for examination under a microscope.

GETTING YOUR TEST RESULTS

Finding out if you have a NET, how it's behaving over time or whether treatment is working can be stressful, especially if you've had to wait a while for results. But planning ahead for results day can help you prepare.

As much as we'd all like test results straight after a test, it takes time. As a rough guide, blood test results can take between one day and eight weeks to come back, scans reports can take one to three weeks and the results of a biopsy can take up to three weeks to come back (though it rarely takes this long unless additional tests on the sample are required). Your care team will give you a better idea of exact times for your results.

As soon as your scan and/or histology results are available, your NET care team will then review them at a specialist meeting and consider which treatments could work best for you. This usually occurs before you have a results appointment with your consultant to discuss what's been discovered, so that you can also talk through treatment options.

Please don't forget.... whatever news you receive - it's that the conversations should always be two-way.

No appointment should involve you only being a passive listener. A big part of meeting with your doctors is to make sure you get the information you need to understand what's happening, so you can make the right choices about your treatment.

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We know that speaking up can be easier said than done, of course, especially if you're feeling nervous or confused or you're struggling to comprehend what you've just heard. But hopefully these suggestions might help you to get more out of the conversation.

- **Prepare a list of questions** to help you remember what you want to find out
- **Take someone with you** to your appointment to help you remember what's said and to ask questions with you. If that's not possible, you can always ask a nurse to come to the meeting with you
- Ask if your consultant is happy for you to **record the conversation** on your phone, so you can listen back later to check you've understood and haven't forgotten anything. Make sure you download an app beforehand if your phone doesn't have a record function
- If any medical language confuses you, **ask for a simple explanation**. Your doctors want you to understand what's happening, and may use NETs jargon without even realising they're doing it
- **Ask for a copy of any letters** that your NET specialists are sending to your GP or care team
- If you have a Clinical Nurse Specialist - **keep in touch**. Use them as a sounding board for concerns, to answer questions and / or explain anything you're having difficulty with
- Remember that you can always **call back after your appointment** to clarify anything you've not understood. It's your health, and you're the boss.

Remember - appointments should always be a two-way conversation: it's an opportunity to exchange information and learn - for both you and your care team.



USEFUL QUESTIONS FOR YOUR RESULTS APPOINTMENTS

About your results

Diagnosis

- Do I have a NET?
- Which part of my body is affected?
- Is the NET growing? What grade is it? What stage? What does this mean?
- What can I expect from this diagnosis - what effect might my NET have on me?
- Who is my main point of contact?
- Who can I call with any questions?
- Will I have a clinical nurse specialist to support me?
- Is it likely that my NET will spread?
- Will I need to have any more tests?
- Have you any written information I can take home with me?
- Who will be involved and who will lead my care?

After treatment or monitoring

- How is my NET? Has it changed?
- What does this mean for me?
- If on treatment - does this affect my treatment? How?
- If not on treatment - do I need to start treatment? If so what? And when?
- Will this mean a change in care team?
- If so, do I still have access to my nurse specialist/point of contact?

About next steps

- What will happen next and when?

About the team

- Am I at a Specialist NET centre / clinic ?
- If not, has my case been discussed by a specialist NET-specific Multidisciplinary Team (MDT) ? (NB We talked about Getting the Right Care on page 9)

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About treatments

- What treatments are most suitable for me and my NET? Do I have to have treatment?
- What is the aim of treatment?
- What are the possible side effects?
- How could the treatments affect my everyday life? - short-term and long-term
- What do you hope the impact of treatment will be?
- Will I be able to keep working during treatment? Or do I need to arrange time - off (e.g. for surgery and recovery)?
- How will I be involved about decisions about my treatment?
- Can I choose where I go for treatment?
- Can I get a second opinion about my treatment?

Depending on where you are along the diagnostic or treatment route, one or two of several things could happen at your results appointment:

Diagnosis

You might be told that your tests results have confirmed the diagnosis or that more tests are needed.

If confirmed you may then have a discussion about what treatment options there are. You will not be expected to decide that day and should be given some time and written information to help you make a decision on what option to take, if any.

After treatment or monitoring

You might be told that things are stable, which means there's been no significant change in your condition. That's not necessarily a bad thing, and in fact can be a very good thing if it means your treatment has helped to get your NET under control.

You might be told that things have improved, for instance if surgery has successfully removed all or part of your NET or your treatment has caused the tumours to shrink or become less active.

Or, unfortunately, you might hear news that isn't what you'd hoped for - that your NET has continued to grow or spread despite treatment. You may even be told that new tumours have been identified.

It's never easy if the news is bad. Some people have said that receiving this news is almost as bad, if not more so, than the original diagnosis. Others, a kind of relief, as they have felt that something was not right and this explains that feeling.

Just as with the diagnosis, you might feel like you just want to be on your own, that you can't hear anymore at that time, - it's often hard to take in what you're being told. Reactions like that are totally natural and, as we've said before, there's no right or wrong way to react. Allow yourself time and even if you have left the consultation, don't be afraid to come back to your team to re-discuss things, as and when you need to. It may be that a different treatment is possible, that may be more effective (it's not always easy to predict response or tumour behaviour). It may be that available treatment is limited to helping alleviate symptoms only.

For more information about any of the NETs described in this handbook, you can:

- talk to your care team,
- call us on 0800 434 6476
- email our nurse team - nurses@netpatientfoundation.org and / or
- visit our website: www.netpatientfoundation.org



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TREATMENTS EXPLAINED



**TREATMENT
ONLY STARTS
WITH YOUR
CONSENT**

TREATMENTS EXPLAINED

In the UK there are guidelines that recommend a **Multi-Disciplinary Team (MDT)** should treat people with cancer, thus several experts together decide on the best treatment plan rather than relying on a single opinion.

Throughout this book we talk about a care team which ideally would include a NET specialist team and other clinical staff who may not be part of the MDT. **Your NET specialist team** (or MDT) is made up of a group of specialists with expertise in NETs. The joint discussions they have are called MDMs (Multi-Disciplinary Meetings). The outcome of an MDM will be discussed with you at your treatment planning appointment.

Because NETs are rarer cancers, your MDT may not be based at your nearest hospital, this can mean that it may take a little longer than you'd like to get results or see your treatment plan. But try to bear in mind that the MDT approach is designed to put you in the best possible position, and do let your doctors know if you have any concerns.

Who's who?

There are many different experts who could play a part in your MDT.

Here's who they are and what they do:

Consultant/Lead Clinician

A senior medical or surgical specialist in a particular area of medicine or surgery - such as an endocrinologist or gastroenterologist.

Clinical Nurse Specialist (CNS)

An expert nurse who helps to plan and carry out your treatment and is often the link between all of the other members of the MDT. Your CNS is there to talk through whatever is on your mind, including any concerns, and can help you and your family to understand your diagnosis, what's planned and what's expected.

Endocrinologist

A consultant specialist in diagnosing and treating illnesses involving endocrine glands and hormones.

Gastroenterologist

A consultant specialist in diagnosing and treating illnesses in the gastrointestinal system (such as stomach and bowel problems).

Surgeon

A consultant surgeon with expertise in the surgical treatment of particular diseases and body systems. For example, a pancreatic surgeon would be consulted for treatment of diseases - including cancer - of the pancreas.

Oncologist

A specialist in diagnosing and treating cancer.

- A medical oncologist diagnoses and treats cancer using chemotherapy and other drugs but doesn't use radiotherapy

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- A clinical oncologist diagnoses and treats cancer using chemotherapy and other drugs and does use radiotherapy.

Nuclear Medicine Physician

A consultant specialist in nuclear medicine scans and treatments.

Radiologist

A consultant specialist in radiology scans and treatments.

- A diagnostic radiologist interprets scans to understand more about your NET and the surrounding area
- An interventional radiologist specialises in treatments carried out within the radiology department such as radiofrequency ablation. (You can read more about these in the treatments section starting on page 72.)

Most radiologists involved in specialist MDTs are both diagnostic and interventional experts.

Pathologist / Histopathologist

A specialist in examining cells, body fluids (urine, blood, etc) and tissue samples for evidence of disease to confirm diagnosis.

Dietician

An expert in diet and nutrition who can help you to eat healthily after being diagnosed with a NET.

Palliative Care Consultant/Team

Specialists in cancer-related symptom control and support. Although often associated with end-of-life care, this team can also offer support at any time during your life with a NET.

Other clinical staff who may be involved in your care - but not necessarily part of the MDT:

General Practitioner (GP)

Your local doctor, who can treat all common conditions and refer you to other services for specialist treatment.

District/Community Nurse

Usually attached to your GP practice, a district or community nurse may offer support during your treatment, for example helping to care for your wounds at home after surgery.

Pharmacist

An expert in drugs and medicines who can help you to manage your cancer treatment and any side effects.

Biochemist/Clinical Scientist

A specialist in analysing and interpreting routine and specialist blood and urine samples such as chromogranins and urinary 5HiAA.

Radiotherapist

A specialist responsible for radiotherapy treatments.

Haematologist

A specialist in diagnosing and treating illnesses related to the blood.

DECIDING ON TREATMENT

Your care team will talk you through which treatments the NET MDT has considered and recommended, including what they hope to achieve. They may also provide you with written information about your treatment / treatment options.

Aims of treatment should be to help you have the best possible quality of life - by addressing what's important to you - through one or a combination of all of the approaches below:

- Removal of all or part of your NET (you can read about the different types of surgery starting on page 62)
- Control of your disease, by slowing or stopping the growth of your NET
- Palliation, or easing of, your symptoms

A lot of people find it helps to take someone with them to appointments when treatments are discussed. It may make it easier to talk through your options and ask questions, and can help you make sure you've understood everything afterwards.

It's a good idea to ask for written information to take home too. This can help you to think through treatments and come up with new questions to ask before making a decision.

GIVING YOUR CONSENT - OR NOT

The next stage is for you to give your consent to treatment. You'll be asked to sign a consent form, which you should never do until you feel totally confident about what's planned. You have control here and it has to be a decision you feel sure of making - so take at least a day to think everything through before signing the form, and if you've got any questions, ask.

Informed consent relies on you being given the information you need to make an informed choice. This information shouldn't cover just the treatment itself, but should also look at any preparation needed, side effects and potential consequences.

Questions like these can help you to get the information you need:

- What exactly does the treatment involve?
- How long does it take?
- Where will treatment take place?
- What are the advantages and disadvantages of the treatment?
- What impact will it have on my everyday life?
- Will I need to take time off work? How long?
- Will there be limitations to what I can do? For how long?
- Will I need someone to look after me or my family?
- What if I'm a carer, parent, or have pets or neighbours who rely on me?

- Could there be side effects? Will these be short- or long-term?
- What can I do to reduce the impact of any side effects?
- Could other treatments be more effective?
- How likely is the treatment to be effective?

All of these matters should be covered during your treatment discussions. So if any areas are missed, ask about them.

It can be helpful to discuss your beliefs and preferences too. For example, are alternatives available to blood transfusion during surgery? How quickly do you need to have the treatment - can you put it back to a different date?

Sometimes talking with someone who has had the same treatment may help. Being shown round the unit or ward you may stay in can be useful too. Remember though, that everyone experiences cancer and cancer treatment differently.

Remember - you can say no to treatment. Your care team must respect your choice and you don't have to give a reason, although it can be useful for your care team to understand your decision so they can plan future treatments with you.

PREPARING FOR TREATMENT

A range of treatments are available for NETs, and your care team will let you know if there's anything specific you need to do to get ready. But there are plenty of things you can do to put yourself in the best position, whatever treatment you're having.

Cancer treatments can put a lot of extra strain on your body, and preparing yourself physically and psychologically can make it easier to cope with treatment and recover afterwards.

So before you start any treatments it's a good idea to think about the following:

Exercise

You don't need to suddenly take up marathon running, but gentle activities like swimming, cycling, jogging and even walking can all help your body to get stronger. If you have issues that affect your mobility, such as arthritis, simple armchair exercises can help too. And you might find that exercise gives your mood a boost.

Dropping bad habits

We don't expect you to radically change your lifestyle because you've been diagnosed with a NET, but if you smoke or drink too much, now's a very good time to think about giving up.

Eating well

Giving your body what it needs is a vital way to stay healthy and boost your recovery. Usually a normal, healthy, well-balanced diet is enough to fuel your body, but sometimes a few simple adjustments may help - especially if your appetite has changed or you find yourself eating less. See section 5 for information and advice on diet and nutrition.

Your wellbeing

Preparing yourself mentally is important too, so think about things that help you relax if you're feeling stressed. Maybe it's spending time with friends, or sitting down with a crossword, or taking a walk in your favourite park. Even a few deep breaths can help to clear your head. Whatever works for you, try and keep it in mind for days when you're not feeling too good.

Try to get enough sleep - It's very easy to get caught up in the frenetic pace of a 24/7 world, but just as exercise and diet play an enormous part in health, so do rest and sleep. If you're struggling to sleep, you can read our advice starting on page 130.

Your treatment

Whether you want to know every detail or not, there are a few basics about treatment it's always worth keeping in mind. So remember that...

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- Everyone reacts to treatments differently, which means that comparing yourself to other people may not be helpful, though others may have useful tips that can help you through treatment
- If you're told something might happen and it doesn't happen, that doesn't mean the treatment hasn't worked
- If your NET can't be cured, the ultimate goal of treatment is often to improve your quality of life - so if you don't feel that's happening, say so.

Your treatment plan and pathway of care

Once you've agreed your treatments with your care team, you'll be given a **treatment plan** explaining what's planned and when. This should cover all aspects of your treatment - including things like visits to wards or units.

The plan ensures that everyone's expectations are addressed, but it's also only the beginning of your treatment - and it can always be adapted to fit your personal needs.

You might hear your care team talk about your **pathway of care** or your **clinical pathway**. Both of these terms refer to the ongoing process of reviewing and refining your treatment. Your progress and response to treatment will be continually monitored and discussed, and choosing one treatment route initially, doesn't rule out other options being used later on.

The main thing to remember, is that you do have control over how treatment happens, when it happens and if it goes ahead. Treatment isn't just something that's done to you - it's a process you can be involved in at every stage.

Avoiding a carcinoid crisis

We have already talked about carcinoid syndrome on page 25, and how it can be triggered by general anaesthetics, certain medical procedures and stress. In extreme cases, carcinoid syndrome can become a medical emergency - "carcinoid crisis" - causing changes to your blood pressure, breathing and consciousness level, it may even result in a coma.

If you're having any surgery or treatments that could put you at risk of "carcinoid crisis", your care team will monitor you carefully and give you an injection or infusion (drip) containing a somatostatin analogue (Octreotide).

We'd recommend you carry one of our carcinoid crisis cards in your wallet or purse. It explains what medical professionals need to do in a crisis. To obtain a card, please contact us on **01926 883487** or at **hello@netpatientfoundation.org**

NET Patient Foundation

AT RISK of Carcinoid Crisis

I have neuroendocrine cancer (NET) and I am at risk of a carcinoid crisis if I have to undergo an anaesthetic or invasive procedure.

hello@netpatientfoundation.org
www.netpatientfoundation.org
Registered charity number: 1092286
UKNET's Bitesize Guidance on Peri-operative Management www.ukinets.org

TYPES OF TREATMENT

A wide variety of surgical and non-surgical treatments are used to help people diagnosed with NETs experience fewer symptoms and live well.

Surgery for NETs

Surgery is usually the first option considered as it is the only currently available treatment with the potential for cure. However it may also play a role in advanced disease - where the tumours may have spread. There are several types and aims of surgery.

Aims of Surgery

Potentially curative surgery

If you have a single tumour, with no evidence of secondary disease (no lymph nodes or metastases) and it can be completely removed, then surgery may be a potentially curative treatment.

The decision on the type and regularity of follow up will be based upon the results of the histopathology review (checking what's been removed under a microscope). Follow up is not always required but expert opinion is essential to assess risk of NET recurrence.

Partial/cyto-reductive/debulking surgery

All of these terms refer to surgery designed to reduce the amount of cancer cells in your body by removing the bulk of a tumour.

This kind of surgery might involve removing:

- All or part of a primary tumour
- All or part of any secondary tumours
- All of the primary tumour and some of the secondary tumours
- Whatever can safely be removed.

This type of surgery is usually undertaken to help improve your symptoms and/or to manage the disease. It's often used in combination with other types of treatment, including somatostatin analogues, chemotherapy, interventional radiology and nuclear medicine therapy.

Debulking a tumour can improve symptoms that have been caused by the size and position of a tumour or by the release of excess hormones into the blood. It can also improve the effectiveness of other treatments, as they will be targeting a smaller amount of tumour.

Pre-emptive/bypass surgery

Occasionally, NETs develop too close to blood vessels and surrounding organs like the bowel, and interfere with how these structures work.

Removing or bypassing these kinds of tumours can help to prevent blockages and other damage, reducing the chance of extra problems developing in the future. This is known as pre-emptive or bypass surgery.

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Types of surgery explained

Keyhole surgery

Also known as a laparoscopy or minimally invasive surgery, keyhole surgery allows surgeons to remove smaller NETs by inserting a tiny tube and surgical tools into your body through small incisions in your skin. The tube contains a light and a camera, which the surgeon uses to see to perform the surgery.

You're given a general anaesthetic before keyhole surgery, but you may only need to stay in hospital for a day or two and the small incisions mean scarring is minimal and recovery time may be shortened.

Bear in mind, though, that keyhole operations are sometimes converted into open surgery during the procedure, if the surgeon decides that this is necessary to ensure surgical success.

Open surgery

For large or multiple tumours, if a NET has spread, or if a NET is in an awkward place that can't be reached through keyhole surgery, open surgery is normally used. You'll be given a general anaesthetic before open surgery.

Depending on the extent of your surgery and the length of your anaesthetic, you may need to be looked after in an intensive care or high dependency unit for a day or two after surgery, after which you'll be transferred to a ward.

You'll need to stay in hospital for between 3 and 14 days after open surgery.

Combination or staged surgery

You might need more than one procedure to treat your NET through surgery. In that case your care team will discuss whether the procedures can be undertaken at the same time or in stages (which means you'll have one operation and then be given time to recover before the next one).

Open and close surgery

This term refers to surgery being started but not completed, either because of a severe deterioration in your condition or because your NET can't be removed. Nowadays, with improved pre-operation care and scanning, this rarely happens.

If surgery is stopped because your condition deteriorates, however, you'll be given full care to recover. Your surgery may then be rescheduled.

And if an operation is stopped because your NET can't be removed, you'll be given time to recover and then your care team will discuss alternative treatments with you.

With any operation, the length of your stay in hospital and the time it takes to recover, will depend on the type and extent of surgery you have, and on whether any complications occur.

Your surgical team will give you full information about any surgery recommended for you. Make sure you ask for the details in writing if you're not offered this - many hospitals produce their own information leaflets.

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Surgery by NET site **Surgery for GI NETs**

Your gastrointestinal tract is the long hollow tube that extends from your mouth to your rectum. It includes your stomach and intestines (the small bowel and large bowel). The linings of this tube are made up of several layers - (see diagram below).

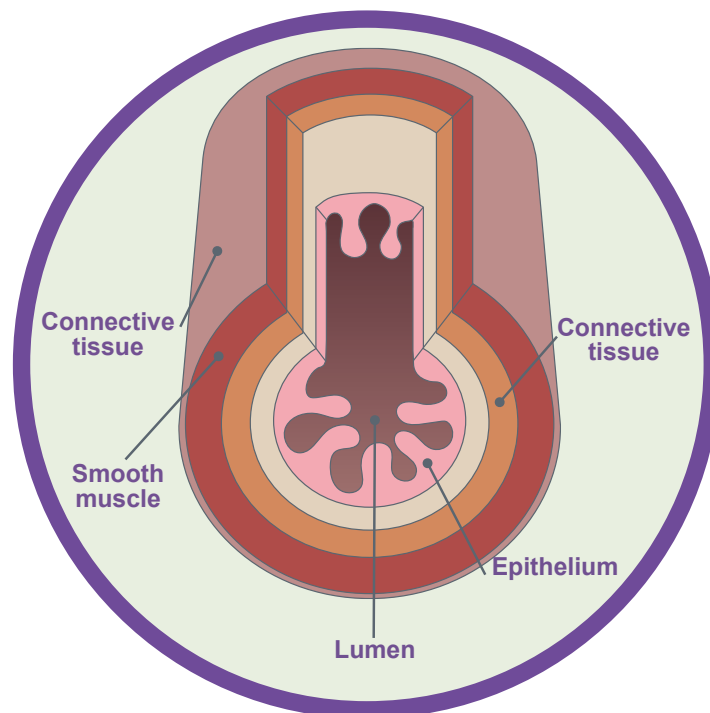
Procedures used to remove (or partially remove/bypass) GI NETs

Local excision, which involves the tumour and surrounding tissue (including local lymph nodes) being removed. For stomach and rectal NETs this can be done via an endoscope or open surgery.

Endoscopic mucosal resection, which is an option when a tumour may only be present on the inner lining of the stomach, duodenum and rectum.

Endoscopic submucosal dissection, which can be used if the tumour has spread to the inner lining of the stomach, duodenum and rectum.

Transanal endoscopic microsurgery, which is used to remove small cancers of the rectum without having to rely on open surgery. It's often used when mucosal resection may not be effective on its own.



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Open surgical procedures for GI NETs

For stomach NETs

- Open local excision (see previous page)
- Partial gastrectomy, when part of the stomach needs to be removed in order to remove the tumour
- Total gastrectomy, when all of the stomach may need to be removed.

For rectal NETs

- Open local excision (see previous page)
- Total mesenteric resection, when a border of non-cancerous rectal tissue and fatty tissue from around the bowel are removed along with a tumour
- Low anterior resection, which can be used to remove a tumour from the upper part of the rectum. In this procedure, the colon is attached to the lower part of the rectum
- Abdominoperineal (AP) resection, which can be used for tumours of the lower rectum. This procedure involves removing all of the rectum, the anal sphincter, some surrounding tissue and lymph nodes. With the rectum completely removed, a hole called a stoma is created in your abdominal wall, so faeces can be diverted to a bag outside your body.

For colonic NETs

Colonic NETs are rare and usually of a higher grade than other bowel NETs, so the first treatment recommended is often chemotherapy.

If surgery is used, it's called a colectomy and involves removing the colon. For most NETs it's only necessary to remove part of the colon however - which is called a hemicolectomy.

For appendiceal NETs

Appendectomy, which involves removing the appendix. This is usually an emergency procedure, as symptoms, if they occur, are similar to appendicitis. If an appendiceal NET measures more than 2cm, has spread beyond the appendix or has burst, further surgery may be needed - such as a hemicolectomy.

For Goblet Cell Carcinomas (or GCCs, found in a small percentage of appendiceal NETs)

GCCs can grow and behave more aggressively than appendiceal NETs, so if you're given this diagnosis further surgery may be recommended even if your tumour is small and doesn't seem to have spread. An oophorectomy (which involves removing the ovaries), with or without a hemicolectomy, may be recommended to women, as GCCs can often spread to the ovaries.

For small bowel NETs

Surgery for small bowel NETs most often involves removing the affected part of the bowel, along with surrounding lymph nodes (which often become matted together into a mass as a result of a small bowel NET).

The most common place for NETs in the small bowel is the ileocaecal valve, where the small and large bowel join, so it's sometimes also necessary to remove a small part of the large bowel.

Your surgeon will take care to leave as much of your healthy bowel in place as possible. Given the complex network of blood vessels and lymph nodes around the small bowel, it's recommended that a surgeon with expertise in visceral surgery (for example a liver, pancreatic and biliary, also known as a hepatobiliary or HPB, specialist), undertakes this procedure.

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Surgery for pancreatic and duodenal NETs

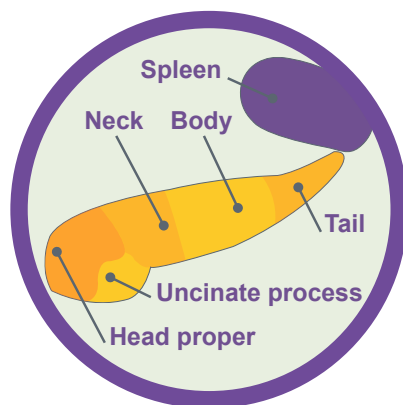
All operations affecting the pancreas and/or duodenum, including NETs, are done at specialist pancreatic cancer centres. There are four main pancreatic procedures:

Enucleation

Usually done using keyhole surgery, this involves carefully removing a NET and leaving the pancreas completely intact. It's often used for small, slow-growing tumours, like insulinomas. For duodenal NETs this may be done via endoscopic mucosal resection and endoscopic submucosal dissection, which are explained on page 64.

Distal pancreatectomy

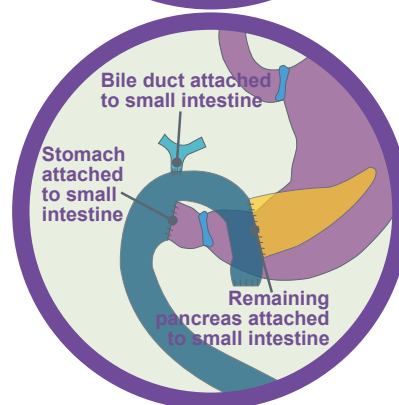
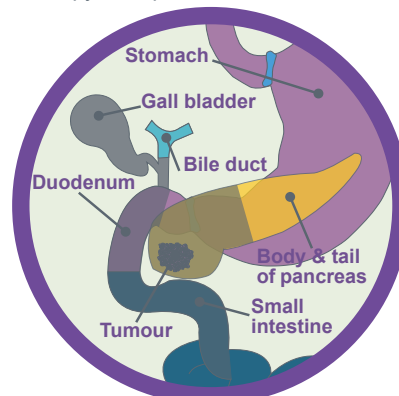
Another operation sometimes done using keyhole surgery, this procedure for NETs in the left part of the pancreas (specifically in the body and/or the tail) involves removing all or part of that side of the pancreas, and possibly the spleen. The spleen may need to be removed if the tail end of the pancreas is attached to the spleen or to prevent complications with the blood flow to the spleen.



Whipples procedure or Pancreatoduodenectomy (aka PPPD)

These procedures are used to treat pancreatic cancers that are found in the head or uncinate process of the pancreas. They may also be used to treat duodenal NETs.

Whipples procedure is a complex operation that involves removing the right part of the pancreas (the head), along with the end of the bile duct, up to and including the lower part of your stomach, including the pyloric sphincter, part of your small intestine (duodenum) and your gall bladder. The PPPD procedure does not include removal of the pyloric sphincter.



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A Whipple's procedure or PPPD can last between four and eight hours. This is partly because it takes time to separate all of the structures that need to be removed, but mostly because of the time taken to ensure all reconnections are correct and free from leaks.

Multi-visceral pancreatic resection

This is a major operation only usually recommended for younger, fitter patients and only carried out in a few specialist pancreatic NET centres.

It's used to treat large, slow-growing NETs that start in the pancreas but grow into other organs like the stomach, liver, kidney and bowels. (Visceral means related to the internal organs, so multi-visceral means involving multiple organs.)

During the surgery, the NET and the affected organs are removed together and kept intact. Major blood vessels often need to be repaired as a result.

This surgery is sometimes combined with other cyto-reductive/debulking treatments designed to reduce the amount of cancer cells in your body. These include ablation, embolisation, radioisotope treatment and chemotherapy, which you can read about elsewhere in this section.

Can pancreas surgery cause diabetes?

The pancreas produces insulin - which controls blood sugar levels - and some major procedures mean it can no longer do this effectively. As a result, some people do need to take insulin and other medications after pancreatic operations to help control their blood sugar. Sometimes this is needed only temporarily as the pancreas recovers, but it can be permanent.

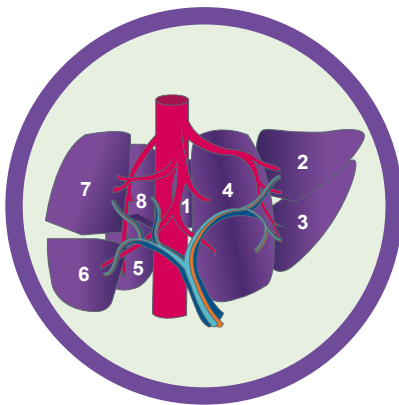
If you are already diabetic but are able to control the condition through your diet, you may need to begin taking insulin following pancreatic surgery. If you are at risk of diabetes but have not yet developed the condition, you might become diabetic earlier than expected because of surgery. If all of your pancreas is removed, you will become diabetic, regardless of any pre-existing risk.

One further point to remember - the pancreas is also involved in digesting food, and it's sometimes necessary to take medicines called Pancreatic Enzyme Replacement Therapy (or PERT for short) to help with this after pancreatic surgery.

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Surgery on the liver

The liver is made up of eight segments in two lobes (the left and right lobe). Each segment has its own blood supply, delivered through branches of the hepatic artery and the portal vein.



Up to 70% of the liver can be removed through surgery, and the remaining area then expands after the operation to become fully functional again. You'll need a careful assessment before any surgery, however, to check that your liver will be able to do this.

All operations on NETs affecting the liver are done at specialist liver centres.

There are many possible surgical options, though what's possible will depend on the location of your NET.

Options include:

- Metastectomy, which involves a small solitary liver tumour being 'scooped' out of the liver
- Wedge resection, which involves the removal of a 'wedge' of liver that contains the tumour
- Segmentectomy, which involves the removal of the whole segment of the liver that contains the tumour
- Partial hepatectomy, which involves the removal of the lobe of the liver that contains the tumour
- Central hepatectomy, which is rarely carried out, but involves the removal of the central segments of the liver
- Extended partial hepatectomy, which involves the removal of either the right or left lobe of the liver and a segment of whichever lobe remains.

If you would like further information on dietary issues relating to GI NET surgery then there is a separate booklet to cover these.

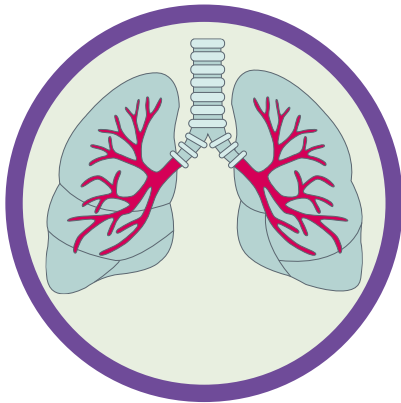
This booklet can be found at www.netpatientfoundation.org

Alternatively you can request a copy by calling us on 01926 883487 or email hello@netpatientfoundation.org

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Surgery on the lung

The lungs are made up of lobes - three on the right and two on the left. You can lead a normal life even after having a whole lung removed, provided you don't have lung disease and exercise regularly following surgery.



All lung surgery should be carried out by a specialist respiratory, thoracic or cardiothoracic surgeon. It's possible to have keyhole surgery of the lung, which is usually done through a procedure called video-assisted thoracoscopy (or VATS). Or you can also have open surgery - either a thoracotomy (which involves an open cut being made in the chest) or a sternotomy (when a cut is made through the breastbone).

As with the liver, there are a number of possible surgical options, though these can be limited by the location of your NET.

Options include:

- Metastectomy, which involves a small lung tumour being 'scooped' out of the lung. This is usually done to treat secondary tumours that have spread from elsewhere

- Wedge resection, which involves the removal of a 'wedge' of lung that contains the tumour
- Segmentectomy, which involves the removal of the lobe of lung that contains the tumour
- Lobectomy, which involves the removal of one or more lobes
- Sleeve resection, which involves the removal of an upper lobe along with part of the main airway. The remaining lung is then attached to the remaining airway
- Pneumonectomy, which involves the removal of an entire lung.

Heart surgery

We explain carcinoid syndrome on page 25. It's caused by excessive hormones being released into your bloodstream by a NET, and as well as triggering symptoms like flushing and diarrhoea. It can cause a plaque-like substance to build up in parts of your heart. It's thought this is the result of having too much of the hormone serotonin in your blood.

The plaque-like substance can stop certain valves in your heart from working properly, affecting blood flow. Depending on how severely the valves are affected, you may need to have surgery to replace them. Heart valve surgery, in NETs, involves replacing one or more of your heart valves, to help improve symptoms and prevent permanent damage to your heart. This might need to happen before you can have surgery to remove a tumour, because it will help your heart to function more effectively and so reduce the risks of surgery.

Non-surgical treatments

Somatostatin analogues (SSAs)

Somatostatin is a substance that occurs naturally in the body. It helps to control the release of hormones into your bloodstream, including several of the ones that NETs can cause to be released.

Somatostatin analogues are drugs created to mimic the behaviour of somatostatin. By helping to control hormone levels, they can reduce symptoms of Carcinoid Syndrome, like diarrhoea, flushing and wheezing.

The most common somatostatin analogues are **lanreotide** (which is marketed as Somatuline) and **octreotide** (which is marketed as Sandostatin).

What's involved?

When you start on a somatostatin analogue, you might be taught how to self-inject a small dose, two or three times a day. Doctors will then assess your tolerance of the drug and how well it helps your symptoms, for up to two weeks. Don't worry if your symptoms get worse for a day or two initially - this is normal and symptoms should not only settle but improve. After this assessment, you'll then be given a longer-acting version of either lanreotide or octreotide.

Alternatively, you might be started straight away on the longer-acting SSA preparations.

Lanreotide can be given by injection at 7, 14, 21 and, more commonly, 28 day intervals, depending on how much you need. This can be self-injected into your thigh or can be given to you by a nurse or family member into your bottom.

If you are injecting yourself or a family member is doing it, a nurse will go through the process with you. You'll also have access to nurse support at home if you need it.

Your nurse specialist or specialist centre pharmacist will give you advice on transporting and storing the medicine, and you can also call the manufacturer's freephone helpline for support.

Octreotide can be given by injection at 14, 21 and, more commonly, 28 day intervals. A nurse usually gives you this injection into your bottom. Again, you'll have access to nurse support at home if you need it.

Your nurse specialist or specialist centre pharmacist will give you advice on transporting and storing the medicine, and you can also call the manufacturer's freephone helpline for support.

Interventional radiology

Radiology means scans - X-rays, ultrasounds, MRIs and CT scans. Interventional radiology means using those scans to perform targeted treatments. Techniques used on NETs include embolisation and ablation.

Embolisation procedures

These are usually undertaken to treat tumours within the liver. As previously mentioned the liver has 2 blood supplies, the Hepatic Artery and the Portal Vein - embolisation involves targeting branches from either of these supplies to reduce or block blood flow to the tumour(s).

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Hepatic artery embolisation (HAE)

Your care team might recommend HAE if you have a NET that:

- Has only spread to your liver
- Is causing lots of hormones to be produced
- Can't be removed by surgery
- Hasn't responded to other treatments.

HAE involves cutting off the blood supply to your NET - because, like any tumour, a NET can only survive if there's blood flowing into it. The treatment can shrink a tumour and reduce the amount of hormones a tumour produces. On rare occasions, it can even destroy a tumour completely.

What's involved?

Different hospitals have slightly different routines, so it's a good idea to ask for written information explaining exactly what you'll need to do before treatment.

You may be asked not to eat or drink for a few hours before HAE treatment and may be given a light sedative and painkiller just before and during the procedure.

You're then given a local anaesthetic to numb your groin, before a small cut is made in your groin. Next, a thin tube is placed through this cut and into the main artery that delivers blood to your liver. You won't feel anything while this happens.

Watching on a screen, your doctor identifies the part of the artery that's supplying blood to the tumour and injects particles or a gelfoam into it. These then swell and block the blood supply to the tumour.

HAE is sometimes done in combination with a dose of chemotherapy - either by injecting chemotherapy into the tube before the particles or gelfoam, or by using beads containing a chemotherapy drug.

You'll need to lie still for about four hours after HAE to reduce the risk of bleeding from the groin site. In most cases, following HAE you may need to stay in hospital overnight.

Portal vein embolisation (PVE)

PVE is used to cut off part of the blood flow to part of the liver.

If you have one or more tumours in one part of the liver, PVE can be used to cut off the blood supply to that area. For example, if your tumours are all in the left lobe, you can cut off the blood supply to the left lobe. This causes the left lobe to shrink and the tumours within it to be starved of blood and nutrients, eventually dying off.

Blood continues to be supplied to the right lobe, which, as the left side shrinks, starts to grow to make up for the left lobe shrinking.

PVE is often used before surgery. By reducing the size of the part of the liver that needs to be removed - and by increasing the part that will remain - doctors can reduce the risk of poor or lost liver function, as well as improving recovery, after surgery.

What's involved?

As with HAE, you may be advised to not eat or drink for a few hours before PVE. And you may be given a mild sedative and/or a painkiller just before the procedure and while it takes place.

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Unlike HAE, PVE is not carried out through the groin. Your doctor makes a small cut in your right side (where the liver is) and, using live scan images, finds the branch of the portal vein that needs to be blocked.

A tube is then inserted through the cut in your side and into that branch of the vein. A dye is injected into the tube to highlight the blood supply, enabling the doctor to target the correct part of the vein. A blocking agent (either a gelfoam, a 'glue' or tiny microbeads) is then fed through the tube to cut off the blood supply.

The procedure can take up to two hours and you'll need to rest in bed afterwards, usually for around four hours. You may need to stay in hospital overnight.

Ablation techniques

Ablation is a treatment that involves inserting a probe or needle into your NET then trying to destroy it using heat or electrical current. It can be used in combination with, or as an alternative to, surgery.

Ablation techniques can be used on liver, lung, pancreatic and adrenal/kidney NETs.

Radiofrequency ablation (RFA)

RFA uses heat from radiofrequency waves to target and kill cancer cells.

What's involved?

RFA is given by inserting a tiny probe - around 1 or 2mm wide - into a tumour. This is usually done through a small cut in your skin, but can also be done during surgery.

Before RFA, you're given either a general anaesthetic or a local anaesthetic and a sedative to help you relax. You then have a CT scan or an ultrasound and your surgeon or radiologist watches the scan to guide the probe into the tumour.

A current is passed through the probe, creating heat that kills cancer cells. You won't feel anything while this happens. It can take up to a couple of hours, depending on the size of the tumour(s), and you usually have to stay in hospital overnight afterwards.

Microwave ablation

Microwave ablation is similar to RFA but uses heat from microwaves rather than radio waves to destroy cancer cells.

What's involved?

A tiny probe is inserted through your skin and into your NET. Multiple probes are sometimes used for larger tumours. Microwaves are then passed from a generator directly into your NETs.

You'll have a local or general anaesthetic before this treatment.

Irreversible electroporation (IRE aka Nanoknife)

This relatively new treatment uses a strong electric current to kill cancer cells. It's done with tiny needles, which are guided into position using an ultrasound or CT scan.

It's particularly useful when surgery, or other ablation techniques, are risky because tumours are located close to structures such as major blood vessels.

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What's involved?

You're given a general anaesthetic before IRE treatment, and the operation takes around 90 minutes. Up to six needles are guided into place around your NET, and electrical pulses are then used to puncture tiny holes in the tumour.

One of the advantages of IRE is that it limits damage to surrounding cells. It's also not as invasive as many other types of surgery, so you can usually go home the day after your treatment. However, because IRE uses direct electrical current, it cannot be used in people who may have a heart condition.

Ablation involves applying heat or voltage directly to a tumour to kill cancer cells.

Embolisation involves injecting substances into the liver to block the blood flow to cancer cells.

Radiotherapy (aka radiation therapy)

Radiotherapy for all cancers involves using radiation to kill cancer cells. There are two main types - internal radiotherapy, when injections and implants are used to give radiotherapy inside your body, and external radiotherapy, when machines outside your body are used to target cancer cells using X-rays. External radiotherapy used to treat cancer is called external beam therapy (EXT) or deep X-ray therapy (DXT).

For NETs, radiotherapy usually involves a type of internal radiotherapy called targeted radiotherapy (or radio-labelled treatment), but external beam therapy can be used to help treat secondary bone tumours.

There are several different types of internal radiotherapy:

Peptide receptor radionuclide therapy (PRRT)

PRRT works by targeting receptors on the surface of NETs.

Before being given PRRT, you'll have either an mIBG scan, an octreotide or Gallium PET scan (you can read about these in the 'Which test is that?' section of this handbook). If your scans show receptors that are sensitive to either mIBG or Octreotide (Octreotide or Gallium positive) then PRRT with that agent may be recommended for you.

Due to the effects that radiation therapy can have on a foetus, baby or young child, PRRT can't be given to pregnant women or breastfeeding mums. All patients will be advised to use barrier methods of contraception (such as condoms, a diaphragm or cervical cap) during PRRT treatment and if you're female you'll be advised not to get pregnant during treatment.

What's involved?

PRRT is a type of very targeted radiotherapy. It involves using a substance that travels directly to NET cells, binds to receptors on those cells and then releases a high dose of radiation designed to kill the cells.

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Once the radiation has been delivered it is then secreted from your body, usually through the kidneys. However you will have radiation in your body for a period of time following treatment, this means that certain precautions are required during that time (such as double-flushing the toilet). Your treatment team will give you written information about these precautions to help with your decision-making about the treatment and to help you make any necessary arrangements at home before you come into hospital for it (for example you may be advised not to share a bed for 7-10 days after treatment).

Each PRRT session begins with an anti-sickness medication followed by an amino acid solution delivered intravenously to protect your kidneys from the effects of the radiation. The radiopeptide is then injected into the patient, followed by additional amino acid solution. In total, the treatment session lasts approximately four hours.

You will usually have four treatments, a minimum of eight to twelve weeks apart (each treatment is called a cycle). You may need to stay in hospital for a night or two after each treatment (exactly how long will depend on the type of treatment), and your care team will let you know when the levels of radioactivity in your body have fallen enough for you to go home.

PRRT can affect your kidneys and blood, so you'll only be offered this treatment if your kidneys and bone marrow (the substance that produces blood cells) are healthy. Both will be checked before you're offered PRRT. You'll also have blood tests every two weeks for 6 - 8 weeks during and after treatment to monitor your health.

Lutetium-177 PRRT

Lutetium-177 is a radioactive substance, which is added to a carrier (radioactive isotope), and delivered through a drip in your arm. It is the treatment of choice for those with either Octreotide or Gallium PET positive disease.

After Lutetium treatment you'll either be allowed home, after several hours, or need to stay overnight. You'll have your own room and visitors, including staff, will only be able to spend a short time with you so they're not exposed to too much radiation.

A day or two after treatment you will be asked to return to the nuclear medicine department for a post-therapy scan. The scan may take up to two hours and will be similar to the one you had to check that Lutetium therapy was suitable for you. The physics team will advise you of the precautions you need to take. These precautions are necessary to reduce the radiation dose to other people with whom you come into contact.

Depending on availability, some centres may use Yttrium-90 (Y-90), rather than Lutetium-177, to treat NETs - this is a slightly different radioactive substance, but with the same cells targeted. With Y-90 you may need to stay in hospital for a few days longer whilst your radiation levels fall. As with other PRRT procedures you will be asked to attend the nuclear medicine department to undergo a post treatment scan. Advice regarding precautions to take will be repeated at this time, before you go home.

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131 I-MIBG PRRT

131 I-MIBG involves using a chemical called Meta-iodobenzylguanidine (MIBG) and a radioactive isotope (iodine-131). It is primarily used to treat adrenal based NETs (PPGL - page 17).

What's involved?

During treatment, small amounts of the iodine-131 can detach from the mIBG. If this happens, the 'free' iodine-131 is then absorbed by the thyroid gland and can cause damage. You will need to take a medicine called potassium iodate or Lugol's iodine one day before and then daily during the treatment. This medicine will stop the thyroid taking up the radioiodine while the treatment takes effect.

After treatment you'll need to stay in hospital for up to a week while your radioactivity levels fall. You'll have your own room and visitors, including staff, will only be able to spend a short time with you so they're not exposed to too much radiation.

On the day of your planned discharge you will return to the nuclear medicine department for a post-therapy scan. The scan may take up to two hours and will be similar to the one you had to check that mIBG therapy was suitable for you. The physics team will monitor you to assess your radiation levels and advise you of the precautions you need to take when you leave hospital. These precautions are necessary to reduce the radiation dose to other people with whom you come into contact.

Selective Internal Radiation Therapy (SIRT)

SIRT is a treatment for NETs that have spread to the liver and can't be removed through surgery. It uses tiny beads - called microspheres or SIR-spheres - to target and kill cancer cells. The beads are coated in a radioactive substance called yttrium-90. SIRT is used for liver only or liver dominant disease - as it does not treat disease outside of the liver.

As with all radiation treatments, there are certain precautions you'll need to take before and after SIRT. Your care team will give you written information about this.

What's involved?

SIRT is a two-stage procedure. Here's how it works:

Stage one

To begin, a thin tube called a catheter is inserted through a small cut in your groin and into the main blood vessel (the hepatic artery) that supplies blood to the liver. A dye is injected into the tube, which helps the doctor to map out the blood supply in your liver and in particular to NETs.

An assessment is then made to check where the blood flows after passing by your tumour, and small particles or coils are injected to stop blood flowing beyond your tumour. This is to prevent the radioactive microspheres used in stage two SIRT from passing into other body parts of your body, such as the stomach and lungs, and exposing them to radiation.

You may need to stay in hospital overnight after this stage but you'll then be able to head home. You'll need to return in one or two weeks to have the irradiated microspheres injected. Stage one is essential to ensure the safe delivery of SIRT.

Stage two

The process for stage two is similar to stage one.

Dye is again injected into a tube so the blood supply can be mapped out and doctors can check that the blockages made during stage one remain intact.

The microspheres are then fed into the catheter and delivered to the tumour(s). They get stuck in the small blood vessels that surround a NET, and the yttrium-90 delivers a dose of radiation that destroys cancer cells.

You'll need to stay on bedrest for 4 - 6 hours post treatment and in hospital overnight if you have SIRT. After 24 hours you will undergo a post treatment scan - this is to check on where the microspheres have settled. If all is well, you will receive post treatment precautions advice and medication (usually a PPI and reducing dose steroid) and then allowed home.

The stomach and liver sit quite close to each other and the radiation dose may increase the levels of acid within the stomach causing irritation. Therefore PPIs are routinely given, (for about four weeks) to help alleviate this. Steroids are given, (a reducing dose over a week - 10 days) to help reduce any potential inflammation response. Please ensure you have these medications before going home.

Chemotherapy and targeted therapies

In NET treatment, chemotherapy can be used before, alongside or after other treatments. When considering whether chemotherapy is right for your NET, your care team will consider whether:

- Your tumour contains a particular type of cell (see page 5 for more information)
- Your tumour is growing quickly (Grading)
- Your doctors want to shrink a tumour before surgery
- Your doctors want to kill more cells after surgery
- The location (primary site) of your tumour makes chemotherapy viable

Chemotherapy kills rapidly-dividing cells in a variety of ways, depending on the drug. Since there are many different types of cancers that all grow differently, many chemotherapy drugs have been developed to target these various growth patterns. Each drug has a different way of working and is effective at a specific time in the life cycle of the cell it targets.

However, a high percentage of NETs have slow to moderately dividing cells, so chemotherapy may not be the first choice of treatment for those NETs. Having said that, certain NETs, such as Pancreatic NETs, may have a particular sensitivity to chemotherapy, even when they are low-moderate grade.

Having examined your NET under a microscope after a biopsy or surgery, your care team will discuss the best options for you and which chemotherapy medications are being considered.

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What's involved?

Chemotherapy is usually given in cycles: a treatment followed by a period of rest. A cycle is usually one, two, three, or four weeks long. A course of chemotherapy is comprised of multiple cycles. Each course is different, but generally consists of four to six cycles.

It may take a relatively short period of time to receive some chemotherapy drugs, while others take hours. It all depends on the treatment regimen that your doctor recommends.

Chemotherapy is usually given as an infusion into a vein (intravenously). The drugs are administered by inserting a tube with a needle into a vein in your arm or into a device in a vein in your chest. However some drugs may be given orally - in tablet form.

If you are to have chemotherapy, you will attend an oncology (cancer) clinic, where you will have a blood test prior to (and on specific days during) treatment, to ensure that your blood cells are at normal levels. Chemotherapy can cause a drop in the number of certain blood cells - for example your white cells. White cells help us fight infection, so if these are reduced too much we can be at increased risk of infection, which in certain instances can be life-threatening. If your "blood count" is ok, you will start/continue chemotherapy as planned. If low, your chemotherapy may be postponed for up to a week, to allow the blood count to return to a safe level to continue.

For intravenous chemotherapy - your chemotherapy nurse will put the needle in at the start of each treatment and remove it when treatment is over. Let your doctor or nurse know right away if you feel pain or burning while you are

getting IV chemotherapy. Occasionally chemotherapy may be given through a PICC or tunnelled line. This is a device that can be inserted into either a vein in upper arm, or just below the collarbone, that can stay in place until all of chemotherapy cycles have finished. Blood can also be sampled from these lines.

You may be given other medications, such as anti-sickness and/or steroids to take for a few days around each treatment part of your chemotherapy cycle - this is to help prevent or minimise any side effects that may occur.

Your care team - and your oncology/chemotherapy nurse - will talk through all of the risks, potential side effects and precautions you may have to take prior to starting treatment.

They will also provide you with a 24hr support number and guide as to what to do if you become unwell at home during treatment.

Targeted therapies

Sunitinib

Sunitinib (which is marketed as Sutent) is used to treat cancer by preventing the activity of a special group of proteins which are known to be involved in the growth and spread of cancer cells. It can also stop cancer cells from developing new blood vessels.

In the UK, Sunitinib is licensed for use in the treatment of Grade 1 and 2, well-differentiated pancreatic NETs, that are continuing to grow ("progressing"), and cannot be removed by surgery

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What's involved?

Sunitinib comes as a capsule. You take the capsules once a day, at the same time each day, with a glass of water. It can be taken with or without food. Avoid grapefruit or grapefruit juice during treatment as this can interfere with the way the drug is used by the body.

You'll have regular blood tests before you start taking Sunitinib and while you're taking it. Treatment with Sunitinib continues for as long as it appears to be controlling your NET, and is well tolerated (that is no or minimal side effects).

Sunitinib may not be given if you have certain health conditions - such as severe hypertension or heart disease - or are on certain drugs.

Please ensure that your care team is aware of all of your medical history and medications.

Everolimus

Everolimus (which is marketed as Afinitor) is used to treat well-differentiated and moderately-differentiated pancreatic NETs that can't be removed by surgery, have spread and are growing. It's also used to treat non-functional gastrointestinal and lung NETs.

It works by blocking a particular protein, called mTOR, that causes cancer cells to grow. Everolimus may also stop cancer cells from developing blood vessels. Without a blood supply, cells are starved of oxygen and nutrients and so can't grow.

In the UK, Everolimus is licensed for use in Grade 1 and 2, advanced non-functioning neuroendocrine tumours that originate from the stomach, bowels, lung or pancreas. That is NETs that are progressing and are inoperable and do not overproduce specific hormones or other related natural substances.

What's involved?

Everolimus comes as a capsule. You take the capsules once a day, at the same time each day, with a glass of water. It can be taken with or without food. Avoid grapefruit or grapefruit juice during treatment as this can interfere with the way the drug is used by the body.

You'll have regular blood tests before you start taking Everolimus and while you're taking it. Treatment with Everolimus continues for as long as it appears to be controlling your NET, and is well tolerated (that is no or minimal side effects).

Everolimus may not be given if you have certain health conditions - such as diabetes or respiratory disease i.e. asthma - or are on certain drugs.

Please ensure that your care team is aware of all of your medical history and medications.

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Interferon Alpha

Interferons are made naturally by the body as part the immune system. They prompt cells to respond to - or 'interfere' with - problems like viruses and bacteria.

Interferon Alpha is a manmade substance designed to mimic interferons. It stimulates immune system cells to attack cancer cells, it interferes with the development of cancer cells, and it causes cancer cells to produce chemicals that attract immune cells.

For NETs, it's given to reduce the symptoms of tumours that have spread, often when other treatments aren't working. And it's sometimes given in combination with a somatostatin analogue (see page 70).

What's involved?

Interferon Alpha is given as an injection into the fatty tissue under your skin. You usually have the injection three times a week, and your care team will probably show you how to do this yourself so you don't have to keep travelling to hospital.

Treatment for high-grade NETs

If you're diagnosed with a High-Grade NET/NEC : that is a Grade 3 NET or NEC (neuroendocrine carcinoma) or a mixed cell tumour - that is a MiNEN* (mixed neuroendocrine -nonneuroendocrine neoplasm), your care team might suggest a treatment plan that is similar to those used for common cancers.

***MiNEN used to be called MANEC (mixed adenocarcinoma neuroendocrine carcinoma)**

Grade 3 neuroendocrine tumours can behave more aggressively than other NETs, especially those with poorly-differentiated tumour cells (PDNEC), therefore you might be given different treatments to other NET patients.

Chemotherapy is the most common treatment for high-grade disease, sometimes in combination with surgery and/or radiotherapy. Your care team will talk you through which types of chemotherapy could be most suitable for your individual situation.

Active surveillance

If your NET isn't causing symptoms or is growing very slowly, your care team may recommend that the best response is to monitor it - rather than starting treatment that may have side effects.

There are various terms used to describe the process of monitoring an illness rather than starting a course of treatment. Your care team might call it active surveillance, active monitoring, watchful waiting or wait and see. Some of these are slightly different, but they all mean your doctors think the best option could be to keep a careful eye on your NET and how / whether symptoms develop.

This can seem odd or unnerving. It's natural to think that if you have a tumour you should do something about it. But active surveillance doesn't mean doing nothing. It means closely watching your condition but not putting you through any treatments that might not be necessary and could cause side effects, which could affect your quality of life.

Will you be ignored?

In a word, no, especially if you're under the care of a NET specialist MDT. If you and your care team decide that active surveillance is the best course of action, you'll have regular tests and check-ups to see how you and your NET are. But for now the disruption to your everyday life will be kept to a minimum - and that isn't always the case when you're going through treatment.

Treatment should improve your quality of life, and sometimes that means not starting treatments that could make your quality of life worse.

There are some risks. Your NET could change quicker than expected, for example, or your general health - other health problems - might get worse, meaning some treatments that may be possible now become unsuitable in the future. (For this reason it's important to have a point of contact in your care team you can get in touch with between surveillance scans and appointments to let them know if your health has changed.)

So if your doctors suggest active surveillance, talk through what it would mean and how they've reached that conclusion - and remember that it's a genuine treatment option which may well be the best choice for you right now. Active surveillance may also be used, after and in between treatments, which can sometimes be years apart.

Active surveillance doesn't mean doing nothing. It means closely watching your condition but not putting you through unnecessary treatments that could cause side effects.

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Clinical trials

Your care team might suggest participating in a clinical trial, as a treatment option. Clinical trials are voluntary research studies conducted in people and designed to answer specific questions about the safety or effectiveness of drugs, vaccines, other therapies, or new ways of using existing treatments.

There are many clinical trials going on at any one time, so there's a chance you might be asked to get involved in one. This could mean something as straightforward as having an extra blood test, or it could mean using a totally new treatment to help doctors understand whether it works.

People often ask whether clinical trials are safe, and the short answer is yes - although as with any treatment you might experience side effects. Years of research and testing will have gone into treatments before you're asked to trial them, so you will not be used as a guinea pig.

Phases of clinical trials

If you're asked to take part in a trial it's most likely to be a phase three test, which is the final stage of testing before a product is launched:

	Phase one	Phase two	Phase three	Phase four
People involved	Small number, usually healthy volunteers	Larger number, with a select number diagnosed with a disease - for example patients with a particular type, stage and grade of NET	Up to several thousand, people diagnosed with a disease - for example patients with a particular type, stage and grade of NET	People prescribed the drug
Purpose	Assess side effects and safe dosage	Assess safe dosage, effectiveness of treatments and side effects	Large-scale comparison with existing treatments	Study a drug's impact after launch or long-term effects

For more information about current UK NET trials, and how we at the NET Patient Foundation support research, visit the research page on the UKINETs website: www.ukinets.org

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What's involved?

Your care team will explain the specifics of any clinical trial, but in many phase three trials participants are divided into 2 groups - group A and group B. Group A will be given either a new treatment on its own or new treatment plus best existing treatment and group B will be given the best existing treatment, for example:

New drug vs paracetamol OR new drug + paracetamol vs paracetamol
(If no existing treatment is effective, you might be given a placebo treatment instead - but you'll be told if placebo treatments are involved beforehand.)

Researchers then monitor your progress, so you might need to have more check-ups, tests and scans than normal.

And the two groups are assessed and compared to see which one seems to be receiving the more effective treatment and least side effects.

If there is early evidence that any treatment involved in a clinical trial has an obvious benefit, the trial might be stopped or all participants might be offered that treatment.

You're the boss

Throughout any clinical trial, you're in control. So if you decide you don't want to take part any more, that's fine. You don't have to explain why - although letting your care team know will help them to plan the best alternative treatment.

The research team has a duty to make sure you understand what's happening and to respond to any concerns you might have. So there's no chance of you being given a treatment and then left in the dark. In fact, being on a trial often means you're monitored more closely and given more chance to share what's on your mind.

Ultimately, the decision is yours - but before you join a clinical trial it makes sense to ask a number of basic questions so you understand exactly what's planned. For example:

- What's the aim of the trial?
- What treatment will I get if I don't take part?
- How long will it last?
- Where is it taking place?
- What will happen if I leave the trial before the end?
- Will I need to take time off work?
- Will any travel costs be covered?
- What are the possible side effects of the new treatment?
- Who can I contact if I have a problem during the trial?

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Are there other types of trials or research that you can be involved in?

The simple answer is yes. Not all trials/research involves treatment - for example the (2016) 100,000 Genomes Project which is currently underway NHS wide. This project is looking at sequencing DNA from a patient's tumour and healthy cells. The two sequences are compared, which may help uncover the exact genomic changes causing an individual's cancer. This information can improve diagnosis. It may also help doctors choose treatments most likely to be effective for each person.

Similar projects, including biobanking, are being undertaken in NET specialist centres in England. Biobanking involves giving a sample of blood (or permission to use tissue from your biopsy or surgery) to be stored for possible future use in clinical research. Other types of research may include looking at how people experience cancer - from the care they receive to how it affects their everyday life.

For more information about the the 100,000 Genomes Project visit the Genomics England website:
www.genomicsengland.co.uk

The future of treatment

New treatments are being developed and tested everyday and existing treatments are being reviewed and re-tested in different combinations.

Research into cancer and cancer treatments is moving forward all the time, so don't be surprised if you're offered a treatment or trial that's not listed on the current trials list.

For further information on how you can get involved or learn more - visit our NET Surveys and Research page on our website:
www.netpatientfoundation.org

The main thing with any new treatment - and any existing treatment, for that matter - is never to feel pressured into anything. Treatment only starts with your consent, so keep asking questions and work with your care team to make the decision that's right for you.

EFFECTS OF NETS AND TREATMENTS



**REMEMBER THAT
THESE ARE JUST
POTENTIAL
SIDE EFFECTS**

SIDE EFFECTS, CONSEQUENCES AND COMPLICATIONS

While we all wish it wasn't the case, cancer treatments can cause side effects. So it's important to know what's normal and what's not - and to let your care team know if you experience anything unexpected.

Cancer treatments work in all kinds of ways, but they usually come down to either removing or killing cancer cells. However that's done, it's a lot for your body to cope with - and that's why there may be consequences or you may experience side effects during or after your treatment.

Often these are fairly minimal and can be easily managed. Sometimes you might experience less common side effects and need help from your care team to deal with them. But the most important thing is, however big or small they might seem, let your care team know.

No side effect is too small to mention

If you notice a change or don't feel well during, or after treatment, it can be tempting to ignore it. You might be worried that if you mention anything your doctors will stop your treatment. Or you might decide to leave it a few weeks rather than saying anything now.

But the sooner your care team know what's happening, the sooner they can begin to improve your treatment.

There are lots of ways treatments can be altered or adjusted. Dosages of drugs can be altered. Chemotherapy regimes can be adjusted. You can be given treatments in a different order. But all of that is only possible if you talk through any changes you notice with your care team.

The sooner your care team know what's happening, the sooner they can begin to improve your treatment.

GENERAL (COMMON) SIDE EFFECTS

If you feel tired . . .

If you feel discomfort or pain . . .

If you feel sick . . .

If your mouth is sore . . .

If you feel sick...

Sometimes you may feel unwell whether that means you actually are sick or feel like you could be.

There are various drugs - called anti-emetics - you can take to control this, so let your care team know if sickness is a problem for you.

And there are things you can do to help manage nausea and sickness, too. It may help to:

- Avoid skipping meals. It can be tempting not to eat if you've been sick, feel sick or don't have an appetite, but not eating can lower your blood sugar levels, causing nausea or making it even worse
- Eat small meals and snacks throughout the day instead of three big meals. Grazing is good!
- Avoid fried food, fatty food and foods that have a strong smell
- Avoid eating or preparing food when you feel sick. (If friends and family have offered to cook for you, take them up on it. Often people are keen to help and this is an ideal way to do it)

- Relax straight after eating. Sit down for a while to help your body digest your food
- Eat with other people to take your mind off how you're feeling
- Add ginger to your diet (however you want - from ginger ale to adding ground ginger to meals). Papaya can help to ease nausea too
- Drink peppermint or chamomile tea or suck on mints or tonic water ice cubes
- Eat light, bland foods like crackers
- Have small sips of drink throughout the day. Non-carbonated or flat, non-diet soft drinks like cola or lemonade can really ease nausea
- Avoid brushing your teeth straight after a meal - try an alcohol free mouthwash or a piece of sugar-free chewing gum
- Wear an anti-sickness bracelet or try complementary therapies like hypnotherapy or acupuncture (the evidence for these isn't conclusive, but people many find them useful).

If you feel tired...

This is a common symptom of NETs, as well as a side effect of a lot of NET treatments, and can be very difficult to deal with. It's not unusual to end up feeling drained even after treatments have finished, and if you're feeling fatigued it can be hard to cope with anything that could make it feel worse.

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You might find it helps to:

Get some exercise

This might be the last thing you fancy doing, but there's a lot of research that suggests doing something active when you have cancer can actually help give your energy and mood a boost. Gentle options like walking and swimming can help a lot, but take care not to overdo it - especially at first.

Get some rest

If you're tired, try to take a nap. Unfortunately fatigue is not always alleviated by sleep and rest, but giving yourself a regular rest time each day, may help with your overall sleep pattern and help recharge your energy levels.

Protect your rest time

It's easy to be overwhelmed by well-meaning visitors, so you could try making a timetable of things you'd like help with and when you'd like visitors. Company is important, but so is having time to rest. And there's a lot to be said for planning how people can help you out, imagine after a day's treatment getting home to a tidied house with the fridge stocked, dog walked and kids bathed and fed! Accepting help, doesn't mean you have to be there to supervise it, and can also help you manage your energy levels.

Focus on sleep

There are things you can try if you're struggling to get a good night's sleep - like going to bed at the same time each night, or avoiding caffeine after lunch, or not looking at your phone, tablet, laptop or even TV screen before you turn in for the night.

Keep your bedroom for sleep - cool temperature, comfortable and no or low technology - there are some relaxation programmes, tapes, CDs or apps that you can listen to, to help you relax and get off to sleep. Check your medications - do they advise on what time to take them? - and try keeping to that time. Some medications such as steroids can interfere with sleeping at night if taken late in the day. Work with your care team to manage any symptoms that may be keeping you awake or disturbing your sleep.

Arrange your life around your energy levels

Prioritise what you need to do and when you need to do it, based on how tired you're feeling. Not everything will need doing here and now, so try setting yourself a goal each day and concentrate on achieving that one thing. This can help to ward off any feeling of failure if you haven't completed everything on your to do list - and you can tick off every achievement as it happens. If working, you may need to talk things through with your employer about reducing or changing the hours you work.. We talk more about work in section 7.

Accept help

This can be difficult to do but, if you feel too tired to do what you normally do, let other people help you out. Your friends and family may well want to support you but not know how, and no one will think any less of you if you're not feeling up to getting the shopping in, vacuuming, walking the dog or cooking - and they may feel better knowing they are doing something that helps you.

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If you feel discomfort or pain...

Pain signals are initially processed in the spinal cord and then in the brain, where there are connections with centres associated with anxiety, emotions, sleep, appetite and memory. This creates a very personal experience of pain for each person. Only the person in pain can really say how painful something is. Because pain is always personal, no two people experience it in the same way.

'Painkillers' are possibly the treatment that most people expect to be given when they have pain. Finding the right treatment or medication and dose for you is important; identifying the cause and type of pain can help in deciding on what drug or treatment to use - if any. The correct dose of any medication is the minimum dose that produces the maximum benefit. Painkillers may not completely stop the pain but may help alleviate it.

There are things that you can do to reduce the effects of pain on your life, such as appropriate exercise, pacing your activity (not doing too much when you feel better) and relaxation. These things may not be obvious and they do not come easily. They may take practice to get the most out of them. However, they can be as effective as taking medication. Remember all treatments should aim to ensure your quality of life - don't feel you have to put up with pain. Talk with your care team about how you would prefer to manage your pain should it occur.

Pain can be the body's way of telling us that something is not quite right - don't ignore it - tell your care team. You can discuss how you would rather deal with it with them - identifying the cause can be vital in helping to minimise it.

If your mouth is sore...

Mouth ulcers, oral thrush and mouth pain can be pretty unpleasant side effects of treatments including chemotherapy, Sunitinib and Everolimus. You should tell your care team straight away if your mouth, tongue or throat hurts so they can help you to identify the cause and deal with it. Ideas that might help alleviate any discomfort include:

- Clean your teeth gently in the morning, before bed and after every meal using a soft toothbrush
- If brushing your teeth stings or makes you feel sick, try gargling with a bicarbonate of soda mouthwash (dissolve one teaspoon in a mug of warm water)
- Avoid mouthwashes that have alcohol in them
- Drink plenty of fluids
- Keep your lips moist with lip balm
- Eat stews, soups, yoghurts, ice cream and other soft food that are easy to chew and swallow
- Suck on ice cubes, frozen pineapple chunks or red ice pops (but not orange or yellow ones, which contain citric acid that can make your mouth worse)
- Avoid acidic fruits like oranges, grapefruits and lemons
- Avoid spirits, tobacco, highly spiced and salty foods, garlic, onions and vinegar.

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If you develop oral thrush (a white coating on your tongue and/or at the back of your throat), let your care team know so that it can be treated quickly and effectively. Thrush can travel to the back of your throat and into your food pipe, making swallowing difficult or uncomfortable.

If you're at increased risk of infection...

Your care team will let you know if your treatment could affect your immune system and make it harder for your body to fight infection. If you're in that situation, it's important to:

- Wash your hands regularly - especially before preparing or eating food and after going to the toilet, changing babies' nappies and clearing up after animals
- Bath or shower every day and wash your clothes, towels and bed linen regularly - try to avoid scented detergents and conditioners as these can irritate the skin
- Try and avoid people who have may have infections such as flu, an "upset tummy" or chickenpox, etc . . .
- Take care not to cut or graze yourself, and clean the area thoroughly and cover it with a sterile dressing if you do
- Prepare food carefully - wash and peel fruit and veg before eating, cook everything thoroughly and avoid raw/ rare meat, runny egg yolks and shellfish (especially if your white blood cell count is low)
- Avoid swimming in public pools, the sea and open water lakes if your white cell count is low
- Your care team will advise on specific precautions and care, and may provide written information.

If you're worried about sex...

Living with and having treatment for a NET can have a big effect on how you feel about yourself, your body image and sex.

Not feeling "in the mood" - reduction or loss of libido - can be experienced by both men and women; cancer and its treatments can leave you feeling fatigued, unattractive, too tired - "not bothered". Recovering from major surgery can affect desire, comfort - even the position you may usually use. It may also alter how you feel about yourself. However, there are benefits in maintaining your normal sex life, not least for your self-esteem and intimate relationship.

Sex should be consensual and enjoyable, however, when under stress or as a result of treatment, some men may experience difficulty in getting or maintaining an erection, some women may experience vaginal dryness, infection (such as thrush) or vaginal spasming (vaginismus), making sex uncomfortable or even painful. There are ways of being intimate without having to have penetrative sex.

If you are experiencing any worries about sex, try to talk things through with your partner and/or your care team - who may be able to help with the issues you're facing.

Your care team will understand that sex is a part of everyday life for most people and they will deal with it sensitively - should you want to talk.

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Precautions for the sexually active

Depending on which treatment you're having, your care team might advise you about precautions you need to take if you are having sex. For example, certain drugs and chemicals (such as chemotherapy and those used in PRRT) can:

- Pass into all body fluids (including sperm and vaginal fluid)
- Affect your fertility
- Cause harm to a developing foetus or breastfed child.

As such, it's important to discuss the potential effects of any treatments with your care team, who will be able to suggest the best ways to respond.

You may be advised to use a condom and/or cap to protect your partner and to avoid getting pregnant (or getting your partner pregnant). While it's not unusual for your sperm count to drop or for your periods to stop during cancer treatment, pregnancy can still happen.

And if you're a mum to a baby or infant, you may be advised against breastfeeding during and after certain treatments.

You might also be advised to avoid penetrative sex (oral, vaginal and anal) if your white cell or platelet count is lowered. We all have normal, healthy bacteria that live on and in our bodies that can be passed on during sex, but if our immune systems are lowered these bacteria can be a source of infection. Oral, vaginal and/or anal sex may also cause bleeding or bruising, if your platelet count is low.

If you're worried about fertility...

Some cancer treatments can affect your ability to have children in the future. This can be a difficult issue to consider, but if your fertility could be affected it's important to talk to your care team about what the impact could be and whether it's likely to be temporary or permanent.

If you might want to have children at some point, you may want to think about sperm banking and/or egg preservation. Some options may be available on the NHS. Otherwise there may be certain restrictions or costs involved, but your care team will be able to talk through what's possible in your situation.

As we have said, try not to be embarrassed about discussing these issues - your care team will understand that this is an important subject and will know how to respond sensitively.

SIDE EFFECTS AND CONSEQUENCES OF SPECIFIC TREATMENTS

Remember that these are all just potential side effects. You might find you get on well with treatment and experience very few of the issues listed here.

Surgery

Your recovery from surgery depends on a lot of different factors, including your general health, where on your body you had surgery, the type and complexity of surgery and whether there were any complications. Your care team will talk you through possible side effects of any procedure you're due to have, but common symptoms after surgery include:

Feeling pain

Your care team will give you drugs and advice to help manage pain. You should begin to feel more comfortable a few days after your operation, though you may still get some discomfort, especially as you start to return to your normal level of activity.

Bleeding

Your care team will explain what you need to do to care for a wound after surgery. If a little bleeding occurs, you might be shown how to cover it again with a clean, dry dressing. If there's a lot of bleeding, though, you'll need to seek help straight away.

Swelling and bruising

These are both normal reactions to surgery, but keep a close eye on any swelling or bruising and let your care team know if it doesn't improve (or gets worse) after a few days.

Infection

If the place where you had surgery is red, feels warm and gets more painful, it could be infected. Let your care team know if you experience these side effects in case you need antibiotics.

Remember that these are all just potential side effects. You might find you get on well with treatment and experience very few of the issues listed here.

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Fluid leaking from your wound

Sometimes fluid that's built up after an operation can seep from your wound. This usually isn't anything to worry about but let your care team know if the amount of fluid increases, it smells bad or the wound is red or warm.

Feeling tired

It's normal to feel wiped out after surgery. This can seem to come and go in the first few days - but by the time you are set to go home you may feel this is improving. However it is not unusual for fatigue to re-emerge once home - usually around the second week. This feeling of being so tired you just want to sleep may be accompanied by feeling slightly low in mood - this, as said, is not uncommon. It is partly down to the anaesthetic and other medications wearing off, partly because your body is using extra energy to heal itself and partly relief that surgery is over.

Feeling low

It's not uncommon to feel down once you get home or up to a couple of weeks after surgery. This is a totally natural reaction to all of the activity of the past few weeks.

You might be home and feeling vulnerable because there's no care team around or call bell to press if you're worried. You might be concerned about whether the operation has worked or what happens next. Or you might be frustrated by what you can and can't do. If this sounds familiar, you can always talk with family and friends, call your specialist nurse and/or arrange a post-op appointment with your GP.

Speaking to your GP ensures they know you're back home and means they can help you deal with any issues. Often just having someone to listen can ease your worries.

Incisional hernia

This is a bulge or lump that can develop next to or along the cut made for your operation. You'll be advised to restrict or avoid activities like lifting, vacuuming, changing the bed and driving for a while after abdominal surgery, to avoid an incisional hernia occurring. This allows time for your body to heal completely, as doing too much too soon can cause permanent weakness to the area, e.g. abdominal wall, and delay healing. It's a good idea, before surgery, to ask for advice and exercises that can help your recovery.

Altered function

If you've had a part of your body removed, that can alter how your body functions. So after bowel or pancreas surgery, for example, you might notice changes in how often you need to go to the toilet or in the appearance of your stools. (You can read more about symptoms like diarrhoea and constipation starting on page 108.)

Or if you've had lung surgery, it's normal to feel tired and short of breath afterwards. You'll be encouraged to take regular, gentle exercise to help your lung(s) recover, but if you've had a whole lung removed then you may always feel slightly tired.

Altered function following surgery can be temporary or longer lasting, and you may need to take medication to manage any consequences you experience.

Side effects of somatostatin analogues (SSAs)

The pharmaceutical companies that manufacture somatostatin analogues (which include drugs like lanreotide and octreotide) list the potential side effects as:

- Loss of appetite
- Feeling and being sick
- Feeling bloated
- Stomach pain and/or cramping
- Diarrhoea and/or steatorrhoea
- Soreness where you're injected.

In fact, as is often the case when you read the information that comes with medicines, the list of side effects for SSAs can seem the same (or worse) as the symptoms you're hoping to reduce.

But while of all these problems can occur, not all of them will, and most people find that the side effects of SSAs are temporary and can be resolved.

Occasionally, certain side effects may develop after you have been on SSAs for some time, even years. These can include gallstones - if you still have a gall-bladder (though you'll have regular scans to monitor for these), leg pain, thinning hair and a slower heart rate. If you experience any of these symptoms, you should discuss them with your care team (please note that unless they are severe, you may not need to stop treatment or reduce your dose).

SSAs can also cause your blood sugars to rise or fall, so this may need to be monitored over time. If you're diabetic, you may need to check your sugar levels more often and possibly increase or decrease your medication. Your care team will also want to discuss the possible impact of the SSAs on your blood sugar, and they, along with your GP, will be able to help you manage any changes in your medication dose.

Do somatostatins cause other side effects?

A lot of people with NETs have told us they've experienced other - mostly mild to moderate - side effects not mentioned in the official literature. So many, in fact, that we launched a piece of research to investigate this in more detail.

Our survey into 'Self-reported symptoms/side effects after commencing SSA' was presented at the European NET Society Conference.

In order of importance / occurrence, NET patients told us they experienced:

- constipation, steatorrhoea, diarrhoea,
- "burden of disease" (psychological impact),
- Vitamin B12 deficiency,
- hair thinning,
- nausea,
- Vitamin A, D, E & K deficiencies,
- weight loss,
- low blood sugars
- gallstones.

For further information about our surveys and patient news visit the NET News and Publications pages on our website : www.netpatientfoundation.org

Side effects of interventional radiology

Embolisation - including hepatic artery embolisation (HAE) and portal vein embolisation (PVE)

Potential side effects include:

- Discomfort or pain in the right side of your abdomen and/or right shoulder (this can usually be controlled with simple painkillers such as paracetamol)
- Bruising or bleeding (usually where treatment took place, so in the groin for HAE and in the abdomen for PVE)
- Feeling hot and developing a temperature (you'll have antibiotics before and after the procedure to reduce this risk)
- Experiencing flu-like symptoms
- Post-embolisation syndrome (a collection of symptoms including fever, nausea/vomiting and pain, experienced within 24-72 hours of treatment).

Very rarely, embolisation can cause the liver and kidneys to deteriorate or stop working completely. This is more common in HAE than PVE, and you'll have regular blood tests to monitor this.

Ablation - including radiofrequency ablation (RFA), microwave ablation and irreversible electroporation (IRE aka NanoKnife)

Potential side effects include :

- Discomfort or pain at the place where ablation took place (this can usually be controlled with simple painkillers such as paracetamol)
- Bruising or bleeding (usually where treatment took place)
- Blood clotting (clots may develop in the blood vessel(s) nearest the area of treatment)
- Feeling hot and developing a temperature or infection (you'll have antibiotics before and after the procedure to reduce this risk)
- Experiencing flu-like symptoms
- An abscess (as the tumour is destroyed and cells die, an abscess can form leading to the same symptoms as an infection. Antibiotics are usually enough to help treat this, but occasionally the abscess may need to be drained or, rarely, may need to be removed through surgery)
- Inflammation of surrounding tissue for example if you have had RFA or IRE to a pancreatic NET, this may cause pancreatitis (inflammation of the pancreas)
- Ablation procedures in the lungs can cause fluid to collect in the lung and can cause lungs to collapse.

Side effects of radiotherapy

Peptide receptor radionuclide therapy (PRRT)

Potential side effects of Lutetium-177, Yttrium-90 and mIBG PRRT include:

- Pain after treatment
- Feeling and being sick (usually only associated with the amino acid infusion given at the time of therapy)
- Diarrhoea
- Feeling tired
- Increased risk of infection
- Kidney damage (though this is rare)
- Low platelet levels.

It's the infusion of amino acids you're given before PRRT that can cause vomiting and nausea, but there are drugs you can take (called anti-emetics) to stop you from being sick - so let your care team know if you feel unwell. Most NET centres now give all patients an anti-emetic before PRRT.

PRRT therapy can also affect your blood cells, in particular your platelets. Platelets are the blood cells that help stop bleeding by forming a scab over a graze or cut. If your platelet count falls you may be at increased risk of bleeding and may notice bruising (even without injury), nosebleeds or bleeding gums.

Your blood count will be carefully monitored during PRRT but if you notice any bruising or bleeding let your care team know straight away. Normally your body will help correct any drop in your platelet count, but on rare occasions you may need a platelet transfusion. Your care team will provide written information about PRRT, including potential side-effects.

Selective Internal Radiation Therapy (SIRT)

Potential side effects of SIRT are similar to the ones caused by embolisation and PRRT therapy. They can include:

First 48 hours

- Feeling and being sick
- Pain in the right side of your abdomen or right shoulder.

First few days

- Feeling hot and developing a temperature or infection (you'll have antibiotics before and after the procedure to reduce this risk)
- Experiencing flu-like symptoms
- Diarrhoea
- Feeling pressure in your abdomen.

For up to six weeks afterwards

- Feeling tired (this is usually fairly mild, so you can still do your usual everyday activities)
- Loss of appetite.

You will be given medication to take for a month after SIRT treatment to reduce the chances of being sick and/or getting stomach ulcers. You'll also be given a dose of steroids that reduces over time, to help limit or prevent any potential liver inflammation.

More serious side effects of SIRT include damage to the lungs, liver and gallbladder, but these are all rare. As we mentioned in the treatments section, stage one of the SIRT procedure is carried out to reduce the risks of serious side effects. Your care team can answer any questions you have about these risks.

Side effects of chemotherapy

There are many different chemotherapy drugs and everybody reacts to them differently, so your care team will discuss specific potential side effects with you. But some common ones include:

- Feeling tired (this can carry on for several months after your treatment ends)
- Feeling and being sick
- Weight loss, diarrhoea and/or constipation (you can read ideas on how to deal with both of these in the nutrition section of this handbook)
- Increased risk of infection
- Hair thinning or loss (see box below)
- Dry skin and skin rashes - particularly on the hands and feet
- Brittle or dry nails
- Numbness or tingling in the hands and feet.

Dealing with hair loss

A lot of people find this tough to cope with - and worrying about it doesn't make you vain.

Losing your hair can be hard to deal with, but is not a definite consequence of all chemotherapy drugs. There are a number of normal cells within our bodies that normally divide rapidly - such as our hair and the lining of our digestive system. This is why certain side effects can occur - however not all chemotherapy causes hair loss.

If it does happen, hair anywhere on your body can be affected, but it can grow back after treatment is completed.

Useful tips people have shared include:

- Have your hair cut short before treatment, because the shift from a shorter style can seem less of a shock
- Use of a wig or scarves or hats: if hair loss is associated with the chemotherapy you are about to receive, your care team can refer you for wig-fitting prior to starting treatment. Some wigs and scarves will be available free on the NHS - the quality and selection of these has much improved over time
- Get in touch with other people who have lost their hair. Your care team will let you know about support groups you can contact
- Be kind to yourself: losing your hair can feel like a big deal because you're reminded of it every time you look in mirror, and our appearance can be strongly linked in with how we see ourselves - but you've always been more than just a hairstyle, and you always will be.

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Let your care team know if you experience any side effects while taking drugs to treat a NET - but don't change your dose or stop taking a drug unless you're advised to.

Targeted therapies and Interferon

Sunitinib

The pharmaceutical company that produces Sunitinib have listed the following as possible side effects:

- Redness, tenderness and blisters on your hands and feet. You can reduce the impact of this by:
 - Moisturising with creams that contain lanolin, urea and/or vitamin A
 - Washing gently using lukewarm water and mild soap
 - Drying your skin gently
 - Using suncream
 - Wearing loose clothing and comfortable shoes
 - Avoiding anything that puts a lot of pressure on your feet or hands.
- Mouth ulcers
- Diarrhoea
- Constipation
- Feeling sick
- Loss of appetite and weight loss (see

the nutrition section of this handbook for ideas on dealing with these issues)

- Feeling tired
- Changes to your hair and skin colour (wearing suncream can help to protect your skin)
- High blood pressure (symptoms of this can include headaches, feeling faint, dizziness and an irregular heartbeat - but there are sometimes no symptoms, so your care team will monitor your blood pressure regularly)
- Indigestion and stomach pain (see the section on nutrition for ideas on dealing with indigestion).

Everolimus

The pharmaceutical company that produces Everolimus have listed the following as possible side effects:

- Mouth ulcers
- Increased risk of infection
- Coughing and feeling short of breath
- Feeling sick
- Loss of appetite and weight loss (see the nutrition section of this handbook for ideas on dealing with these issues)
- Diarrhoea
- Constipation
- Changes in blood sugar levels
- Fever
- Feeling tired
- A red rash.

Look out for infections

Potential signs of infection include a headache, a cough, a sore throat, pain when going to the toilet and feeling cold or shivery. Contact your care team straight away if you experience these symptoms or your temperature is higher than 38°C.

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Interferon Alpha

Potential effects of Interferon Alpha include:

- Pain, redness, itching or swelling where you've had the injection
- Thinning hair (this is more likely after a high dose or long course of Interferon)
- Dizziness
- Loss of appetite
- Changes in the way things taste (see the nutrition section of this handbook for more on this)
- Increased risk of infection
- Feeling tired and breathless
- Feeling weak
- Flu-like symptoms
- Diarrhoea
- Tummy pain
- Feeling sick
- Experiencing emotional changes, including depression
- Struggling to sleep
- Headaches
- Weight loss (see the nutrition section of this handbook for more on this)
- Itchy skin or rashes
- Coughing
- Sudden sharp pain.

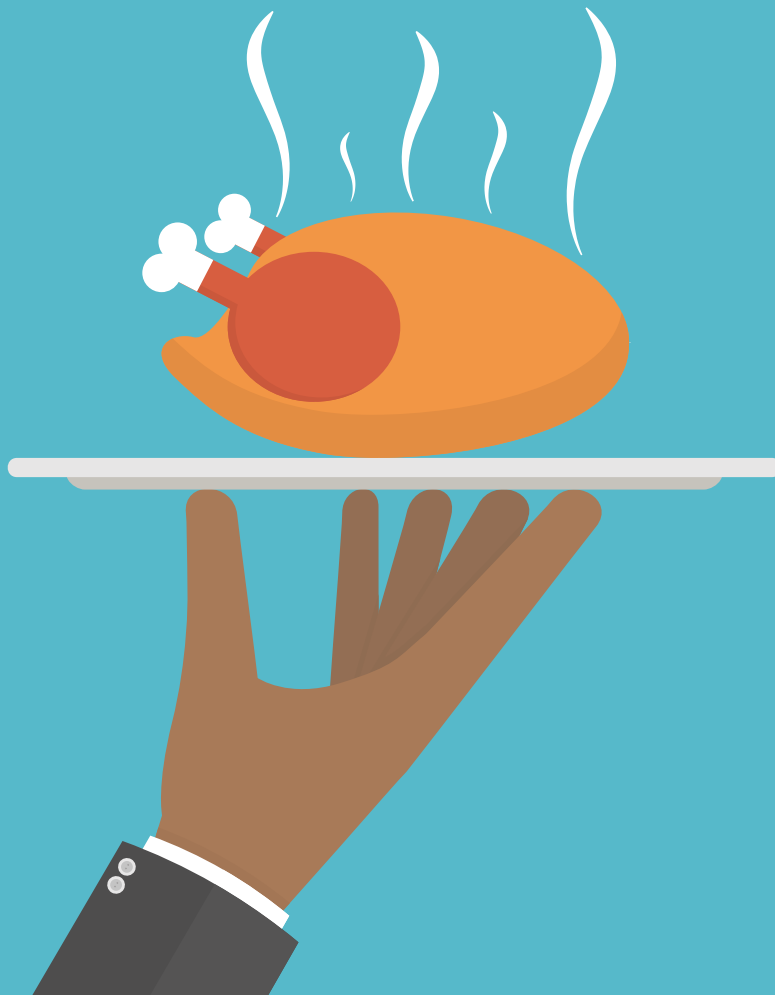
We know that's a long list (and there are other, less common side effects too) but remember that you definitely won't get all of these, if any.

If you experience any side effects or new symptoms during any treatment, it's important to mention them to your care team - however minor they may seem to you.

In the UK the MHRA (Medicines and Healthcare Products Regulatory Authority) have the Yellow Card Scheme to help monitor safety of all medicines and healthcare products to ensure they are safe for those who use them.

For more information visit the website: <https://yellowcard.mhra.gov.uk/>

DIET AND NUTRITION



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**THERE'S NO ONE
DIET SUITABLE
FOR EVERYONE**

NUTRITION

We have based this section on the questions we're asked the most frequently - and hope it'll help you to feel more confident about what to put on your plate.

Is there a special NET diet?

This is the question about nutrition we're asked more than any other - and, in a word, the answer is no.

There's no one specific diet suitable for everybody who has a NET. There may be adjustments you need to make to what you eat. You may need to add things to your diet based on your general health, your treatment, the type of NET you have or if you're losing weight. But there isn't a special diet that everyone should follow.

Unsurprisingly, though, as when you're dealing with any kind of cancer, eating well makes sense. A normal, healthy, well-balanced diet can help you to:

- Stay at a healthy weight
- Maintain a healthy immune system, which can protect you from infections
- Cope with treatment
- Maintain your fitness level, so you have the energy to exercise and do everyday tasks
- Recover and heal after treatment.

If you're losing weight because of your NET or if your dietician has advised you to eat a special diet, then follow the specialist advice you've been given.

So before we look at how you might need to alter your diet following a NET diagnosis, let's remind ourselves of the advice for a healthy, balanced diet and take a look at what happens in our body when we eat (see digestion pull-out diagram on page 100)

Fruit and vegetables

At least five a day - try to get a good mix.

Starchy carbohydrates

Choose wholegrain and high fibre breads, rice, pasta and potatoes.

Oils and spreads

Look for unsaturated options and don't use too much - but remember that you do need a little fat in your diet.

Proteins

Meat, beans, pulses, eggs, nuts and at least two portions of fish a week.

Milk and dairy

Go for lower fat, low-sugar milk, yoghurt and cheese.

Keep well hydrated

Aim for 8-10 glasses/cups a day - water, lower fat milk, low-sugar/sugar-free drinks, tea and coffee.

Go easy on fat, salt and sugar

Limit things like chocolate, cakes, biscuits, soft drinks, butter and ice cream.

Keep well hydrated

Aim for 8-10 glasses/cups a day – water, lower fat milk, low-sugar/sugar-free drinks, tea and coffee



Fruit and vegetables



Fat, salt and sugar

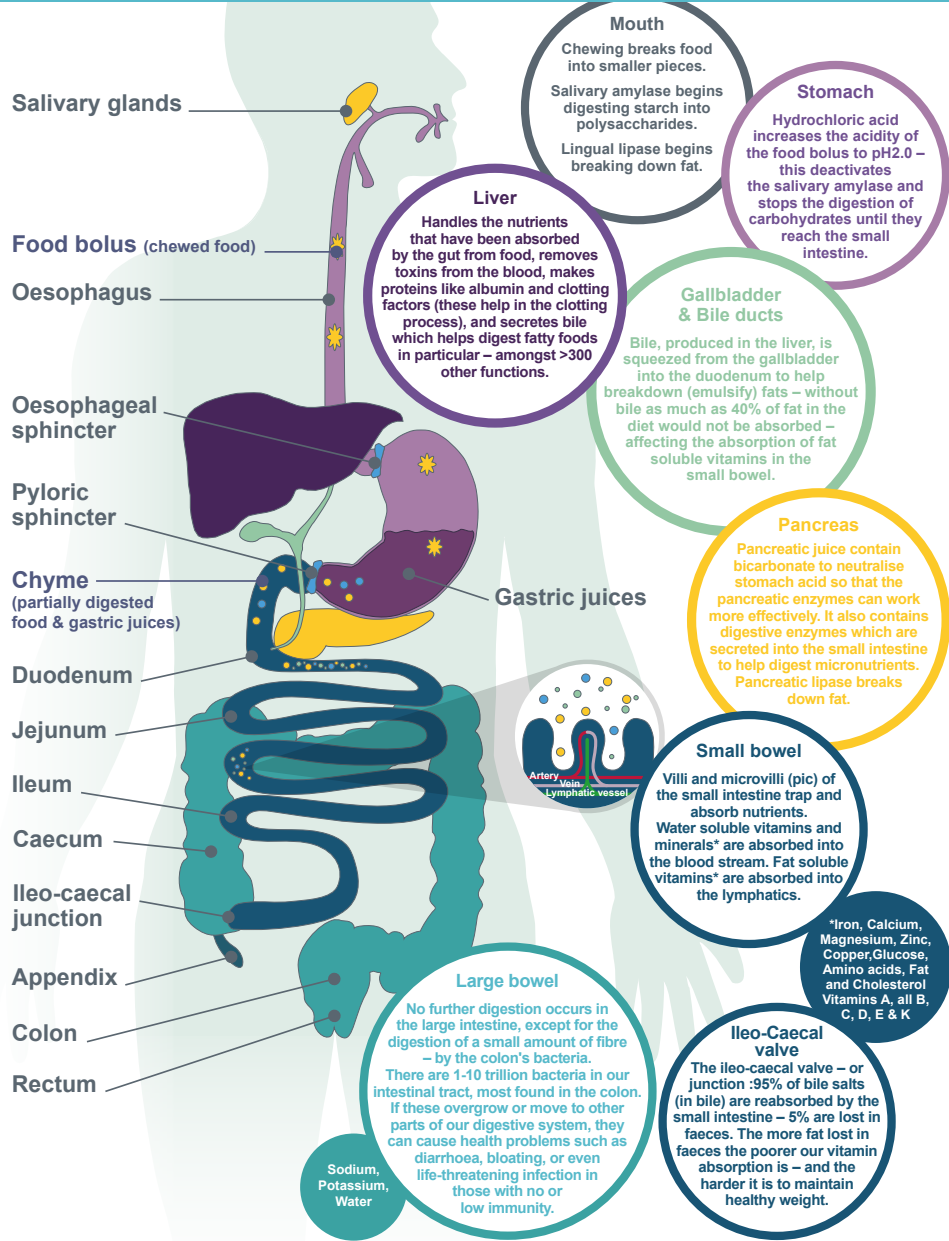


Proteins





DIGESTIVE SYSTEM



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The big food myth busted

Sugar is not your enemy!

If anyone tells you that avoiding sugar can stop cancer cells from growing, ignore them! This idea has been doing the rounds for a while - but it's just not true. Every cell in the body needs sugar to do its job. Starve your cells of sugar and they can't work properly.

- Yes, hidden sugars can be a problem because they make it hard to know how much we're eating.
- Yes, eating too much sugar can contribute to problems like obesity.
- And, yes, you do need to control your blood sugar levels if you have diabetes.

But none of that means you should cut out sugar completely. Instead, try and be aware of how much you're eating and don't overdo it.

Eating well with a NET

If you have a specific syndrome or symptoms because of your NET or NET treatment, making simple, small adjustments to your diet can mean they affect you less often - or stop happening completely.

If you have carcinoid syndrome

Carcinoid syndrome (which you can read about on page 25) can occur when NETs release too much of the hormone serotonin. High amounts of serotonin cause levels of an amino acid called

tryptophan to drop: tryptophan is turned into the vitamin niacin (aka vitamin B3) in your body. So if you have carcinoid syndrome, your levels of niacin might be too low - and there are two things you can do in response:

- High-protein foods contain tryptophan, so eating more of those is a good idea. Fish, lean meat, eggs, low fat dairy foods, pulses, nuts and products containing whey protein are ideal
- Ask your care team about prescribing either a Vitamin B3 (Niacin) or a vitamin B strong compound daily tablet.

Vitamins and mineral supplements

Before taking supplements, we'd recommend that you have a full vitamin and mineral blood screen test. This can identify any significant deficiencies and make sure any changes to your diet are appropriate. Certain deficiencies might need medication, rather than food, and the test will show this. Your care team can let you know more about this test and what the results mean for you.

Foods that can trigger carcinoid syndrome

You might find that certain foods trigger carcinoid syndrome symptoms - stomach pain, diarrhoea and/or flushing. Different foods affect different people, so the best way to identify any problems is to keep a food diary for two weeks. Keep a record of:

- Type of food
- Portion size
- Symptoms

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If you find that something does appear to trigger your symptoms, try reducing the amount that you eat. If that doesn't work, you might need to stop eating it - either temporarily or for good.

Food should be enjoyable, so if you find that a food you love triggers symptoms but doesn't make you feel too unwell, you could try limiting how much you eat - rather than giving it up completely. If a bar of chocolate causes flushing, for instance, you might find that a single square is OK - and can still feel like a treat.

Common triggers include:

- Large meals
- High-fat and/or highly spiced foods
- Alcohol
- Foods HIGH in substances called amines. These include:
 - Mature, aged and blue cheeses
 - Alcohol
 - Smoked and salted fish and meat
 - Fermented tofu
 - Miso
 - Sauerkraut
 - High-caffeine foods
 - Chocolate
 - Peanuts
 - Brazil nuts
 - Raspberries
 - Soy bean products like soy sauce
 - Broad beans.

But rather than just advise what to avoid - alternatives to foods HIGH in amines are those LOW in amines

- So enjoy:

- Fresh lean meats, fresh poultry, fresh fish
- Most vegetables - but cooked may be better tolerated than raw
- Fruits in moderate amounts - but not banana, avocado, raspberries
- Grain foods, starchy foods - soluble or lower fibre, or soft cooked grains may be most tolerated
- Fresh, mild, low fat cheeses and dairy
 - for example low fat cottage cheese, ricotta, mozzarella, yogurt or kefir, cream cheese, milk or lactose-free milk
- Fresh soyfoods - soymilk, edamame.

Functional pancreatic and duodenal NETs

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

Insulinomas (pancreatic)

Insulinomas pump out insulin, which lowers blood sugar levels. Changing your diet can't stop an insulinoma from doing this, but it can help you to have more control over your blood sugar levels.

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

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In general:

- **Eating low-GI or “slow-release” carbs helps to keep your blood sugar levels stable for longer, avoiding highs and lows**
- **Eating high-GI carbs is useful to get your blood sugars back up if they drop very low (which is known as hypoglycaemia).**

Handy tip: having a bedtime snack can stop your blood sugars dropping too much while you sleep.

Low-GI foods

- Most vegetables (exceptions include carrots, parsnips and swedes)
- Some fruits (including apples, cherries, pears and strawberries)
- Nuts and seeds
- Bread made with wholegrain or sourdough
- Bran-based and wholegrain cereals
- Whole-wheat pasta, noodles, pearl barley or quinoa
- Jacket potatoes with the skins on
- Bean, lentils and pulses
- Brown and basmati rice
- Wholegrain crackers and crisp breads.

Eating a low-GI diet is a great way to keep your energy levels more constant, which can help you to overcome tiredness - one of the major side effects of NETs.

High-GI foods

The following are useful to keep to hand if you're at risk of becoming hypoglycaemic:

- Dextrose tablets or oral glucose paste
- Wine gums
- Liquorice allsorts
- Energy/sports drinks - the non-diet versions
- Ribena - non-diet
- Soft drinks - non-diet.

If you need to have high-GI foods regularly to counter low blood sugars, it can be easier to put on weight, as the body stores excess glucose as fat. If you're worried about managing blood sugars and/or weight, speak to your care team about putting you in touch with a dietician.

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Gastrinomas (pancreatic and duodenal)

Gastrinomas (pancreatic and duodenal) produce the hormone gastrin, which stimulates secretion of gastric acid (HCl). It is released by G cells in the stomach, duodenum, and the pancreas. This can cause indigestion, sickness, diarrhoea, and weight loss. You may also experience difficulty in swallowing (dysphagia). Too much gastrin can lead to stomach and/or duodenal irritation, ulcers and/or bleeding, this can lead to anaemia.

If you have a gastrinoma you may be prescribed medications to reduce or block the production of acid and to help correct anaemia (either in tablet or injection form).

Dietary advice includes avoiding foods that might increase symptoms of heartburn or indigestion, these include:

- Large meals
- Spicy flavourings
- Citrus fruits - and juices
- High fat foods
- High fibre foods
- Pickles or vinegar.

If you are having difficulty in swallowing - soft or puréed foods may be easier to eat. Ask about seeing a dietician and supplemental foods/drinks to help you maintain your nutritional intake.

Glucagonomas

Because they produce large amounts of the hormone glucagon - which increases blood sugar levels - glucagonomas can cause a range of issues related to blood sugar, including diabetes. If you are diagnosed with diabetes, your care team will give you advice on how your diet needs to change.

Glucagonomas can also cause diarrhoea, a sore mouth and weight loss - all of which are covered in the next section, starting on page 106.

VIPomas

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

- Increase the amount of potassium-rich food and drink in your diet (see p105 for examples)
- Drink 10-12 cups/glasses of non-alcoholic, caffeine-free drinks every day.

VIP-related diarrhoea can be severe. You may find that rehydration sachets and/or supplements - taken alongside potassium-rich food and drinks - help.

If your symptoms persist or get worse, though, let your care team know immediately. You may need to go into hospital for rehydration via a drip or to have a treatment such as potassium replacement.

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Health problems can also be caused if potassium levels are raised too quickly or too high, so speak to your care team if you're worried about this. And bear in mind that VIPomas can

also lead to weight loss. We look at ways to maintain your weight in the next section, starting on page 106.

High potassium food and drinks

- Tomato juice
- Prunes
- Avocados
- Swiss-style muesli
- Kidney beans
- High-bran cereals
- Dried dates
- Nuts
- Figs
- Raisins and sultanas
- Dried apricots
- Potatoes
- Oranges
- Bananas
- Nutrition shakes like Complan.

Somatostatinomas

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

You may also notice that your stools are pale, float in the toilet and/or are difficult to flush away. We discuss all of these issues in the following section.

A quick note on 'miracle diets'

It's very easy to find tabloid news stories and online forum discussions suggesting that all kinds of alternative diets - from sugar-free to dairy-free to nothing-but-juice - can help to slow down cancer. Unfortunately, not only is there very little evidence to support these, but they could actually be unsafe if they deprive your body of vital nutrients.

So if you are tempted to try new diets or to stop eating certain things, please talk to your care team and nutritionist/dietician first. They'll be able to give an expert opinion on what's really most likely to work for you.

Nutraceuticals

There are some promising studies looking into 'nutraceuticals', which are nutrients that may act like medicines. This includes things like curcumin and green tea compounds.

These aren't available as standalone treatments yet, but might be useful alongside more traditional options. If you're interested in joining a study into nutraceuticals or are thinking of trying them, ask your care team and nutritionist/dietician.

COMMON NUTRITION PROBLEMS WITH NETs

NETs and/or their treatments can lead to a number of unpleasant or even distressing problems related to your weight and how your body processes food - but there are ways that you can help yourself to reduce or control how these may impact on your life.

For each of the following problems the key to help manage them is in understanding the cause - if that cause can be identified and removed that should help. However not all causes can be removed or treated - and so we have put together a few handy tips that may help reduce the impact these problems may have on your life.

Losing weight

If you find yourself losing weight without trying to, you should let your care team know so they can refer you to a nutritionist or dietician for tailored advice. And if you find that eating becomes a chore rather than a pleasure, try to chat about how you're feeling with your nutritionist/dietician.

It can be difficult if people comment on your weight loss or what you're eating (or not eating). You may find, being encouraged to eat, especially when it's the last thing you want to do, irritating or upsetting.

But try to remember that food is your friend - and if you want ice cream for breakfast or can only manage a few mouthfuls of a meal, that's far better than eating nothing at all. So concentrate on the flavour and enjoy.

A few tips people have shared with us for eating after a NET diagnosis include:

- **Eating little and often** - small, frequent meals and snacks rather than 3 large meals for breakfast, lunch and dinner
- **Using a side plate or saucer** - which can seem less daunting than a larger plate and help food seem more manageable and appetising
- **Eating when you feel hungry or at regular intervals 2-3 hourly** - rather than at set times **e.g. breakfast, lunch and dinner**
- **Chopping up food small** - to make it easier to stomach if you're not feeling well
- **Not forcing it** - if you really can't face a plateful of food, try a few bites, then wait an hour or 2 and try again later but try not to skip food. Not eating (or taking a supplement) can make symptoms like nausea worse
- **Avoid strong-smelling food** - it's more likely to make you feel worse if you're feeling sick - though **strong tasting/high flavour** foods may help stimulate your appetite

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- **Not overdoing your favourite foods**
- sometimes when we're unwell or feeling sick, we want comfort food, however, if that's all you eat it may not remain your favourite food very long - you don't want to put yourself off it/ them. So try to alter your intake and maybe have your comfort food as a reward!
- **Taking control when you eat out** -
ask for a small portion, a child's portion or a doggy bag, and speak to the waiter about portion sizes. And if you only fancy a starter or pudding, ask for it to be brought out with everyone's main courses.

Foods to help you maintain or gain weight

Your dietician will let you know specific foods to help you maintain your weight. Possible options include:

High-protein foods

Fish, lean meat, eggs, dairy foods, pulses, nuts and products containing whey protein.

Energy-boosting food

For example foods high in fat and/or sugar, like oils, nuts, butter and margarine, and full-fat dairy products, like whole milk, full-fat cheese, full-cream yoghurts and double cream.

Fortified milk

Add 3-4 tablespoons of skimmed milk powder to a pint of milk to increase its protein and calorie content, then use it as you'd usually use milk.

Breakfast cereals

Try adding dried fruits, nuts, sugar, honey, yoghurt, evaporated milk and cream to your cereals, and eat with fortified milk or a nutrition shake.

Stews and casseroles

Add noodles, lentils, beans, cream and sour cream for a bigger energy boost.

Sandwiches, toast, biscuits and jacket potatoes

Extra fillings and toppings like butter, margarine, mayo, cheese, peanut butter, olives and avocado can all help.

Vegetables

Add grated cheese, oil, butter and margarine to your veg to include a little more fat while you get your five a day.

Salads

Oils, mayo, salad cream, salad dressing, Greek yoghurt, nuts and seeds can all help you to maintain your weight.

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Drinks to stop weight loss

If your mouth is hurting or you can't stomach the thought of a meal, drinking can be easier than eating. Try these ideas between meals rather than with meals, to avoid filling yourself up too much:

Milky drinks

Now's the perfect time for hot chocolate, Horlicks, Ovaltine and Nesquik - made with full-fat milk.

Milk with extras

Make fortified milk by adding 3-4 tablespoons of skimmed milk powder to full-fat milk, then add a scoop of ice cream or whey protein powder.

Milkshakes and smoothies

Try full fat milkshakes, yoghurt drinks and fortified drinks like Complan and Nurishment. You can add ice cream to these too.

High-energy shots and fortified soups

These can be ideal if milk isn't your thing.

Custard, rice pudding, semolina and porridge

Top them up with syrup, honey, jam or molasses.

Diarrhoea

Excess hormones, infections, treatments including surgery and certain 'trigger foods' can all cause diarrhoea when you have a NET.

It's important to try and understand what the cause is and whether it's likely to be temporary or a long-term issue. So if you do get diarrhoea you should always let your care team know and describe the details to them (how often it's happening, when it's happening, what it looks like etc.). There are specific medicines and treatments depending on what's causing the problems.

If you look at the digestion pull-out diagram on page 100, you can see what happens where: if you have had part of your pancreas removed the cause of diarrhoea may be different to having had part of your small bowel removed - and so the treatment will be different.

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These ideas can also help:

- **Eat little and often, instead of having big meals**
- **Eat low-fibre, starchy foods** like white bread, rice, pasta and potatoes without their skins
- **Try and eat foods rich in soluble fibre** (which slow digestion) rather than insoluble fibre (which speeds up digestion). This includes things like oats, nuts, seeds, beans, peas, lentils, apricots and jams with a high fruit content
- **Peel and cook fruit and vegetables.** For tomatoes, remove the skins and seeds
- **Avoid spicy and fatty foods and caffeine**, all of which can cause or make diarrhoea worse
- **Drink smooth juices**, rather than juices with bits in
- **Pro-biotic drinks** may help (unless you're having chemotherapy, in which case check with your care team first)
- **Have plenty of drinks**, ideally 8-10 cups/glasses a day. This won't help stop your diarrhoea but will help to stop you getting dehydrated. Try to avoid drinking with food though, as this can flush food through your system.

Steatorrhoea

This can be caused by treatments including somatostatin analogues and surgery, which can affect how the pancreas works. Your body becomes unable to absorb fat properly, so your stool becomes abnormally fatty. This makes it very smelly, greasy and frothy. It can also be difficult to flush away.

If you're diagnosed with steatorrhoea, you might need to:

- **Reduce the amount of fatty foods you eat**, until the condition is under control
- **Have pancreatic enzyme replacement therapy (PERT).** This involves taking capsules, just before or when you eat, which contain the enzymes usually produced by your pancreas to help break down food. Your care team will let you know how many to take, but you'll probably start on a low dose and gradually increase it until your symptoms are under control. You may also need to alter how many capsules you take based on what you eat, as richer foods may require more PERT. Everyone is different, so you can safely adjust your dose based on your symptoms or what you're about to eat!
- **Take vitamin supplements as recommended by your care team/dietician.** If your body isn't absorbing enough vitamin A, D, E, K and/or B12, you may be given supplements to make up for this.

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Constipation

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

- **Drink plenty of water** - ideally a few more glasses/cups on top of the usual 8-10 per day
- **Drink prune juice, or syrup of figs**
- **Keep mobile and do some exercise**
- **Eat a high-fibre diet** (see box below).

Wind and feeling bloated

These symptoms can be linked to both diarrhoea and constipation. You might find it helps to:

- **Avoid foods that make you gassy**
Different people react to different foods, but onions, garlic, cabbage, cauliflower, broccoli, nuts, spicy food and beans can all make you feel bloated, burp or pass wind. If these are problems for you, talk them through with your dietician or nutritionist. They may recommend you try a special diet called FODMAP* for a few weeks

High-fibre foods

Starchy carbohydrates

Including lots of breads (wholemeal, brown, rye, granary and white bread with fibre added), wholegrain pasta, brown rice, jacket potatoes and food containing wholemeal, brown and soya flour.

Cereals

Look for wholegrain options like bran cereals, Weetabix, porridge, muesli and shredded wheat.

Vegetables

High-fibre options include broccoli, peas and Brussels sprouts, but all fresh, frozen and tinned veg contain some fibre.

Beans, lentils and pulses

Fruit Including pears, bananas, berries, currants, grapefruit, oranges, prunes, dried fruit and tinned fruit. If you're seeking fibre, eat fruit with the skins on and eat any edible seeds.

Biscuits

Wholegrain biscuits like digestives, flapjacks, nutty options, oatcakes and Ryvita all contain fibre.

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- **Try a low-fibre (soluble fibre) diet**
- **Avoid fizzy drinks and chewing/bubble gum**
- **Eat regularly** Skipping meals is more likely to make gas build up
- **Chew your food well** It'll stop you from swallowing too much air.

*You can find out more about FODMAP online, but if you think this diet may help you, we'd strongly recommend you involve your dietician so they can help and guide you through it. If the problem doesn't go away after a few days, talk to your care team. And in the meantime keep a record of how often you go to the loo - it can be useful for your team to know.

Narrowed bowel

If you have a small bowel NET that can't be removed, then problems may occur that have the same effect as a bowel obstruction. Serotonin released by a small bowel NET can cause fibrosis, for example, leading to narrowing or kinking of the bowel (you can read about this on page 32).

And if you've had surgery to remove part of your bowel (large or small), sometimes narrowing can occur where the surgeon has made a new connection. This can increase the risk of your bowel being partially or completely blocked.

Bowel obstruction is an emergency situation

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

If you have a narrowed bowel, or if you want to reduce the risk of bowel obstruction you will need to see a Dietitian. They will decide what kind of foods are likely to pass through your bowel with ease.

There are also drinks and supplements you can take to get the nutrients you need. These can be useful if you usually eat a healthy, varied diet and are struggling to manage your nutritional intake.

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Indigestion and acid reflux

NETs including gastrominas can cause these problems - as can certain treatments and medications. You can help to reduce their impact by:

- **Avoiding acidic foods** including citrus fruits and juices and tomato-based products
- **Avoiding spicy foods**
- **Staying upright after meals.** Lying down can make the problem worse.

Feeling full

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

- **Eat little and often**, having smaller snacks and meals
- **Don't drink with or before food.** It can make you feel fuller faster, so wait until after you've eaten to have a drink
- **Avoid fatty, greasy and rich foods**, as these can make you feel fuller sooner
- **Wait to have pudding.** Leave it a couple of hours rather than trying to force it down straight after your meal.

Dumping syndrome

This can occur if you've had stomach surgery.

Usually, most of the starchy and sugary food you eat is broken down for digestion by the stomach. If you've had all or part of your stomach removed, however, the small bowel has to help with this process. To enable the small bowel to dissolve starch and sugar, water is drawn into the small bowel - often from the blood that circulates around your body.

This can cause you to feel faint or dizzy after eating. It can also cause an erratic heart rate, bloating, nausea and diarrhoea. Helpful tips to reduce these symptoms include:

- **Eating little, often and slowly**, smaller snacks and meals
- **Avoiding or reducing starchy and sugary foods**, such as cakes and pastries
- **Avoiding soups or liquid foods**, until symptoms start to improve
- **Eating a low-fibre diet**, and gradually increasing or re-introducing fibre as symptoms improve
- **Resting after eating**, for between 25 and 45 minutes.

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Losing your sense of taste

This can happen as a result of cancer treatment, often causing people to lose their appetite as they no longer get any pleasure from eating. To help prevent that from happening you can try to:

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

Altered taste

Changes to your mouth or certain drugs or treatments can alter how things taste, which can be frustrating, unpleasant or surprising - you may even discover a sweet tooth for the first time, or no longer have one. To make changes easier to deal with, you could:

- **Leave food to cool before you eat it.** Things often taste stronger when they're straight out of the oven
- **Try cold meats rather than hot ones.** People often find the taste of meat changes, but you might find cold cuts more palatable. Or try high-protein alternatives like fish, eggs, cheese and dairy products
- **Avoid foods that contain saccharine** if you find things taste bitter
- **Gargle water with a squeeze of lemon juice before eating** if you find things taste metallic. Using plastic cutlery can help too
- **Try palate-cleansing foods before eating**, such as sorbet (but not the citrus ones, which may trigger indigestion), celery sticks, fresh mint or parsley
- **Explore new tastes.** Try food you've not tried or like before. You may find you now taste things differently.

Feeling sick

We covered this in the section on side effects, but because it's related to food we wanted to include it here too. Remember you can speak to your care team about anti-sickness drugs, and you might also find it helps to:

- Add ginger to your diet (however you want - from ginger ale to adding ground ginger to meals). Some people find papaya helps too
- Drink peppermint tea or suck on mints
- Drink chamomile tea to settle the stomach (and if you don't like the smell you can get chamomile capsules and powders)
- Eat small meals and snacks throughout the day instead of three big meals (and try not to skip meals, which can make nausea worse)
- Avoid fried food, fatty food and foods that have a strong smell
- Not eat or prepare food when you feel sick
- Take it easy straight after eating
- Eat with other people to take your mind off how you're feeling
- Eat light, bland foods like water crackers
- Have small sips of drink throughout the day. Flat or non-carbonated, full-calorie soft drinks like cola, lemonade and Lucozade can really help
- Avoid brushing your teeth straight after a meal - try palate cleansing foods if you want to freshen your mouth, like fresh parsley or mint, sorbet and celery sticks
- Wear an anti-sickness bracelet or try complementary therapies like hypnotherapy or acupuncture.

Pain in your mouth

We covered this one in the side effects section too, but it's worth repeating here because it can have a big impact on your ability to eat a balanced diet. If this is a problem you experience, you can, try to:

- Clean your teeth gently in the morning, before bed and after every meal using a soft toothbrush
- If brushing your teeth stings or makes you feel sick, try gargling with a bicarbonate of soda mouthwash (dissolve one teaspoon in a mug of warm water)
- Avoid mouthwashes that have alcohol in them
- Drink plenty of fluids
- Keep your lips moist with lip balm
- Eat stews, soups, yoghurts, ice cream and other soft food
- Suck on ice cubes, frozen pineapple chunks or red ice pops (but not orange or yellow ones, which contain citric acid that can make your mouth worse)
- Avoid acidic fruits like oranges, grapefruits and lemons
- Avoid spirits, tobacco, spicy and salty food, garlic, onions and vinegar.

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Fatigue

Extreme tiredness is experienced by almost everyone with a NET, at some time, caused either by the disease itself or by treatments - and many of the tips listed in this section can help to reduce fatigue too.

For specific issues related to fatigue, such as anaemia, eating specific foods can help. For example increasing your iron and magnesium levels can help with anaemia.

And eating a healthy, well-balanced diet can help to increase your energy levels. Many dieticians would recommend that fresh is best - so try to avoid eating too many processed or fast foods. To help with this, you could try to cook and freeze or refrigerate a batch of fresh food during periods when you don't feel so tired.

Then on the days when you really don't have the energy to cook, you just need to turn on the microwave, reheat in the oven or on the hob to make a healthy meal.

Alternatively, you could always take up friends and family on any offers to cook for you. People are often very keen to help, and cooking is a simple way to make a big difference.

A final word on food

As we started this section by saying, there's no one diet suitable for everyone with a NET.

But whether or not you need to make adjustments or additions to what you eat, try to remember that food should always be more than fuel. Eating is a social activity, and the many forms and flavours of food are there to be enjoyed.

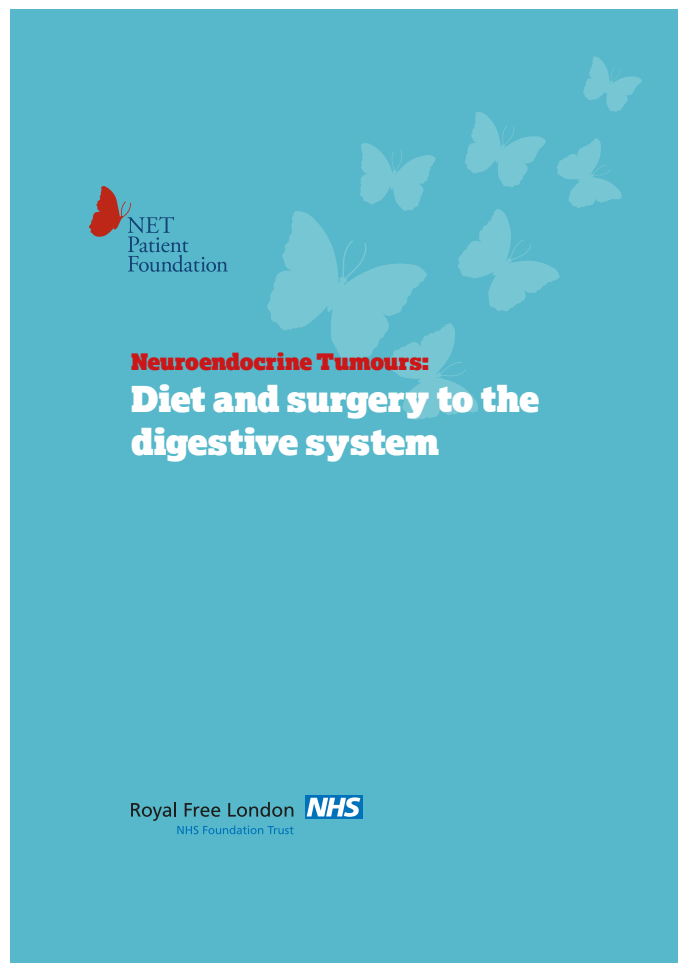
We know there might be times when your relationship with food changes. There might be times when eating is the last thing you want to do. But remember that you're the one in control - and finding ways to use your diet to control your symptoms and improve how you feel can give your confidence and your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

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If you would like further information on dietary issues relating to surgery then there is a separate booklet to cover these.

This booklet can be found at www.netpatientfoundation.org

Alternatively you can request a copy by calling us on 01926 883487 or email hello@netpatientfoundation.org



LOOKING AFTER YOURSELF



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**MAKE TIME TO
DO THE THINGS
YOU'VE ALWAYS
ENJOYED**

LOOKING AFTER YOURSELF

NETs can affect your body, your mind and your life in all kinds of ways, so in this section we focus on some of the challenges you might face and ideas that can help you to deal with them.

There are the physical effects of NET and the various treatments, as described in earlier sections of this book. **But there is also the emotional impact.** In this section we will talk about some of the feelings you may experience and some of the practical ways which may help.

We'll talk about the reality of living with NET.

We can't tell you that everything is going to be OK or that your life won't change. Or that relationships and emotions won't sometimes get messy as you adjust to life with a NET. Important aspects of your life - your relationships, work life and social life - will be affected to some degree.

There will be times when life feels great, of course. Plenty of people live well with NETs for many years, and we very much hope that will be the case for you.

Living with a NET has been described as like being on a rollercoaster.

So there may well be times when things aren't easy, and this section is here to help you deal with those times.

EMOTIONAL WELLBEING

How we think and feel is often influenced by our memories, experiences, relationships, beliefs, . . . as well as our hopes for and concerns about the future.

Being diagnosed with cancer can throw our thoughts and emotions into chaos. It's completely natural to experience a whole range of different feelings - often at the same time - and trying to work out how you feel, or think you should feel, can be distressing.

One thing that's certain is that there's no right way of reacting to the news that you have cancer. But it can help to try to identify and name the emotions you're feeling.

Separate out and name the emotions you are feeling. Just as with physical health, where identifying the symptom and cause can help treatment - in emotional health, identifying the feeling and why you feel that way can help in dealing with it.

Most thoughts and feelings are helpful, but some can become harmful and may negatively affect our decision-making and quality of life. We'll discuss this later.

But for now, here are some of the emotions you may experience as you react to life with a NET.

Shock

A cancer diagnosis is almost always a shock, even if you've had a suspicion that it might be coming. If your NET hasn't made you feel unwell and your diagnosis has followed a routine health check, the diagnosis of cancer can be especially hard to deal with. If you have been told your symptoms were due to another condition, such as IBS, menopause or asthma, then the shock may be combined with disbelief, you may question whether this diagnosis could be wrong too.

Relief

This may sound strange, but if you've been unwell for a long time and had negative tests, or received treatment for another condition, or even been told that your symptoms are in your head, then getting a definite, accurate diagnosis can sometimes come as a genuine relief.

Fear

You might find the same questions keep circling through your head - about the future, about treatments, about the people close to you. It can be scary to be diagnosed with cancer - and especially a type of cancer that few people seem to know about - and feeling anxious or scared is completely understandable.

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Anger

This is another very common feeling. After all, why wouldn't you feel angry? No matter how calm and rational you are, it's hard to avoid the fact that cancer isn't fair. If you've been unwell for some time and struggled to get the right diagnosis, that sense of anger can easily be amplified.

You might have moments when you suddenly feel furious, or you might constantly feel irritated and snap at people over little things. It's a natural reaction, but it's important not to let anger overwhelm you. We'll look at ways to cope with your feelings later in this section.

Confusion/ uncertainty

There are a lot of reasons you might feel confused or uncertain - about the future, about what this illness means, about how your life might change. Even getting your head around what NETs are and making decisions about treatment can be tricky. It's easy to feel overwhelmed and for confusion to turn into anxiety, so try not to keep your worries to yourself. Speaking to your care team and the people close to you can often help you to work through uncertainty.

Loneliness or isolation

Even if you're surrounded by family and friends, there might be times when you feel no one really knows what you're going through. It can help to be honest with people about how you're feeling, though we know that's sometimes easier said than done. If you are feeling isolated or withdrawn, you might find it helps to talk to others in a similar situation. Taking

part in a support group or online forum can introduce you to others, some may be newly diagnosed with NET, some may have lived with it for years. You can find out more about our NET Natter groups, our online forums and support at www.netpatientfoundation.org

Sadness

People often feel sad about how a NET might change their body, their health, their lifestyle or their relationships. If you are feeling low, it can help to focus on things that you can control right now - and especially on things that you enjoy doing. We'll look at ways to cope later in this section, but one point to remember about sadness is that it's a normal response and you won't always feel this way.

If feelings of sadness start to grow stronger over time, this can feel overwhelming and seem almost impossible to escape from, but there are things you can do, talking with your care team is one - and they may be able to provide you with access to further support. Depression is more than a temporary period of feeling low in mood and can affect both your emotional and physical well-being. We talk more about depression later in this section.

Hope

Hope is expectation - it can strengthen resolve and give confidence. But sometimes can be hard to maintain - if you're feeling any or all of the emotions mentioned in this section it can be difficult to feel hopeful. Lack of hope may also trigger some of these feelings. Talking through expectations of care and treatments - agreeing realistic aims and achievable goals can help maintain hope and may improve how you feel.

TELLING PEOPLE ABOUT YOUR NET

Letting your family and friends know you have cancer is not an easy thing to do, but planning the conversation beforehand can help.

It's natural to worry about how people close to you will react when you tell them you have a NET, especially if you generally prefer to keep things to yourself. But it's also a conversation that often seems worse when you imagine it than it actually turns out to be - planning how you want it to go can be a big help.

Some people find they are able to talk about their experiences and feelings straight away, even if they are not completely clear about their diagnosis. Others prefer to take time to think things through and get all the information they need first. And while only you can really know how you want to approach these conversations, you might find it's useful to:

Decide who you want to tell and when

Who, when and how much you want to tell is up to you. Your partner, family member or friend may have been with you when you were told you had a NET. You may have been alone. Deciding who knows is your decision.

Work out what you want to say

You can't always know in what direction a conversation will go, but it can be useful to try to plan what you want to say first. You could introduce the news gradually by explaining that you have something difficult to say.

Think about how much you want to say

It can be easier to start with a few sentences about your diagnosis and then let people take in what you've said.

Be prepared for silences

People often go quiet during difficult conversations, it's a natural reaction. Just as you may have experienced shock, disbelief and anger, so might the people you're talking to.

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Take some information about NETs

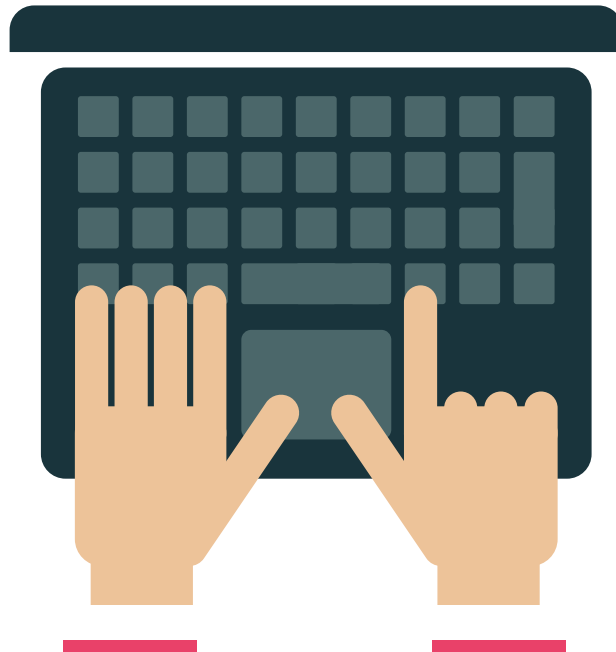
It may be helpful to have some written information about your diagnosis - from either your care team or the pages at the start of this handbook. Giving out something your loved ones can read, can help to answer some of the questions they may have - some that you may still be working through yourself.

Ask a nurse or doctor to help

It's not a problem to ask a member of your care team to be with you during difficult conversations.

Accept help

Many people's natural response is to ask how they can help, what can they do. Think about this - and take them up on their offer. If there's nothing you can think of at the time - ask them to ask you again at a later date. It can be hard to ask for help - letting people know you may find this difficult can encourage them to check in with you now and again to repeat the offer. Allowing people to help, may not only benefit you, but also them.



TALKING ABOUT HOW YOU FEEL

In general, it's a good idea to find someone you feel completely at ease with, and who will let you speak openly and honestly, without judging what you say.

Telling people you have cancer may not be the only, or even the most difficult, conversation you may have. Sharing what's on your mind can help you to put things in perspective - as long as you find the right person or people to talk to for you.

This could be the first time your friends and family members have spoken about cancer, so explaining what you need might help them to feel more comfortable. From what we have been told by those living with a NET, let others know it's ok to ask how you are and talk about your condition and treatments, but maybe not always let it dominate the conversation. That it's ok to talk about what's going on in their lives, how they are feeling, their recent holiday or job change . . . to what's happening on Eastenders, or the football, etc.

Responding to how others react to your diagnosis

Loved ones may fear losing you or become worried about what effect your diagnosis will have on them - on their lives. It can be difficult to deal with how others are feeling, when trying to sort through your own emotions.

Some may find it hard to know what to say to you, what to talk about - as they try to help, they may say or do things that hurt your feelings or offend you. Their fears or concerns about their own health, may affect their ability to help you.

Others may rush to give you their opinion(s) or advice on what you should do - from "how you must feel" to special diets to certain treatments to magical cures.

However well meant - how others behave, can be upsetting - tell them. Whilst you can appreciate their concern - if they aren't helping you - tell them.

We can't always change how others behave - but we can change how we respond to that behaviour.

So if you do hear anything that concerns you, or are worried about how to deal with how loved ones react - talk it over with someone you trust - including your care team.

Other people you can talk to

There may be times that you might not want to talk to those closest to you. If this happens:

You can arrange to talk to your specialist nurse, care team or GP, over the phone or during an appointment. It's a good idea to explain why you want an appointment when you book it, to ensure you are given time to talk, rather than a routine 5 or 10 minute slot.

Your care team and/or GP can also arrange for you to speak to a counsellor or therapist. This can be particularly helpful if you're feeling low or struggling with exactly how you, or loved ones, are feeling.

You can also talk to other people with NET at support groups (including our NET Natter sessions) and online or speak to one of our specialist nurses

We also offer a free telephone counselling service which is available to anyone affected by a Neuroendocrine Cancer; patients, family and friends.



To find out more about the support services we offer visit the "How we can support you" page on our website: www.netpatientfoundation.org or call us on 0800 434 6476

CHALLENGES OF LIVING WITH A NET

So far the focus of this section has been on the initial diagnosis, but for many people who have been told they have a NET, diagnosis is just the start of what may be many months or years of living with this condition.

As you may have read in earlier parts of this handbook, living with NET means adjusting to a **new normal**.

The whole process of being diagnosed with and treated for cancer is abnormal. No one expects the sudden shift to a life of tests, treatments and unfamiliar medical language, and however realistic we are about our lives not lasting forever, being confronted with our mortality through a cancer diagnosis isn't something that's easy to deal with.

Whilst your care team can make recommendations for treatment - the decision about what treatments you receive is yours. Which all sounds very clear cut, however, how you feel about this may be far from that precise - and there may be times when life feels very uncertain - giving rise to anxieties and fears.

How much healthcare involvement you have will depend upon your particular type of NET and the decisions you make about how your NET is treated.

Here we will talk about some of the situations those living with NETs, have found to be challenging emotionally.

Starting treatment...

Even if you feel fully informed about what to expect and are glad that treatment is beginning, it's natural to feel anxious: Will the treatment work? How will you know if it's worked? Will it change how you look or feel? Talking through these concerns, and getting the information you need, that may help alleviate worries, can really help.

It's also important to try and keep a check on how you're feeling as treatment progresses. Some treatments, like steroids or chemotherapy, can affect how you think and feel. Steroids can give you a bit of a buzz, but can also make you feel irritable or edgy. So if you think your treatment is affecting your mood, let your care team know.

Having a scan (aka 'scanxiety')...

If you're partway through treatment, have finished treatment or your condition is under surveillance, you might feel anxious whenever you're due for a scan or check-up. This is so common there's even a name for it - scanxiety. Even if you feel well and your symptoms haven't changed or you have no symptoms, the time between having a scan or test and getting the results can seem endless - even it's only a day or two.

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It can help to talk to your care team or specialist nurse to make sure you understand the exact time-frames and the options available to you. It might be possible to arrange a phone call or next-day appointment for when your results are available.

Day-to-day...

Living with a chronic (long-term) condition can be challenging, both physically and emotionally.

With a NET, you may live for many months or years with few or no symptoms, so other people may find it hard to understand what you're going through, they may even question your diagnosis, or forget you have cancer. Symptoms, particularly those that aren't obvious or visible, such as chronic fatigue, may be felt to be misunderstood by the people around you. This can lead to feeling resentful - that others don't understand - rather than, sad or guilty - that you can't do as much as you'd like to.

The lack of awareness about NETs might also leave you feeling frustrated and isolated. If that's the case, try to let people know what's on your mind - and talk to your care team, too. They might be able to point you towards support groups, information events and online forums where you can share your experiences with other people who understand your situation, who may have helpful tips and advice, and who may well also be working to raise awareness.

When your NET comes back (recurrence) or gets worse (progression)...

You may have had treatment that has either potentially cured your NET, removed all visible disease or reduced its size and spread. You may have been told that your disease has been unchanged (stable) for some time.

Hearing that your NET has returned, grown or that you now have new sites of disease can come as a huge shock - many people tell us this is as difficult to deal with as an initial diagnosis, some have said it almost feels worse. Even if you knew it was a possibility, or suspected it might be happening, this news can be a shock, and may be accompanied by feeling a sense of failure, despair, anger or even hopelessness. It may even make you doubt your ability to make decisions about future care. Should any of these feelings occur, talk to your care team about them - they will understand, and will want to support you.

You might feel it's important to immediately find out whether any other treatment is available, what that treatment would involve and what the risks are. You might want to start another treatment straight away, or you might want to take some time away from hospitals and appointments.

Whatever decision you do make, it's vital that you feel comfortable with it and are confident that it's the best thing to do - even if you decide to say no to further treatment if offered.

RELATIONSHIPS AND CANCER

A cancer diagnosis can bring you closer to your partner, family and friends, but it can also put a strain on those relationships.

There's no normal way for relationships to develop after a cancer diagnosis.

You might find the support you receive from the people closest to you makes a vital difference to your well-being. However if people act differently or don't react as you'd hoped this can put your relationship under strain. Your response to your diagnosis may make you question certain relationships and friendships.

Your partner, friends and family may well go through the same emotions you experienced when you heard your diagnosis. They might be scared, sad, angry, confused or all of these at the same time, not just for you, but also themselves, and it's not always easy to express those feelings. And as we have said - it can hard to deal with the feelings of others when trying to cope with your own.

Sadly, some relationships can falter or even end. This may be a relief, but can also be devastating on top of everything else you're dealing with.

Whatever your experience, talking honestly about how you're feeling - your hopes, fears and concerns - and encouraging others to do so too can help.

Talking to your partner

Cancer can definitely make bonds stronger, but it can also put extra pressure on even the closest relationships and increase tensions between couples who may already be struggling.

You might feel like a burden or feel guilty that your NET has become such a focus in your life. You might feel that you and your partner no longer have the same priorities. You might feel that your partner has become distant or started smothering you. And your partner might be desperate to support you but be unsure of what to do.

Whatever your situation, try and be honest. Getting issues out in the open without blame or criticism can help you to feel closer, and can help you to explain what support you need from each other.

Making time to do the things you've always enjoyed can make a big difference too. You might have cancer, but that need not define who you are.

Talking to children

Speaking to your children about cancer can be incredibly tough. The sort of conversations you have will depend on how old your children are, of course, but try to talk honestly without giving so much information that it becomes overwhelming. You know your children best and can judge how much information they can take in at one time.

Be prepared to repeat information. That doesn't mean they haven't been listening - they might just need more time to follow what you're saying. You might want to stop every so often so they can ask questions, too.

However old they are, it can help to think about ways for your children to get involved in your care - whether that means going for a walk with you, helping out around the house or just being there with you.

And if you sense that your children want to open up but are worried about causing you more anxiety, you could encourage them to speak to a friend, relative or teacher. You can look online for support groups for children who have relatives with cancer (see box below for some useful sites), but it may also be helpful to discuss this with your care team - they may have links with professionals or groups who can help.

Information and support for your children:

www.macmillan.org.uk

www.maggiescentres.org - Kids Days and Teen Days

www.riprap.org.uk

Talking to family and friends

You might find your family and friends are asking themselves a lot of questions about how they should behave around you. Answering these can make your relationships a lot easier. They could be wondering:

- What you want them to do
- What you can and can't do
- What different treatments involve
- Whether they can ask about your NET
- Whether they'll seem selfish if they talk about themselves
- How you'll react if they say the wrong thing.

Talking through issues like that and letting people know how much you value their friendship can make things a lot less awkward.

Don't be afraid to ask for practical and emotional support - or to make plans to do things you both/all enjoy.

And if you do find that friendships drift apart, try not to let it get you down. That can happen whether or not you're diagnosed with cancer, and what matters most right now is spending time with people whose company you value and enjoy and who make you feel valued in return.

FINDING WAYS TO COPE

There are plenty of things you can do to get through bad days, from laughing with friends to working out exactly what's making you stressed.

Having coping strategies in place is a good idea for lots of reasons. It helps you work out which things make you feel better. It helps you understand when you are likely to struggle. And it helps you to respond to difficult situations and feelings in a positive way, rather than in ways that could make you feel worse.

Coping strategies don't need to be complicated - they're just ways to help you relax if treatments, tests or living with a NET get you down. You might find it helps to:

Challenge unhelpful thoughts

If you're feeling stressed or worried, you might find your mind draws your attention to negative thoughts and memories. It can help to take a step back and question what you're thinking. Is there another way of looking at what's on your mind? Are your worries based on assumptions that might not be true? If a friend was in your situation, what would you say to them? This takes practice, but can help you to look at the world a little differently.

Challenge angry thoughts

If you find yourself feeling angry, question what's making you feel that way. Is it really an important issue? Is there a more balanced way of looking at the situation? What are the costs and benefits of how you're feeling? It's not easy, but it's a useful skill to learn.

Describe how you're feeling rather than acting on your feelings

Telling someone why you're feeling angry is usually more helpful than keeping it to yourself and acting in an irritable way. Describing your feelings can start a conversation, whereas acting on them can make talking and hopefully resolving issues, more difficult.

Accept strong feelings

Don't feel bad or punish yourself for feeling strong emotions - there's no right or wrong way to feel. But try and talk about and work through your feelings so they become easier to manage.

Use relaxation techniques

Place both feet flat on the ground. Breathe in through your nose - as deep down into your belly as you comfortably can - then out through your mouth. Repeat this five times. Simple breathing techniques like this can help you to feel calmer if you're angry or stressed.

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So can meditation or spending time with people who make you laugh. It's all about finding out what works for you.

Do what you love to do

It's easy to stop doing the things you've always enjoyed and to end up feeling worse as a result. So put time in your diary to meet with friends or go to the cinema or play sport or simply have a long soak in the bath. Knowing you have something to look forward to can lift your mood, and doing things that give you a sense of achievement can help you feel in control. Talking of which...

Take control

Learning more about cancer and getting involved in decisions about your treatment can help you to feel in less of a whirlwind. Sharing information with loved ones can help them to understand your condition too. So, as we've said

throughout this guide, ask questions and keep asking them until you completely understand the answer and what it means for you.

Spend time with the right people

Now isn't the time to be with people who make you worry or leave you feeling negative, so focus on relationships that you trust, that put a smile on your face and with whom you can be yourself.

Give mindfulness a go

Mindfulness encourages you to give full attention to your body, your mind and your surroundings, without judging what you're experiencing. You might find it helps you to be more aware of your thoughts and feelings and to respond to them differently. There are lots of books, apps and CDs to help you practise mindfulness techniques.

Signs of depression

Everyone feels low sometimes, but if you find you feel sad and hopeless for weeks at a time and lose interest in things you used to enjoy, you might be getting depressed.

There are lots of symptoms of depression. These include:

- **Psychological symptoms** like feeling hopeless and tearful, having an ongoing low mood and low self-esteem
- **Physical symptoms** like moving or speaking more slowly than normal, unexplained aches and changes in appetite and weight
- **Social symptoms** like neglecting your hobbies and not wanting to take part in social activities or leave the house.

If you experience any of these symptoms most of the time for more than two weeks, it's important to speak to your GP or specialist nurse to find help.

STRUGGLING TO SLEEP?

If your symptoms or thoughts are keeping you awake, tiredness can leave you feeling frustrated and overwhelmed. Here are some ideas for getting a good night's rest.

- **If you aren't asleep after 20 minutes, get out of bed.** Spend a little time doing something that makes you feel relaxed - like reading or listening to the radio - then head back to bed when you're feeling sleepy
- **Do the same things before bed each night.** Rituals like having a bath, reading or having a small snack can help your body get into a routine
- **Get up at the same time each day.** Getting up at a consistent time can also help to create a routine
- **Don't sleep too much during the day.** If fatigue or sleeplessness is an issue - you may find that a rest period or short nap during the day can help - but keep it short - no more than half an hour - as any longer may contribute to difficulties sleeping at night
- **Avoid eating late at night - particularly a big meal:** snacking can help with energy levels and help maintain blood sugar levels, but it can be difficult to sleep with a full stomach! (but make sure you don't go to bed hungry, either)
- **Be careful with caffeine, cigarettes, alcohol and strenuous exercise.** Try to avoid these from mid-afternoon onwards
- **Keep your bed as a place for sleeping and sex.** If up and about during the day, try not to do things like watch TV, talk on the phone, eat or use your phone in bed. Make sure your bedroom is cool in temperature, comfortable and not too bright
- **Write down what's on your mind.** If worries are keeping you awake, try getting up, writing them down and making a plan of what you can do about them in the morning.

PHYSICAL ACTIVITY - EXERCISE AND NETs

Whether you've always kept active or haven't pulled on a pair of trainers for years, there are plenty of reasons to exercise after you've been diagnosed with a NET - and many ways to get the fitness habit.

Staying active during and after cancer treatment makes a lot of sense. It can boost your energy levels and your mood. It can help your bones, muscles and heart to stay strong. It can help you to stay at a healthy weight. It can help you to sleep better and improve your appetite. And it can increase your range of movement and control side effects like constipation.

Your care team can advise you on how much exercise is right for you. This will depend on:

- How active you were before your diagnosis
- The type of NET you have
- The treatment you're having
- Any side effects you're experiencing
- Whether you have any other health problems.

It's important to build up gradually and set yourself realistic goals - whether that means going for a walk, joining an exercise class or running a 10km race. Do this and you're more likely to carry on exercising regularly.

Keeping a record of your progress can help, and so can reminding yourself of the benefits of exercise if you start to struggle. And make sure you choose activities you enjoy, otherwise it can be much harder to stick with them.

Ideas for getting active

Whether you prefer to exercise alone, with friends and family or as part of a class or group, there are a number of options. You could:

- Join a walking or running club
- Go dancing
- Cycle to the shops instead of driving
- Go for a swim or join a water aerobics class
- Try stretching classes like Yoga, Tai Chi and Pilates.

Household tasks can make a difference too. Gardening, vacuuming, washing the car and mowing the lawn can all help you to build up your strength and stamina - but do take note of medical advice - especially if you have recently had surgery.

What really matters is to take things at your own pace. So drink plenty of water, don't exercise if you feel unwell and let your care team know if you have any concerns.

You'll find plenty of local gyms and sports clubs online, and your care team might be able to refer you to a structured exercise programme to help you get the most out of being active.



Always check with your care team before starting any new exercise programme.

THERE IS NO SCRIPT...

We want to finish this section by saying there probably will be times when you will feel low - and there's absolutely nothing wrong with that.

There's no script to living with a NET, and no right way to feel. It's natural to feel negative or angry sometimes and to laugh and feel happy too.

Though comparing yourself with others isn't always useful, sharing experiences and talking with others living with NETs can be a real boost.

And while some of the words that are used to discuss cancer - victim, fighter, survivor, battle - might inspire you, they may not fit with how you see yourself or your experience.

The main thing to remember is that there is help if you feel overwhelmed or low. Often the best support comes from family and friends. Your care team and the NET Patient Foundation team are always here for you too.

Whatever you're feeling now is absolutely natural. So be kind to yourself, treat yourself as you would your best friend - take time to enjoy trusted and valued relationships. You may live with a NET for many years - taking care of your emotional life as well as your physical life - can help you live that time well.

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PRACTICAL ISSUES



**LOOK AFTER
YOURSELF
BY GETTING
PREPARED**

THE PRACTICAL STUFF

As we have said in previous sections, having a NET diagnosis can have an effect on all aspects of your life: this section looks at some of the practical, everyday aspects - from your ability to work to getting insurance to travel. We'll talk through some of the support that is available to help you with some of these practical challenges.

Work and NETs

One question many people ask after a NET diagnosis is 'Will I be able to keep on working?' The answer depends on your individual situation, of course, but often people are able to keep working for many years with a NET.

You do not have to inform your employer of your diagnosis, but it may help if you need to take time off now or in the future - for appointments or treatments. However before you do so, it may be worth checking your employment contract and discussing your situation with an advisor, from Citizens Advice Bureau, Maggie's Centre, Macmillan or your Professional Union.

Most employers are supportive, however others may not be. You are protected by law from unfair or unreasonable treatment or discrimination at work.

***The Equality Act 2010, or the Disability Discrimination Act 1995 (and its extension, the Disability Discrimination Order 2006 if you live in Northern Ireland), do not just apply to employees - job applicants and the self-employed are also protected.**

When you do decide to inform your employer it may be helpful to ask:

- What policies/information does the company have about this kind of situation?
- If required how soon can sick pay arrangements be confirmed?
- What kind of reasonable adjustments, if any, might be possible to help me do my job now?
- Should my health change - what reasonable adjustments may be possible?
- Can we discuss how or whether we will let other people, for example colleagues, know about my NET?

Once you've told your employer about your NET they have a duty to make 'reasonable adjustments' to make sure you are not at a disadvantage because of your illness.

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Reasonable adjustments might include:

- Letting you have time off to go to appointments
- Changing your job description to remove tasks you may now find difficult
- Giving you extra breaks to cope with being tired
- Changing where you work - for example a change of office or department.

What is considered 'reasonable' depends on how much the adjustment will cost, how practical it is and how much of a benefit it will be, but failure to make adjustments could count as discrimination.

Most employers are willing to make changes - for example allowing you to work flexible hours - but if you find that's not the case it can help to ask a member of your care team to talk to your employer.

And remember that you have the right to privacy, so if you tell your manager about your NET but don't want your colleagues to know, your manager should respect that.

Talking to colleagues

It's up to you who you tell about your NET at work, but letting people know can help them understand what to expect and what support you might need. If your side effects mean you're often fatigued, for example, your colleagues may be able to help reduce your workload.

You may find that people act differently or seem awkward - just as you might experience when you tell your friends and family. Being open and letting people know if you're happy to answer questions or talk about your situation often helps.

Equally, you may decide you would rather not tell people at work about your NET. Some people find this is a useful way to cope because it helps this area of your life to feel more normal. If your symptoms or side effects increase, however, it may become more difficult to keep your illness to yourself.

Taking time off work

You may need to take days, weeks or a longer period off work during treatment for your NET. This may have a financial impact on your life - and we'll talk about some of the benefits and financial help that may be available to you in the next section.

If you do need to take an extended period off work, it may help to contact an independent financial advisor for suggestions on the best course of action. If you have private insurance such as income protection cover, mortgage protection or critical illness cover, get independent advice before contacting your insurance company to begin making a claim.

It can also be useful to talk to your manager about what you would like to happen while you are away. You might prefer to forget about work completely while you focus on your treatment, or you might appreciate the odd email letting you know any news. Some people choose to visit work a few times while they are away to keep in touch and to get prepared before returning to work.

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Working during treatment

Depending on the type of treatment you have, and the type of work you do, you might decide to keep working - especially if you're self-employed.

Ask your care team for advice if you are planning to keep working throughout treatment, and try and put a back-up plan in place if you do need to take some time off.

If you are self-employed

It can be a very difficult decision to take time off if you work for yourself. As well as worrying about paying the bills, you might be concerned about what will happen to the business you've invested so much time and energy in building up. Business groups and voluntary organisations offer a range of services to support small businesses, and you may be entitled to claim benefits if your income falls.

Useful contacts if you're self-employed

For information and advice, contact:

- Turn2us - www.turn2us.org.uk
- Citizens Advice - www.citizensadvice.org.uk
- The Money Advice Service - Freephone **0800 138 7777**

Local Citizens Advice services offer advice from over 3,500 locations, in person and over the phone.

Adviceline - is a relatively new phone service in the UK.

To contact Adviceline:

- In England call **03444 111 444** or find local contact details via the search option at www.citizensadvice.org.uk
- In Wales call **03444 77 20 20**
- If you use TextRelay, call **03444 111 445**.

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Returning to work

If you take time off work but feel ready to return after treatment, it can help to meet up with your manager (and an occupational health advisor, if there is one) beforehand to agree a 'return to work' plan.

This is a good opportunity to explain how you are feeling and to discuss any concerns. Many people find a phased return to work is the best option - to begin with you could work shorter shifts or not take on all of your usual responsibilities.

Try to avoid the temptation to immediately pick up where you left off. Allow yourself regular rest breaks and if you start to feel tired, let your manager know. If you feel you need to change the work that you do or alter your job description, you should discuss this with your employer as soon as possible. They have a duty to be flexible to help you carry on working.

If you have been claiming benefits while you were away from work, remember to let the Department of Work and Pensions know that you are working again.

Remember - your employer has a duty to be flexible to help you carry on working.

Taking early retirement

Rather than returning to work, you may want to take early retirement either for health or personal reasons. If you do that, it's essential to take advice from your pension administrator. Talking to an independent financial advisor is also recommended.

Depending on your pension scheme, you may be able to take early payment due to ill health.

If you have a pension scheme connected to your work, you may receive a higher amount of pension if you retire for health reasons, but if you're fit to work the amount you receive could be lowered.

BENEFITS AND FINANCIAL HELP

The financial costs of cancer can easily mount up, which can add to concerns about living with NET, but finding out if you are entitled to financial assistance such as benefits, grants and other monies can ease the strain.



There are lots of ways that living with a NET can affect your income.

Travel costs and parking charges can get expensive if you have regular hospital appointments. Your supermarket bill can go up if you're keeping to a different diet. If you need to work fewer hours or give up your job because of your illness, it can be difficult to cope with these additional costs.

Applying for benefits

The benefits system can feel like a maze, making it difficult to know what sort of help you may be eligible for - especially as benefit regulations change fairly often. Information on benefits can be found at: www.gov.uk/browse/benefits

However, we would strongly recommend that you speak to an expert before applying.

Staff at your local council and at charities including Citizens Advice, Maggie's Centres and Macmillan can help to guide you through the process and give you up-to-date information.

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Benefits related to your NET

UK legislation considers a cancer diagnosis as a disability. That's because - like many other health problems that may not be visible, such as mental health issues and severe fatigue - cancer has a substantial and long-term impact on your ability to do everyday activities.



The following information was accurate when this handbook was printed.

There are two main types of support available related to disability.

- **The Personal Independence Payment (PIP)** helps with some of the extra costs caused by long-term ill-health or a disability if you're aged 16 to 64. The amount you may receive depends on how your condition affects you, not the condition itself. You'll need an assessment to work out the level of help you get. Your rate will be regularly reassessed to make sure you're getting the right support. However, special circumstances may apply if your cancer diagnosis is advanced or high-grade

- The **Attendance Allowance** is a benefit for people aged 65 and over who have difficulty looking after themselves. You must have needed care for at least six months to be eligible for Attendance Allowance, and the amount you receive depends on the amount of care you need. Other benefits you may receive may increase if you get attendance allowance.

To apply for PIP or Attendance Allowance, you will need to complete a form explaining how your NET affects you and you may be assessed by an independent healthcare professional.

Your care team, GP and the NET Patient Foundation will be happy to support you through this process.

Other benefits and payments

There are a number of other ways you might be able to get financial help:

- **Statutory Sick Pay**, which will be paid by your employer for up to 28 weeks. You need to tell your employer that you are unwell no less than seven days after you become ill, and it's important to ask a GP (or your care team if you are in hospital) for a Statement of Fitness for Work to cover the time you are unwell. You may need this statement to claim benefits
- **Occupational or company sick pay**, which you may be able to claim in addition to Statutory Sick Pay - check your contract (or ask your HR team) for more information

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- **Employment and Support Allowance (ESA).** There are two types of ESA - one depends on how much national insurance you have paid, the other is related to your income. You may be eligible for either or both, depending on your income, savings and national insurance contributions
- Alternatively, depending on your situation and where you live, you might need to apply for Universal Credit instead of ESA
- If you're **self-employed**, you may still qualify for Employment Support Allowance or **Universal Credit**
- If you're not able to keep working because of your NET or if your earnings drop, you might be entitled to an **income tax refund**
- **Income Support** if you're aged between 16 and the State Pension age. This will depend on your savings, the number of hours you work and your household costs. (Income Support is gradually being replaced by **Universal Credit**)
- **Working tax credit** - a means tested state benefit payment available to those who are working (either employed or self-employed) and on a low income. This is also being replaced by **Universal Credit**.

If you are caring for someone with a NET...

Organisations such as Carers UK can guide you through what's available - as well as offering practical advice on looking after yourself while caring for someone else.

Financial help for carers includes:

- **Carer's Allowance**, a weekly payment based on criteria including the number of hours you spend caring for someone and your weekly earnings. The person you care for must receive Attendance Allowance, Disability Living Allowance or the Personal Independence Payment for you to qualify for Carer's Allowance
- **Carer's Credit**, which provides national insurance credits if you need to take time off work to care for someone. This prevents shortfalls in your national insurance payments that could affect your State Pension entitlement.

Additional financial help

Some charities offer one-off grants to help people cope with the costs of cancer, and schemes such as the NHS Low Income Scheme might enable you to claim back travel expenses if you are on a low income.

Some hospitals also offer reduced parking charges for people with cancer, and schemes exist to help you buy or hire cars, scooters or powered wheelchairs, if you are eligible for certain benefits.

Your care team and advisors at charities such as Citizens Advice, Maggie's Centres and Macmillan will be able to let you know what may be available and who to contact to access these schemes.

TRAVELLING AND NETs

Whether you need to take a trip for work, a mini-break or just want to get away from it all, you can reduce the stress of travelling and look after yourself by getting prepared in advance.

If you love to travel, there's no reason why trips in the UK or overseas should be any less enjoyable if you have a NET. They can be the perfect way to relax and reflect - you just might need to spend a little more time planning your trip than usual.

Talk to your care team

If you're planning a holiday to get away from appointments and hospitals for a while, you should speak to your doctor or specialist nurse before planning your trip.

They can let you know if you're fit to travel and give you documents you might need if your destination is overseas - like copies of your prescriptions, confirmation of fitness to travel (required by some airlines) and a basic report explaining your condition, your medication and your care needs. (It's a good idea to get these translated into the local language(s) before you travel.)

They can also talk you through any precautions you may need to take depending on where you're travelling to and for how long. They can discuss with you the best time for you to travel if you're currently having treatment.

And as well as speaking to your UK care team, you can check out whether there is a NET service in the area or country to which you are travelling.

Call our NET Patient Foundation freephone number - **0800 434 6476** - to find out more or for an up-to-date list of UK and European NET Centres of Excellence visit: www.enets.org

Take your side effects into account

If you're often tired at certain times of day or get fatigued easily, can you arrange your travel schedule to take account of this? If you need to eat a special diet, will the food and drink you need be easily available where you're going? If you have diarrhoea, how easily can you control it and what facilities are available during your journey and at your destination?

Asking yourself questions like these and arranging your trip around any issues can stop symptoms or side effects from limiting your enjoyment. Your care team will have plenty of ideas if you're worried about specific problems.

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Make special arrangements in plenty of time

Will you need help getting on and off planes, trains or ships? Would it help to arrange early boarding if you're flying? Do you need help walking or climbing stairs?

Many travel companies have medical officers who can offer practical advice, and contacting airlines, train companies, tour companies and hotels before travelling makes it much easier to ensure help is available where needed. For further information visit the Disability equipment and transport pages at www.gov.uk

Preparing for your trip **Vaccinations**

Ask your care team for advice if you're thinking of travelling somewhere that means you'll need vaccinations.

Vaccinations reduce the risk of getting ill while you're travelling, but you may not be able to have them (or may have to wait to have them) if you've had treatment that can affect your immune system - for example chemotherapy or radiotherapy.

That's because some 'live' vaccines contain small amounts of viruses or bacteria, and if your immune system is suppressed these can make you ill. Other types of 'inactive' vaccines don't contain live viruses but may be less effective if your immunity is lowered.

Travelling with medication

Make sure you have enough medication for your whole trip - but check any restrictions before you travel on medication you need to take with you, because some countries will not allow you to bring certain medications in.

Carrying morphine or medications that contain codeine without a prescription can be a criminal act. Contact the embassy or high commission of the country you're visiting to find out more.

If you do travel with medication, carry it in your hand luggage in the original container and packaging, because customs officers may want to see it. And if you're travelling with a licence for controlled drugs or with letters from your doctor, make sure you keep those in your hand luggage too.

If you're travelling for more than three months and have medication for that length of time, you may need to get a personal medicine licence from the Home Office Drugs Licensing and Compliance Unit - visit www.gov.uk for more information.

Remember that you may need to buy small cool bags (available from chemists) to carry medicines that you need to keep cool. Make sure to check that there's a fridge you can use at your destination, too.

And it's a good idea to carry a list (and email it to yourself) of all the generic names of any drugs you're taking, along with your doses, in case you need to find more when you're overseas. Brand names of drugs can vary, so the names you're used to might not be recognised elsewhere.

Speak to your pharmacist about when to take medication if you're travelling across time zones. It might be easiest to gradually shift to fit with the local time.

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MedicAlert and carcinoid crisis cards

Before travelling, you might want to get a MedicAlert disc or bracelet so that doctors know about your NET if you need urgent medical attention.

Alternatively, if you are taking your mobile phone with you - basic information, such as your diagnosis, allergies, medications and carcinoid crisis protocol can all be stored in the emergency information facility. This can be accessed by emergency responders, even if you have a lock screen activated.

If you are not aware of this facility, please refer to the handbook for your device or contact the manufacturer, to find out more.

The NET Patient Foundation also provides wallet alert cards highlighting the risk of carcinoid crisis or bowel obstruction. We also provide another card to explain that your NET means you may need to use the toilet urgently. You can get these by calling us at the NET Patient Foundation on **01926 883487**.



Travel checklist

- Medication in original packaging
- MedicAlert disc or bracelet
- NET Patient Foundation wallet alert card(s)
- Doctor's letters, certificates and licences
- Copies of your prescriptions
- Extra medical supplies
- Travel insurance policy and documents
- List of your medication, with doses and including generic names
- Cool bags for medications
- Passport and proof of UK residence (e.g. driver's licence)
- European Health Insurance Card (if you're travelling to the EEA or Switzerland)
- Name and contact details of local NET service (if there is one)



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Staying healthy during your trip

Diarrhoea and sickness

Diarrhoea and nausea may be symptoms you usually experience. If that's the case, you should be able to deal with this as you normally would at home - for example by increasing your medication or adjusting your diet. NB if uncertain about the quality of drinking water - drink bottled water only.

Diarrhoea and sickness that start or increase while you are travelling can ruin a trip and be potentially serious. Here are some precautions you can take to avoid these travel-related issues:

- If you're worried that water might not be clean, avoid ice in drinks and salads that may have been washed in tap water, drink only bottled water (make sure the lids are sealed) and boil all water before you clean your teeth
- Don't drink unpasteurised milk or eat ice-cream made with unpasteurised milk
- Always eat food that is fresh and avoid raw food if you have any concerns about it
- Ensure your food is thoroughly cooked and still hot. If you have any doubts, don't eat it!
- Avoid food that has been left in the open air, reheated or exposed to flies
- Try not to swallow water if you are swimming (in pools, lakes, rivers and the sea).

Staying safe in the sun

Protecting your skin from the sun is always important, and some treatments can make your skin more sensitive, meaning it's even more important to

follow the usual advice. So if you're out in the sun:

- Use suncream that has a high sun protection factor - reapply at regular intervals
- Stay out of direct sunlight, especially during the hottest times of the day
- Wear a wide-brimmed hat
- Spend plenty of time in the shade
- Wear loose clothing made of cotton or natural fibres
- Drink plenty of water.

Your care team will give you specific advice if you NET treatment is likely to have increased your sensitivity to the sun.

Getting healthcare abroad

For UK residents / passport holders, if you're visiting a country in the European Economic Area (that's all EU countries plus Iceland, Liechtenstein and Norway) or Switzerland, you should apply for a free European Health Insurance Card online before travelling. These entitle UK residents to free or reduced-cost health treatment in these countries.

Some other countries, including Australia, New Zealand, Barbados, Jersey and Russia have reciprocal healthcare agreements with the UK, meaning treatment will be free or the cost will be reduced.

Elsewhere, you may well need to pay for the full cost of healthcare, which is why it's important to take out comprehensive travel insurance.

Before you travel, search online to find out if there is a NET service close to your destination.

INSURANCE

Travel insurance

It can be difficult or expensive to get travel insurance after you've been diagnosed with cancer, and searching for comprehensive cover can be frustrating. However, there are reputable companies who will provide cover for NET patients at reasonable cost.

Please either contact us for further details by calling the freephone NET Patient Foundation number - **0800 434 6476** or visit our website for NET patient experiences and recommendations.

You can also get in touch with other people with NETs - for example via our Facebook page - to find out which insurers they have had good experiences with recently.

Once you've found companies that could help, we'd recommend you phone to discuss your situation rather than using an online application form. Ask to speak to a senior insurance consultant, and have information from your care team with you so you can explain exactly what your situation is.

Many insurers do struggle to understand what NET is, and how it behaves and may affect those living with it, but with persistence you can find companies do get it, and will give you the cover you need at reasonable cost. Make sure you allow plenty of time to search for the best deal and when you find it, spread the word!

Life insurance

Like travel insurance, life insurance becomes more expensive and harder to find once you've been diagnosed with a NET.

If you try to buy life insurance cover following a cancer diagnosis, you will usually have to pay an above-average premium. Some insurers may refuse to insure you altogether. To get the clearest picture of your situation, it may be worth seeking independent financial advice before speaking to insurance companies.

Whether or not you are able to get cover usually depends on the type of cancer you have and what stage it is at, so when you apply for policies make sure you speak to insurance consultants over the phone (rather than applying online) and have all of the details of your condition handy - staging, grading, function etc. Your insurer will want to see a medical report and may ask you to have a medical assessment.

Some insurance companies and brokers specialise in cover for people with cancer and/or incurable illnesses, so again it's worth asking for recommendations at our Facebook page. Remember, though, that an insurer will always make a decision based on your individual situation.

DRIVING AND NETs

When do you need to let the DVLA know that you've been diagnosed with a NET?

For car and motorcycle licences

You'll need to check with your care team about your specific situation, but (at the time of printing) you don't need to tell the DVLA you have cancer unless:

- Your care team says you are not fit to drive
- You develop problems with your brain, nervous system or blood sugar control
- You're restricted to certain types of vehicles or vehicles that have been adapted for you
- Your treatment and medication causes side effects that could affect your driving.

It's your responsibility to tell the DVLA if your NET could affect your driving, and you can be fined up to £1,000 if you don't let them know - and prosecuted if you're in an accident.

If you're advised not to drive for a short period of time - for example after surgery - you do not need to inform the DVLA. However, driving when you've been advised not to by your care team will invalidate your insurance.

Remember if your situation changes and you're told to contact the DVLA, you must make that call.

If you do need to tell the DVLA about your condition, you need to fill in form G1, which is available at www.gov.uk/cancer-and-driving or in Post Offices.

For bus, coach and lorry licences

You must tell the DVLA if your condition will affect your driving if you hold a bus, coach or lorry licence. In that case you'll need to fill in form C1V.

Check your car insurance

Whether or not you need to tell the DVLA, it's worth looking at your car insurance policy to find out whether you need to let your insurance company know about your NET. Some policies are no longer valid if you don't let your insurers know about a change in your health.

For the latest information on when you must tell the DVLA about your health, head to www.gov.uk/cancer-and-driving

To speak to an advisor at the DVLA drivers' medical enquiries service, call 0300 790 6806

THE FUTURE



**YOU ARE NOT
ALONE!**

THE NEW NORMAL

Living with the uncertainty of a NET diagnosis can be extremely difficult. NETs are a complex and unpredictable group of cancers, and your new 'normal' may feel very different to your life before diagnosis. This can cause a lot of emotional strain, not just for you but for those close to you.

Whatever treatment you've had for your NET and however stable your cancer is, not knowing what the future holds can make you feel very vulnerable.

Many people living with a NET, tell us they live well, making some adjustments to their lives - depending on their symptoms and treatments. However they also describe periods of anxiety and apprehension, usually around the times of scans or appointments. Understanding 'follow up' timings and agreeing when and how results will be available, can help.

Ongoing tests

Exactly which follow-up tests you may need depends on your individual situation. You might have blood tests and scans to monitor your health, the progress of your NET, and/or your response to treatments.

You might find it helps to ask for more information. If your care team recommends a test, it can ease your mind to find out why it's necessary, what it could show and what could happen as a result.

It can be hard not to worry about the outcome of these tests, even if you feel well. This is perfectly normal. One of the main challenges described by people living with a NET is this constancy - the sense that your NET is always there. You live with the "new normal", and for long periods may even forget it's there, but these intervals where you need follow-up tests are a constant reminder that cancer is an ongoing part of your life.

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Getting used to your new normal

The whole process of being diagnosed with, and treated for cancer is abnormal. No one expects the sudden shift to a life of tests, treatments and unfamiliar medical language, and however realistic we are about our lives not lasting forever, being confronted with our mortality through a cancer diagnosis isn't something that's easy to get used to.

Your recent experiences will have changed you and become part of your personal history, and coming to terms with that isn't about ignoring it or trying to go back to how your life was. It's usually more realistic to think about getting used to your new normal.

Part of that new normal will probably be an ongoing sense of uncertainty. It's natural to worry about your NET spreading or getting worse, and that uncertainty can cause a lot of tension.

You might find it makes you feel irritable and frightened. Making plans can become more difficult too if you're not sure about the future. And you might want more specific information about what could happen than your care team are able to give you.

A lot of people find it helps to try and regain a sense of control and get back into a routine - whether that means going to the supermarket, gradually returning to work or taking a walk with friends a few times a week. This can help you to feel more confident too. Talking to others who are in a similar situation on our NET Natter groups or on our Facebook page can be helpful too.

It's usually more realistic to think about getting used to your new normal - rather than trying to get back to normal.

Coping with changing emotions

The impact NETs have on your life and your emotions can depend on what stage you are at in your life, what your previous experiences are, what options are open to you and what your priorities are. These factors are individual to every person with a NET.

Often the emotions you experience are shared by the people around you, and having a family member or friend who is there to support you can make a huge difference. It can also be hard for those close to you to know how to help.

Living with a NET may feel like an emotional rollercoaster ride. Managing expectations - both your own and other people's - can be challenging. Your care team should always include you in the decision about your care so you have a better idea of what to expect, but how much information you want about your disease and treatment options is completely up to you.

Try not to feel pressured into finding out more than you're comfortable with because the people close to you want to know more. It's not unusual for those around you - and even some medical professionals, such as your GP - to have little awareness or knowledge about NETs - it is an uncommon cancer. This can be frustrating, or make you feel isolated.

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It can also make you feel as though you have to become the expert... and often you are, but those around you, including your GP, will often be willing to learn and find out more for you - to ensure you're not alone in dealing with this.

It's not always easy but try not to be overwhelmed by other people's experiences of cancer. The world can seem to bombard you with notions of how you should feel or behave. From films to newspaper headlines to blogs, stories of people battling, fighting and surviving cancer are everywhere. Some people find this terminology inspiring, but others find that it is unrealistic and inappropriate.

Whoever you are and however you feel, your experience is unique to you - and you will find your own way to cope.

Feelings after treatment

People may expect you to feel more positive following treatment, and you may, but you may also have a sense of anti-climax - an "is that it?" feeling.

Even if you've felt fairly calm throughout your treatment, this can be the time when emotions surface as you reflect on your situation and wonder what the future holds.

You may feel less confident if you're not able to do all of the things you used to do or if you're experiencing physical symptoms because of your NET or treatment.

Conversely, you may feel that having time to reflect after treatment allows you to understand and concentrate on what really matters to you.

However you're feeling, the advice we've given throughout this book on coping with your emotions remains the same.

For most people, part of the challenge of this time is about achieving a sense of balance. There will be times when you feel good and times when you struggle, and working out what's causing those feelings and what helps you to respond can give you a greater sense of control.

The time after treatment can be one of the most emotionally challenging periods of a NET diagnosis - so be kind with yourself.

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Responding to new symptoms

It's natural to feel differently about your body and to monitor changes more carefully after a NET diagnosis. You might start feeling anxious about aches, pains and lumps you would probably have ignored in the past.

This isn't a bad thing - it's important to look out for potential issues, and your care team will let you know specific symptoms to watch for that could be related to your NET or to your treatment.

It can be difficult if you start becoming overwhelmed by worries about your health, although often this becomes easier to manage over time. But if you are struggling to cope, worrying about unexplained symptoms - such as inability to sleep, feeling irritable, easily distracted - it can help to talk to whoever you feel most comfortable and confident opening up to.

Try to keep things in perspective by asking yourself a series of questions too. Have you had a symptom like this before? If you have, what caused it? Are there other things apart from your NET that could have prompted this issue - a lack of sleep, tension, dehydration, an injury etc.? Going through this process can help you to feel more in control of your fears.

It's not silly - and it's certainly not a waste of anyone's time - to ask questions or talk about anything that concerns you.

It's always better to mention something that turns out to be nothing than it is to stay silent and ignore a potential problem.

PLANNING FOR YOUR FUTURE

Being diagnosed with a NET may mean you want to put more arrangements in place for the future.

Even if you've been told that your life expectancy is good, just thinking about issues like that can prompt you to do the things we all know we should do, but often put off to later - like making a will.

If you want to make a will, it's usually best to use a solicitor. You may have one already, but can find one through:

- The Law Society for England and Wales - www.lawsociety.org.uk
- The Law Society Scotland - www.lawscot.org.uk
- The Law Society of Northern Ireland - www.lawsoc-ni.org

In the following section, we discuss the care and support you can expect if you may be reaching the end of your life. This is a very difficult subject to think about, and it may be that you would prefer not to read about it at this time.

If you are told you may be reaching the end of your life

Not everyone with a NET will die from their cancer, but they may die with their cancer. This means death may occur from another cause - such as another health issue, an accident or "natural causes".

But there may come a day when your care team has to tell you that your illness has reached a point where further treatment is unlikely to work.

Hearing this news can be an enormous shock, even if it only confirms what you have been suspecting for some time.

There's no right or wrong way to respond to hearing that you may be reaching the end of your life. You may feel relieved. You may feel a huge sense of disbelief. You may just feel numb.

If you have any questions about any of the subjects we discuss here, you can call us, and you always talk to your care team.

End of life care

End of life care should help you to live as well as possible and to die with dignity. It should also reflect your wishes, and your care team will discuss these with you and take them into account as you jointly plan your care.

End of life care can include psychological, social and spiritual support for you, your family and your loved ones, as well as physical support (such as pain relief).

You may receive end of life care at home, in a care home, in a hospital or in a hospice.

End of life care should begin when you need it and may last a few days, weeks, or several months.

People in lots of different situations can benefit from end of life care. Some may be expected to die within the next few hours or days. Others receive end of life care over many months.

Good end of life care is tailored to the person who needs it. You and the people close to you should be at the centre of decisions about your care.

www.nhs.uk/Planners/end-of-life-care/Pages/planning-ahead.aspx

LETTING IT ALL SINK IN

There is a lot of information in this handbook, and this section in particular looks at some very difficult issues. We hope you'll use the book again and again to support you through your life with a NET - but we would like to finish by drawing out a few key points we hope you won't forget.

You are not your NET

A NET diagnosis shouldn't define who you are. It will change your life and may make you feel very different, or uncertain - but you will always be much more than your NET.

Everyone's situation is unique

Your illness is as individual as you are. The type of NET you have, its location, its staging, its grading and its function all set you apart from anyone else you meet. So while it can be hugely helpful to meet with people in a similar situation and share your experiences, try not to compare yourself with anyone else.

Incurable and terminal are not the same thing

Incurable means a condition can't be cured. Terminal means it can reasonably be expected to end a person's life in a limited amount of time. NETs are often incurable but certainly not always terminal.

Treatment doesn't happen to you

It happens with you. You have every right to be involved in every stage of your treatment, so ask questions, take time to make decisions and don't say yes to anything unless you're absolutely sure you understand what's planned, and are in agreement with that plan.

Straight-talking ...

... can be anything but straightforward, however letting those closest to you know how you are feeling, and what's going on, can be very empowering - for you, and helpful for them.

Living with a NET is at times unpredictable, but hiding the emotions that uncertainty causes, doesn't really make them go away. Being honest with yourself, as well as loved ones - is a first step in learning to handle difficult emotions.

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You're not alone

We started this book by saying this and we want to finish by emphasising the same very important point.

Having any cancer can feel lonely and isolating at times, this can seem especially so when you have an uncommon cancer, that few have heard of.

There are many people - your family and friends, work colleagues, your care team, specialist nurse and GP - and organisations, like the NET Patient Foundation, who can help you cope with your experience of cancer.

More importantly, they can be used to help you to help yourself - giving back the feeling of control, in a situation which may initially feel overwhelming.



CONTACT DETAILS

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FURTHER RESOURCES

We hope you have found this handbook useful and informative for yourself and family.

This is just one of the many resources that we have on offer.

You may also find it useful to watch some videos explaining NETs, like our 'Guide to NETs' or maybe our 'Frequently Asked Questions' video, featuring NET specialists from around the UK.

Please visit the Videos page on our website:
www.netpatientfoundation.org

