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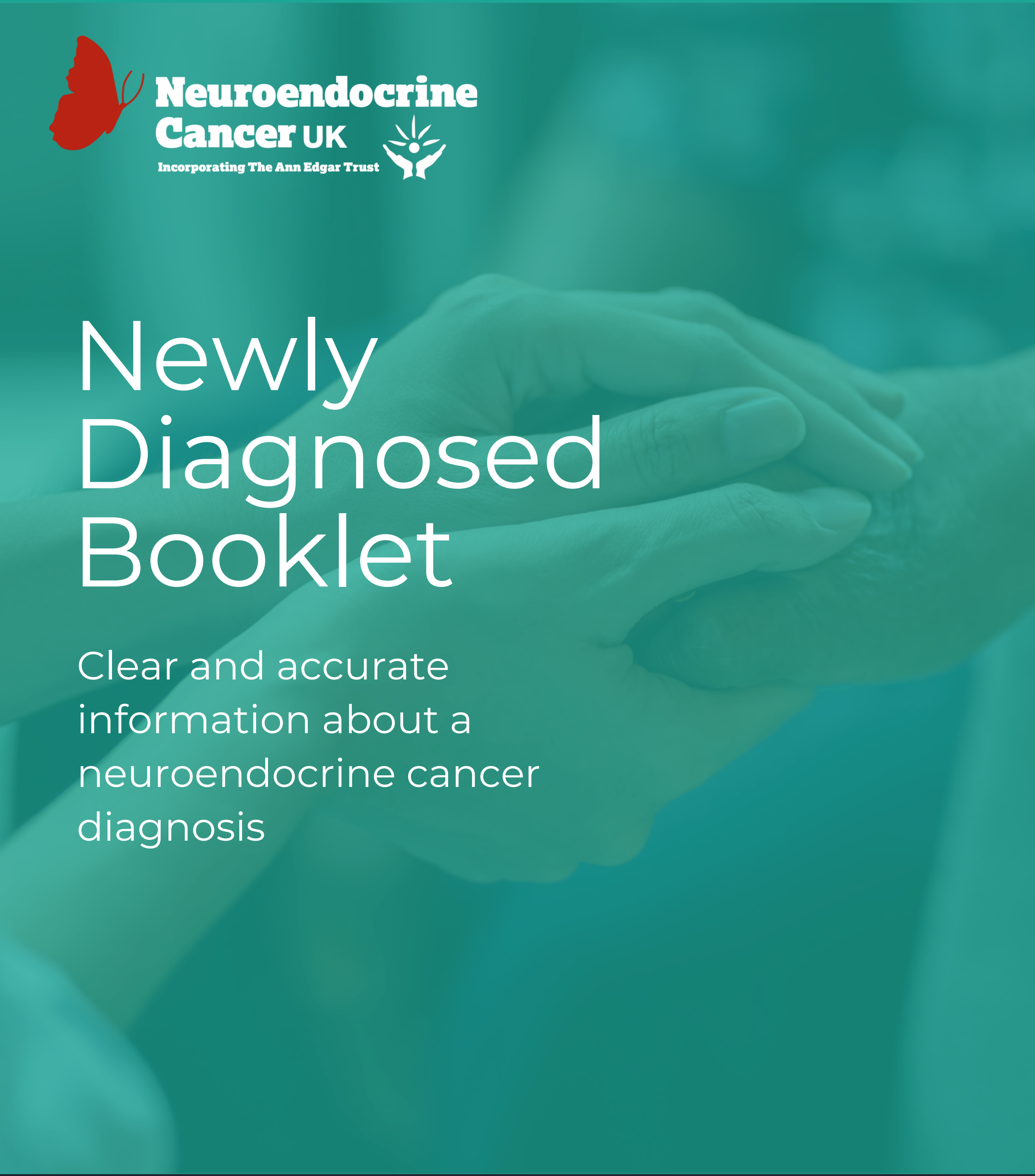


Neuroendocrine Cancer UK
Incorporating The Ann Edgar Trust

Newly Diagnosed Booklet

Clear and accurate information about a neuroendocrine cancer diagnosis

www.neuroendocrinecancer.org.uk
Registered Charity Number: 1092386

Welcome

Neuroendocrine Cancer UK is a UK-wide charity solely dedicated to providing support and information to those affected by neuroendocrine cancer.

Neuroendocrine Cancer UK was co-founded, more than 20 years ago, by people affected by neuroendocrine cancer for people affected by neuroendocrine cancer - and that mission continues through to today.

Our vision is of a world in which people know how to recognise, diagnose, treat, care for, and ultimately cure patients with neuroendocrine cancer.

If you, or someone you care about, has neuroendocrine cancer, we are here for you.

This booklet has been developed, working with our patient ambassadors and wider community, to provide clear and accurate information about a diagnosis that can sometimes seem complex and unclear.

For further information and details about our support services please visit our website: **www.neuroendocrinecancer.org.uk**

Contents

Contact Us

Speak confidentially with our support services team for information and advice on your neuroendocrine cancer diagnosis

Information & Support Helpline

0800 434 6476
Open Tues-Thurs
10am-4pm

Please Note: The helpline is not a general enquiry or clinical emergency line.

If you require urgent medical assistance - call the emergency services and notify your specialist team.

General Enquiries

01926 883487
hello@nc-uk.org

Visit the ‘Contact Us’ page on our website for full details.

Neuroendocrine Cancer UK, Holly House, 74 Upper Holly Walk, Leamington Spa, Warwickshire, CV32 4JL

What is neuroendocrine cancer?

→ Neuroendocrine cancer is cancer that starts in the neuroendocrine cells

Neuroendocrine cells exist throughout the body. They translate signals from the brain (neuro) into the production of hormones and similar chemicals (endocrine) to ensure our bodies function normally.

These cells make up a coordinated communication network - the neuroendocrine system. In health, this system controls and regulates hormone and similar chemical release to keep us well.

→ Each year in the UK, around 6000 people are diagnosed with a neuroendocrine cancer

But there are different types of neuroendocrine cancer, depending on where they start, how quickly or slowly they may grow and whether their ability to release hormones is affected or not.

We hope this booklet, and further resources on our website, will help you to understand your neuroendocrine cancer and how it might affect you.

What are neuroendocrine cells?

Our bodies are made up of billions of cells including neuroendocrine cells. In health, neuroendocrine cells, help regulate our bodily functions by releasing substances that circulate throughout the body, substances such as hormones.

Hormones are chemical messengers that travel throughout the body, targeting certain cells and organs, to stimulate an action or function. They are essential to normal body health.

Hormones help us to:

- Grow
- Respond to stress, ‘fight or flight response’
- Digest food and control blood sugars
- Determine our sexual function and appearance
- Sleep - amongst many other functions

Cancer and neuroendocrine cells: Cancer is a condition where cells within the body start to grow and reproduce uncontrollably. These cells can invade surrounding healthy tissue, including organs and some can spread to other parts of the body (metastasise) through blood vessels or the lymphatic system. When neuroendocrine cells become cancerous they stop working normally. They start to grow uncontrollably (sometimes at different rates) and their ability to release hormones may also be affected (may release higher than normal amounts).

Normal cells and cancer cells

Normal cells have rules

- They develop and grow in a controlled manner
- They do what they are programmed to do, then die off to be replaced by new cells
- If damaged they try to repair themselves or die off
- They tend not travel to other parts of the body
- If they have a particular function, this will occur normally
- If they do grow beyond normal size they tend to push against neighbouring cells, rather than through them

In cancer the rules are forgotten

- There is uncontrolled growth
- Lack of cell repair and replacement or death, which can result in tumour formation of immature, abnormal (cancerous) cells
- They will travel to other parts of the body and settle (metastasise)
- If they have a particular function, this can become abnormal or altered
- When they do grow beyond their normal size they will invade neighbouring cells and structures (infiltration)

Normal cells and cancer cells

Although science has identified some causes, associations and risks of developing cancer:

Internal

For example a faulty gene as seen in breast cancer and BRCA gene

External

For example exposure to a carcinogen (cancer-causing agent) such as smoking or exposure to certain chemicals

There is no single specific cause, association or risk factor for all neuroendocrine cancers.

However, one classification, neuroendocrine carcinoma, MAY share similar associations or risks to more common organ specific cancers. For example, sun exposure and neuroendocrine carcinoma of the skin (also known in medical terms as Merkel Cell Carcinoma).

Is neuroendocrine cancer genetic?

Most neuroendocrine cancers occur ‘sporadically’, this means that there is no currently known genetic (inherited) link to how or why they have developed.

However, there are a number of rare inherited genetic conditions that can increase someone's lifetime risk of developing a neuroendocrine cancer, these include:

- Multiple Endocrine Neoplasia MEN types 1-5
- Familial medullary thyroid cancer (FMTC)
- Familial phaeochromocytoma +/- paraganglioma (FPPGL)
- Parathyroid hyperplasia
- Familial isolated pituitary adenoma (FIPA)
- Succinate dehydrogenase (SDH) disorders
- Von-Hippel Lindau
- Neurofibromatosis 1

If you are affected by any of these conditions, further information and support is available through our charity colleagues at AMEND: www.amend.org.uk

Is neuroendocrine cancer genetic?

Genetic testing can sometimes identify specific faults that might be helping a person’s cancer cells grow / help doctors decide which treatment is best for a patient. **This is sometimes called personalised medicine.**

Genetic testing is free for most known genetic conditions, on the NHS, if you are referred for it by a hospital specialist. You will generally only be referred if you have a suspected genetic health condition or if you have a particular type of cancer. It should be noted that current testing looks to identify known genetic mutations and fusions.

While there are private facilities available that offer genetic testing and whole genome sequencing, we would recommend discussion with your specialist team beforehand. This may help to confirm whether this would be helpful to you or not.

Please note: if a recommended treatment requires testing this will be offered to you.

For further information on genetics and genomic testing please visit the NHS UK website:

NHS Testing:
www.nhs.uk/conditions/genetic-and-genomic-testing/

or **Genomics England:**
www.genomicsengland.co.uk/

You may also find **RARECAN** (BioResource Information) helpful:
https://rarecan.com/bioresource/

Not all neuroendocrine cancers are the same

Neuroendocrine cancer can develop almost anywhere in the body, and they don't all behave in the same way.

Signs, symptoms, tests and treatments may be different dependent on the primary site, stage AND behaviour (growth rate and functionality) of your neuroendocrine cancer.

- → Primary site refers to where a cancer starts to grow
- → Secondary site or metastasis, refers to where a cancer may have spread

The most common sites in which metastases can occur are local lymph nodes, liver, lungs and/or bones.

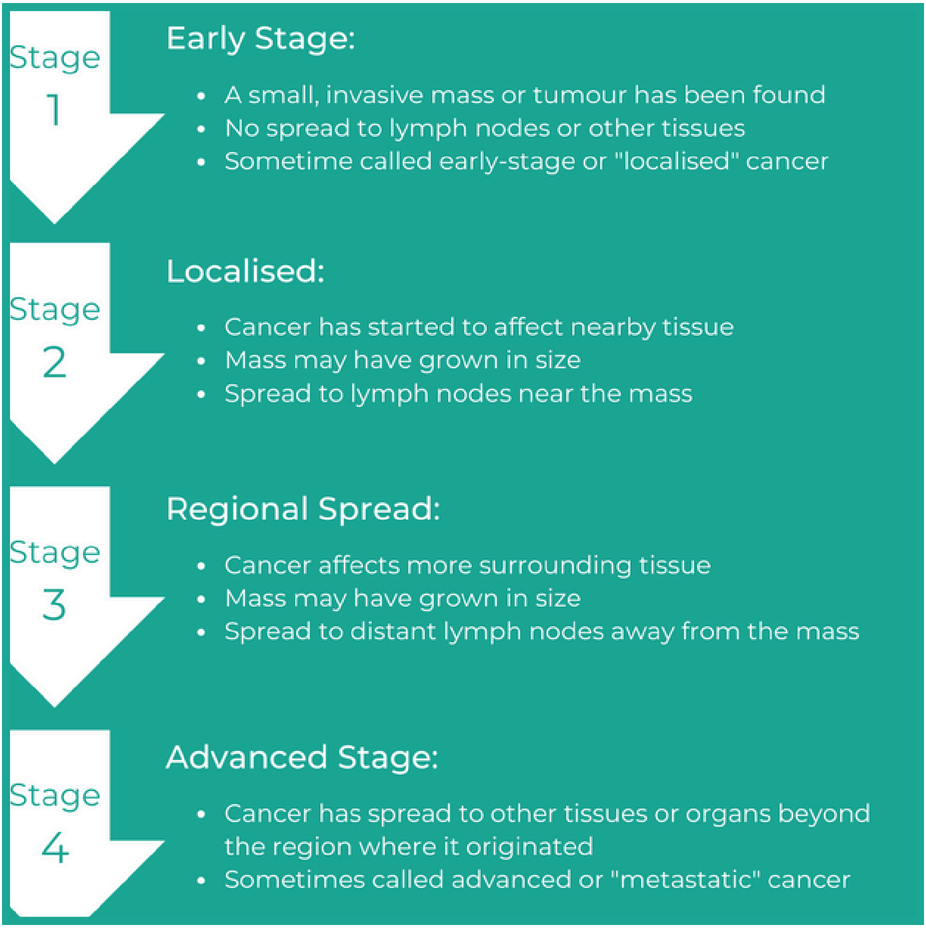
But as with primary sites, metastases can occur almost anywhere in the body.

On the following pages we look at sites, staging and grading.

Primary sites

Area of the body	Primary site(s)
Head & Neck	Pituitary gland, Mouth, Tonsils, Larynx, Thyroid: Medullary Thyroid Carcinoma, Parathyroid, Peri-orbital (in, around or near the eye), Carotid body (Paraganglioma)
Chest	Breast, Lung, Thymus
Gastrointestinal (GI): Mouth through to Anus	Oesophagus, Stomach, Duodenum, Jejunum, Ileum, Appendix, Colon, Sigmoid, Rectum, Anus
HepatoPancreatoBiliary (HPB): Liver, Pancreas, Gallbladder & Bile Ducts	Liver, Pancreas, Gallbladder, Bile Ducts
Urinary System	Adrenal (Phaeochromocytoma), Renal (Kidney), Bladder, Ureter
Reproductive System	Ovary, Uterus, Cervix, Vagina, Vulva, Testicle, Prostate
Skin	Merkel Cell Carcinoma

Staging



Stage 1

Early Stage:

- A small, invasive mass or tumour has been found
- No spread to lymph nodes or other tissues
- Sometime called early-stage or "localised" cancer

Stage 2

Localised:

- Cancer has started to affect nearby tissue
- Mass may have grown in size
- Spread to lymph nodes near the mass

Stage 3

Regional Spread:

- Cancer affects more surrounding tissue
- Mass may have grown in size
- Spread to distant lymph nodes away from the mass

Stage 4

Advanced Stage:

- Cancer has spread to other tissues or organs beyond the region where it originated
- Sometimes called advanced or "metastatic" cancer

Histopathology

- Examining neuroendocrine cancer cells under a microscope (histopathology) can provide vital information about how it is likely to behave, in terms of growth and potential to spread.
- It is also important in treatment decision-making, to ensure the most appropriate anti-cancer therapy is offered. This process is called grading.
- It is vitally important that this grading examination is undertaken by an expert, a histopathologist* with experience in examining neuroendocrine cancer.

Histopathologists* are expert doctors who are responsible for diagnosing and studying disease in tissues and organs, including cancer. They carefully examine samples, taken by aspiration, biopsy or surgery, to determine a diagnosis.

Grading & Differentiation

There are 2 key factors that can help accurately grade neuroendocrine cancer

- Differentiation: which refers to cell appearance
- Mitotic rate: which refers to how quickly or slowly cancer cells are dividing and growing

Differentiation refers to how different the cancer cell looks like compared to what it should look like as a normal cell, therefore we can divide neuroendocrine cancers into 2 main groups:

Neuroendocrine Tumours (NETs)

NETs are well-differentiated cancers. Called so because although abnormal, with evidence of cancerous change, the neuroendocrine cancer cells that form the tumour, have kept many of the characteristics of a normal neuroendocrine cell. Their 'mitotic rate' can vary from slow to rapid growth, graded 1-3

Neuroendocrine Carcinomas (NECs)

NECs are poorly-differentiated cancers. In NECs, the neuroendocrine cancer cells have become very abnormal, losing many of the features of a normal neuroendocrine cell. Their cell size may also be affected - leading to them being classified as either small cell or large cell NECs. Their mitotic rate is consistently high, so not graded.

The importance of ensuring you have an accurate grade cannot be over emphasised as it is a key determinant of both treatment planning and decision-making, alongside how it is used to determine prognosis (where prognosis is the prediction of the most likely course of disease as well as the treatment response, rather than life-expectancy).

Mitotic rate is a measure of how fast cancer cells are dividing and growing. To find the mitotic rate, the number of cells actively dividing in a certain amount of cancer tissue, is counted. This may be reported in histopathology reports using the abbreviation MiB-1 or Mitoses per 10 HPF.

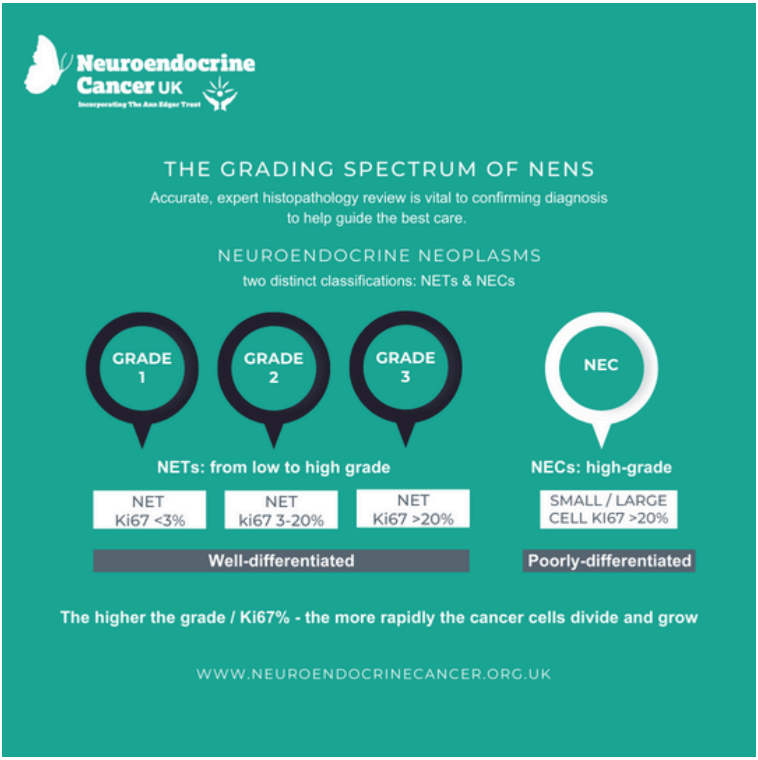
However, for most neuroendocrine cancers, histopathologists use something called Ki67 to ‘stain’ or identify actively dividing cancer cells.

Ki67 is a protein that is present during all of the active stages of the cell cycle, a valuable marker of proliferation (cell division and growth), often expressed as a percentage (%).

You may see the term Ki67 followed by a percentage, used in your clinical letters or reports. The higher the Ki67% the more rapidly the cells are dividing and growing.

Grading & Differentiation

- Neuroendocrine Tumours (NETs) are well-differentiated cancers with different grade categories (different rates of growth).
- Neuroendocrine Carcinomas (NECs) are poorly-differentiated cancers, a distinct group from NETs, with a consistently high Ki67, and therefore are not routinely assigned a grade (though some may call them Grade 3).



Neuroendocrine Cancer UK
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THE GRADING SPECTRUM OF NENS

Accurate, expert histopathology review is vital to confirming diagnosis to help guide the best care.

NEUROENDOCRINE NEOPLASMS

two distinct classifications: NETs & NECs

NETs: from low to high grade

NECs: high-grade

NET Ki67 <3%	NET ki67 3-20%	NET Ki67 >20%	SMALL / LARGE CELL KI67 >20%
Well-differentiated			Poorly-differentiated

The higher the grade / Ki67% - the more rapidly the cancer cells divide and grow

WWW.NEUROENDOCRINECANCER.ORG.UK

Why is grading so important?

NET gradings

- Grade 1 is a well-differentiated cancer with a Ki67 less than 3%
- Grade 2 is a well-differentiated cancer with a Ki67 between 3 and 20%
- Grade 3 is a well-differentiated cancer with a Ki67 more than 20%

The exact cut-off criteria between G1-3 NETs may differ depending on primary site.

For example, in lung, where well-differentiated tumours are currently often referred to as either typical or atypical carcinoids, rather than NETs, the cut off is:

→ Typical carcinoid: A well-differentiated lung neuroendocrine cancer with a Ki67 of less than 5% would be considered low-grade.

→ Atypical carcinoid: A well-differentiated lung neuroendocrine cancer with a Ki67 between 5 - 30% may be considered moderate-grade.

→ NEC: poorly-differentiated, either small or large cell carcinomas, with a Ki67 more than 30%.

Functioning or non-functioning?

You may hear your doctor or nurse use the term ‘non-functioning’ or ‘functioning’, when they talk about your neuroendocrine cancer.

Non-functioning

Neuroendocrine cancer cells usually retain their ability to release normal amounts of hormone or chemicals.

Functioning

Neuroendocrine cancer cells produce and release abnormal, that is higher than normal, amounts of the hormone or chemical they are usually responsible for. This abnormal release can result in hormone-associated symptoms / syndromes.

Please note: less than half of all neuroendocrine cancers are functioning.

Those that are, are mostly neuroendocrine tumours (NETs) rather than neuroendocrine carcinomas (NECs)

Visit: www.yourhormones.info for more information

Summary

Neuroendocrine Tumours (NETs) are:

- Well-differentiated cancers
- May be Grade 1-3, depending on their Ki67%
- May be Stage 1-4, depending on where they are, how big, and whether they have spread (metastasised)
- May be functioning or non-functioning

Neuroendocrine Carcinomas (NECs) are:

- Poorly-differentiated cancers
- Have high Ki67 (above 20%) so may behave in the same way as more common cancers
- May be small cell or large cell type in appearance
- May be Stage 1-4, depending on where they are, how big, and whether they have spread (metastasised)
- Are usually non-functioning (N.B. paraneoplastic syndromes* may occur)

*Paraneoplastic syndromes are rare disorders that may occur when the immune system has a reaction to a cancerous tumour

Your care

Treatment and care after a neuroendocrine cancer diagnosis

Specialist Care

We understand that being diagnosed with neuroendocrine cancer can be a challenging and overwhelming experience. That is why it is crucial you receive the best possible care from experts who specialise in this complex type of cancer and that you have your case reviewed by a specialised, accredited “NET” specific Multi-Disciplinary Team (NET MDT) regularly.

Please visit **www.neuroendocrinecancer.org.uk** for a comprehensive list of all Centres of Excellence (CoE) or experienced neuroendocrine cancer MDTs and Clinics across the UK.

On our website you will also find advice on how to obtain a referral to one of these centres and guidance on how to best prepare for your appointments, including speaking with your doctor, and a list of useful questions to ask during your appointments.

Multidisciplinary Team (MDT) & Care Decision-Making

The core function of a multidisciplinary team (MDT) is to bring together a group of healthcare professionals from different fields in order to determine a treatment plan.

The team will review your test and scan results at one, or more, dedicated team meetings and discuss your individual care.

This discussion will lead to an agreed plan of care with consideration of alternative options. After the meeting, a member of the MDT will:

- Inform you of the outcome either face-to-face or over the phone
- Offer you spoken and written information about your care and treatment
- Offer you the opportunity to ask questions and talk about how you are doing
- Send a copy of the MDT meeting record to your GP / the healthcare professional who referred you
- Keep your GP up-to-date with your care and treatment - usually by letter
- Offer you copies of letters written about your care to other health professionals, including your GP

- Offer you access to a clinical nurse specialist (CNS), especially when informing you of your diagnosis if this had not already happened
- Let you know about local and national support services
- Regularly review your case - unless the MDT outcome and agreed decision is to discharge you from further follow up or to another service

The MDT will offer you information and support to make sense of any clinical advice from the MDT meeting

They will give you the opportunity to ask questions and voice your preferences / concerns, before coming to an agreement on care and asking you to consent to that treatment / ongoing plan of care.

You have the right to choose - whether this means agreeing with treatment plan / care or not.

Treatment is not something that just happens to you. Your informed consent is required

Your appointment

We know that listening to and trying to understand certain types of information can be difficult, especially if you're feeling nervous, anxious or vulnerable and it can be hard to think of the questions you may want to ask, whilst trying to make sense of what you may have been told.

It may help, instead, to think about what answers you are looking for, as this can help you to decide what kind of questions to ask.

The following suggestions might help you to get more out of your consultation(s):

Prepare a list of questions you might want to ask.

- This can help you to remember what you wanted to ask. List them in order of what you may want to ask and you can share this list with your doctor or nurse at your appointment.
- If you are finding it difficult to ask these questions you can hand them to your doctor or nurse, and if you don't feel able to deal with them at the time, you can ask to go through them at a later time.

- 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 your specialist nurse to come into the consultation with you OR ask if your consultant is happy for you to record the conversation on your phone, or recording device, so you can listen back later to check you've understood and haven't forgotten anything. N.B. If using your phone, 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 medical terms without even realising they're doing it. Ask for written information and for a copy of any letters that your specialist doctor / team are sending to your GP / (local) care team.

- If you have a Clinical Nurse Specialist – keep in touch. Use them as a sounding board for concerns, to answer questions / to explain anything you may be having difficulty with understanding.

- Remember that you can always call back after your appointment to clarify anything you've not understood. It is your health, so it is important that you have the information you need.

Treatment

There are a number of treatments available for neuroendocrine cancer but at all times the aims and risk/benefit of any treatment, alongside your preferences for care, should be considered to ensure your physical and psychological well being.

It is important to note that not all treatments are suitable for all types of neuroendocrine cancer.

The timing of treatment and the order in which you may be offered treatments, if more than one is suitable for you, may also vary from person to person, even when the type, stage and grade of neuroendocrine cancer (NET or NEC) may be similar.

Treatment aims can vary, from attempting to cure neuroendocrine cancer, to controlling disease symptoms, to improving both prognosis (length of life) and quality-of-life.

Your physical and mental well-being should be at the forefront of all considerations.

The key aim of treatment should be to help you have the best possible care and quality of life, by ensuring access to appropriate treatment, management of symptoms and addressing what's most important to you.

Not everyone diagnosed with a neuroendocrine cancer will need to be on treatment, or at least not immediately, and though that may seem strange, it may also be a relief.

Surveillance: using regular scans, tests and clinical review, can be used to check your cancer and general health for any signs of change that may mean that a treatment might need to be considered.

Further information on treatments is available on our website: www.neuroendocrinecancer.org.uk

Following diagnosis

One thing that's certain is that there's no right or wrong way in how you react to or feel about the news that you have cancer.

But there are a number of things you can do to get you through the next few days, weeks, months, even years.

Having coping strategies in place is a good idea for lots of reasons.

They can help you work out which things make you feel better, help you understand when / if you are likely to struggle, and help you to respond to difficult situations and feelings in a positive way, rather than in ways that could make you feel worse, physically and mentally.

→ Coping strategies don't need to be complicated. They may help with managing uncomfortable feelings, signpost you to information and resources, and support your overall well-being.

For further information about the support we provide please visit our website here: www.neuroendocrinecancer.org.uk

Receiving a diagnosis of neuroendocrine cancer can be an unexpected and challenging moment in your life.

You may find our short video on ‘dealing with a diagnosis’ helpful to watch. It is available on our YouTube channel @neuroendocrinecanceruk

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We understand the range of emotions and questions that may arise during this time, and we’re here to provide you with the support and information you need.

It is not unusual to experience anxiety, even if you have been given the ‘all clear’. Months, even years, after treatment, certain things may trigger uncomfortable feelings, for example, the anniversary of a diagnosis, a cancer in a friend, a TV storyline or a new ache or pain you may experience.

This is a normal reaction to having a cancer diagnosis and can keep you alert for changes in health that may require a review or further investigation.

What can help?

Looking after yourself and your emotional wellbeing

How we think and feel is often influenced by our memories, experiences, relationships, beliefs, those around us, as well as our hopes for and concerns about the future.

Many people with neuroendocrine cancer, have disease that may not be curable, but is treatable - meaning that you may live well for years, and we very much hope this will be the case for you.

However, we know that there may be times when the ‘reality’ of living with, rather than after, cancer ‘hits home’, the potentially long-term nature of it has its own impact, even if you feel physically well.

But taking care of yourself, mentally and physically is as important as the care and support you may feel you need to provide as a partner, parent, sibling, family member or friend.

Relationships, Family & Friends

Personal relationships may change during cancer and its treatments, and there can be a grieving for the way things were or for things that might not now happen. Some relationships get stronger during cancer treatment. Others are weakened. Nearly all couples and family relationships feel more stress than usual when cancer occurs. Concerns may include:

- Knowing how to best support each other and how to communicate
- Dealing with new feelings that come up
- Making decisions
- Juggling lots of roles (such as childcare, housekeeping, work, and caregiving)
- Changes in your social life
- Changes in your daily routine
- Not feeling connected sexually

Please visit our YouTube page @neuroendocrinecanceruk and search for our ‘Newly Diagnosed’ video.

What can help?

Exercise & Keeping Active

Research has shown that exercise is safe, possible and helpful for many people with cancer. Being physically active means any movement that uses your muscles and more energy than when you're resting. Being physically active doesn't have to mean joining a gym or an exercise class. It can also be walking to the shops, walking up the stairs, gardening or dancing!

How active you are and what type of activity you can and want to do will depend on:

- The type of cancer you have
- Your treatment and any side effects you have
- How physically active you are already
- What activities you enjoy

It's difficult to write exercise guidelines to cover everyone.

Everyone is different in terms of how much exercise they can do, what type of cancer they have and what treatment they may be receiving. We recommend that you check with your specialist team before starting any exercise regimen.

Diet & Nutrition

There is no single specific diet that is recommended for those with neuroendocrine cancer. However, some adjustments, depending on symptom experience, may help with self-care. We would recommend a discussion with your specialist team and/or dietitian before making any adjustments.

Work & Finances

Following diagnosis, if employed, you may wonder if you will be able to continue working or whether you will want to. The answer depends on your individual situation, of course, but often people are able to keep working, though some adjustment to hours, responsibilities or tasks may be needed, whether that's temporarily or long-term.

Both the Equality Act and the Disability Discrimination Act offer a degree of employment protection with a requirement to 'reasonably adjust' working hours or role.

Employment, Benefits and Financial advice is best gained from a registered, qualified, advisor. We recommend a discussion with such an advisor from Maggie's Centres, Macmillan, Citizen's Advice, or an independent financial advisor, depending on your circumstances.

Additional support available

‘Natter’ Support Groups

Our community based online or face-to-face meetings that offer an opportunity to meet others also affected by neuroendocrine cancer; you, your family, and friends, to share experiences: connecting people facing similar challenges, building a network of support.

Contact natters@nc-uk.org for further details or visit the Natter support group page on our website.

Counselling & Group Therapy Programmes

Our counsellors have a specialised understanding of the complex issues that can arise in being diagnosed, and living with, neuroendocrine cancer over time.

The service provides both individual and family sessions, alongside group therapy programmes.

Visit the counselling page on our website or call the Helpline for further details.

Podcasts & Videos

Our podcast series covers a wide range of topics, from initial diagnosis, treatments, and follow-up care to tending to your mental health:

Please visit **www.neuroendocrinecancer.org.uk** and navigate to our podcasts

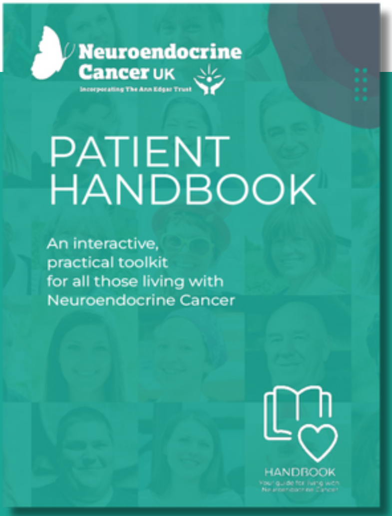
Please visit our YouTube channel: **www.youtube.com/@neuroendocrinecanceruk** for real-life patient experiences and educational videos from the experts involved in your care

Virtual Patient Handbook

Clear, two-way communication, between you and the person you care about can help you to adapt as changes occur.

You may be okay with some of the changes to your relationship and uncomfortable with others, or they may feel the same. Many of the feelings and considerations discussed in our Handbook may ‘touch a chord’ or mean something to you.

Please visit our website: **www.neuroendocrinecancer.org.uk** and search for ‘Virtual Patient Handbook’ or scan the QR code below.



Neuroendocrine Cancer UK

PATIENT HANDBOOK

An interactive, practical toolkit for all those living with Neuroendocrine Cancer

HANDBOOK

Scan this QR code with your phone to visit the Virtual Patient Handbook

A meaningful legacy

This Newly Diagnosed Booklet was made possible through the incredible fundraising that took place **in memory of Azmat (Phopo Azi).**

During 2023, Deen, Raees, Guni, Arjun and Hamza climbed Mount Snowdon and in doing so, over 300 of their supporters raised a phenomenal £93,554!

Part of this sum has gone towards the cost of producing this booklet in the hopes that it provides support and valuable information to anyone diagnosed with neuroendocrine cancer, now, and in the future. We believe that this incredible fundraising achievement has created a meaningful legacy for Azmat and her loved ones, which will be felt for years to come.

Feedback from our community

> “ The experience and insight of the team at NCUK has been invaluable to both myself and my wife. Neither of us had ever used a Helpline before. And we did not expect a charitable resource to be such an absolute wealth of information and kindness. We are now just a wee bit calmer and less doom and gloom whilst also being realistic'ish about the future.

What an absolute relief! To have found a community who don't offer me platitudes, but truly empathise with what I am going through. I honestly thought I was the only one with a cancer no-one had heard of, but this network of new friends has given me such support. And best of all, such reliable information.

Neuroendocrine Cancer UK was co-founded, more than 20 years ago, BY people affected by neuroendocrine cancer FOR people affected by neuroendocrine cancer, and that mission of providing accurate, reliable information and support continues through to today.

At Neuroendocrine Cancer UK we're here to help from diagnosis, through treatment and beyond.

Please visit www.neuroendocrinecancer.org.uk for up to date information relevant to all those affected by neuroendocrine cancer.

DISCLAIMER: Neuroendocrine Cancer UK is not a clinical or healthcare service - it is an information and support organisation. This booklet is for informational or educational purposes only, and does not substitute expert professional medical advice or consultations with neuroendocrine cancer expert healthcare professionals. We, therefore, strongly recommend that you always seek the advice of your doctor or other qualified healthcare provider with any questions you may have regarding a medical condition or treatment, including diet, before undertaking a new healthcare regimen or altering your current healthcare regimen. At 'Neuroendocrine Cancer UK', we are dedicated to providing evidence-based, expert-informed, accurate and appropriate information to individuals and families affected by neuroendocrine cancer. However, while this booklet may help inform consultations and discussions with your team, we would recommend that you do not disregard expert professional medical advice or delay in seeking advice because of something you may have read in this booklet.

www.neuroendocrinecancer.org.uk
Registered Charity Number: 1092386