



NEUROENDOCRINE CANCER

# GETTING THE RIGHT CARE

AND BEING PREPARED

2023

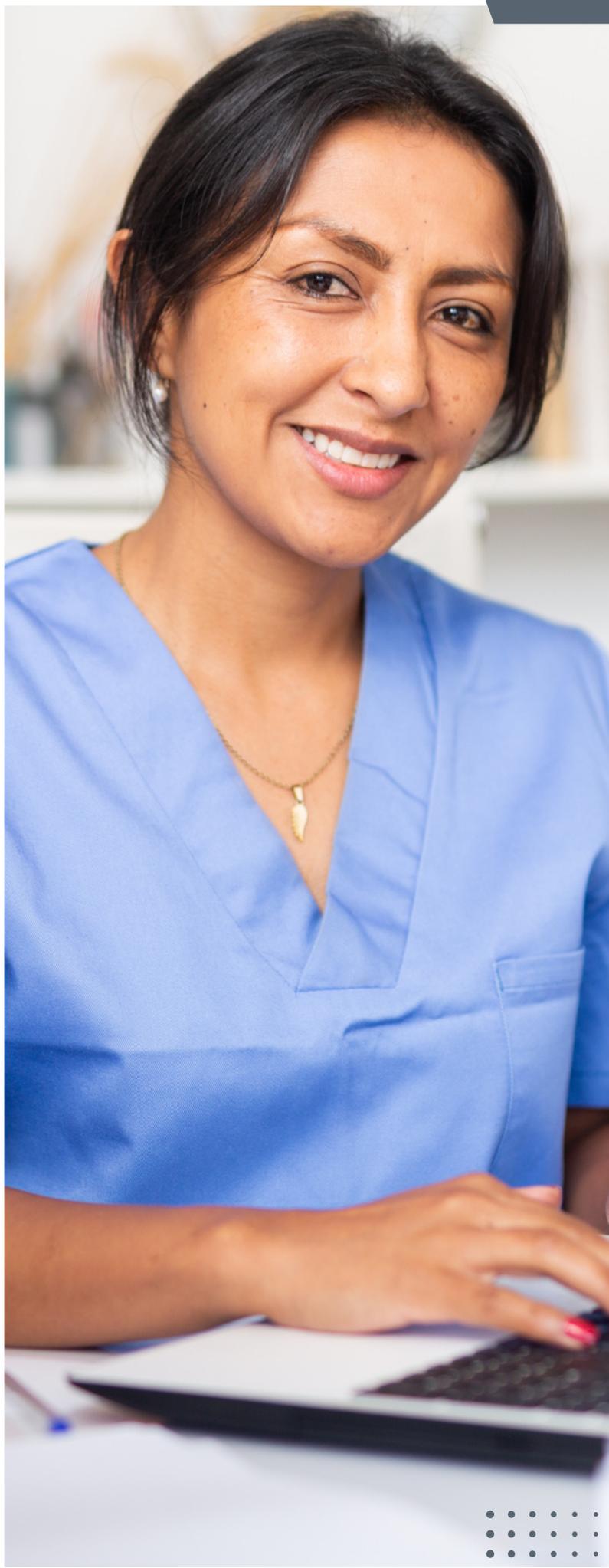




As soon as you're diagnosed with Neuroendocrine Cancer, it's vital to get the best possible advice and treatment from the right team of people and across the UK there are procedures in place to ensure this happens.

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

In this guide we list the current experts, clinics and Centres of Excellence and information about getting a referral to one of these centres. You can also find guidance on ways in which to be best prepared, including speaking with your doctor, and useful questions to ask at your appointments.



## UK Centres of Excellence

You may be referred to one automatically, but if that doesn't happen you can ask for a referral to be made. Keep reading for advice on being referred.



At Neuroendocrine Cancer UK we work with all of the UK's specialist Neuroendocrine Cancer services either directly or through UKI NETS. The UK and Ireland Neuroendocrine Tumour Society (UKINETS) is a professional organisation made up of the UK and Ireland's experts and other experts and allied healthcare professionals who work in the field of Neuroendocrine Cancer. The society keeps an up-to-date list of experts, clinics and accredited Centres of Excellence.

[Learn More >>](#)

**Here you will find a list of ENETS accredited Neuroendocrine Cancer Centres of Excellence – alongside acknowledged specialist MDTs and clinics.**





## Getting referred to a specialist “NET” team

Referrals to specialist Neuroendocrine Cancer services work slightly differently across the UK – there is no currently agreed pathway. 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.

Wherever you are and whoever is caring for you, it is vital to get information and advice from a specialist Neuroendocrine Cancer specific MDT as soon as possible. You may not need to travel for this – an advantage if there is some distance between where you live, and the specialist team is based – but your local team and the specialist MDT must be willing to communicate and work collaboratively with each other to provide you with the right care.

## Multidisciplinary team (MDT)

A multidisciplinary team (MDT) is made up of disease specific experts including surgeons, radiologists, histopathologists, oncologists, clinical nurse specialists, allied health professionals, and multidisciplinary team coordinators and has a designated lead clinician.

Because Neuroendocrine Cancer is uncommon, 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.





## Being prepared

Any type of cancer can cause your life to change in all kinds of ways and Neuroendocrine Cancer is 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.

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



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 Neuroendocrine Cancer. However, having the information you need at the time you need it can help.

Being informed is not about suddenly having to spend hours reading medical textbooks or scouring websites about the neuroendocrine system or about being on the receiving end of a deluge of information. It's about being given the time to get your head around some of the facts and potential implications of a Neuroendocrine Cancer diagnosis.

The time to read through and/or listen to explanations on tests and treatments – the time to ask questions, to talk about concerns... to be listened - to being heard.

The information and time to make decisions that affect you, that can help you to make informed choices, that respect your wishes and that are realistic in aims and expectations of care.

Being informed and being prepared can help you through tests, treatments and care – building a partnership of trust, communication and support between you, your loved ones and your specialist team.



### **TREATMENTS**

Being prepared for treatments 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. What are the aims of treatment? Are there alternatives?

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### **APPOINTMENTS**

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.

[CLICK HERE TO LEARN MORE](#)



### **FAMILY & FRIENDS**

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.

## Working with your healthcare team

Grading is then divided into four specific categories – depending on growth rate (and cancer cell appearance – also known as differentiation).



Being diagnosed with Neuroendocrine Cancer can mean a new or increased involvement in healthcare – with various tests, treatments and appointments taking place. It is likely that you will see a lot of your healthcare team, not only over the days, weeks and months around your diagnosis, but for many months and years afterwards – indeed, follow up may continue for the rest of your life. It may be that you have been or will be referred, at some point, to a Neuroendocrine Cancer Centre of Excellence, or specialist clinic, to be seen by a doctor working within a Neuroendocrine Cancer Multidisciplinary Team (an MDT).

You might only see one or two people from this team when you go to appointments, but they will all be working ‘behind the scenes’ to create the best outcomes for you. Some people find talking with medical staff easy, whilst others may find this difficult, especially if the road to diagnosis has been difficult and long – trust may take time to develop. But it is important to be able to talk through your understanding, concerns and questions with your specialist care team – as this will help to be able to work together – so that any and all decisions about your care are fully informed – and your wishes, concerns and choices are known and respected.



## Suggestions and tips for working with your specialist care team:

- Ask questions
- Never be afraid to let your nurse/doctor know if they say something or use terms you do not understand – they may be so familiar with certain terms that it can be easy to forget sometimes that these terms are not used in everyday life.
- Use a diary, notepad or phone App, to keep track of appointments, tests, questions, and other bits of information that you may find useful.
- Make sure you have a point of contact – and information of the days/times they may be available and the best way to contact them – is it by phone, email, message service?
- Take a friend or family member with you to consultations – if there is someone you would like to speak or ask questions on your behalf – let your team know who this is – so that they know who in particular you would like involved in your care.
- Do let your team know not only about any symptoms you may be experiencing – but also how you are feeling in yourself and about your care.
- Do let your team know about any medications, supplements or complementary therapies you may be taking – including any changes. If your treatment plan includes starting a new drug, there may be interactions – these can be avoided if your team knows about anything you may be taking.
- Let them know about any dependents – including pets – that may need care to be arranged should you need to go into hospital or any other circumstances that may affect your decision-making on care. Personality clashes can happen in all walks of life – even in healthcare. We all find it easier to get along with some people more than others. If this happens – and is affecting the communication between you and the healthcare professional you see, you can ask to see another member of the team.
- If you are unhappy about any aspect of your care – ask to speak with a member of the team you trust, to see if you can talk this through.
- If you really cant do this – or if you would like help in doing this – you can contact the PALS team. PALS is the Patient Advocacy and Liaison Team – and they work within hospitals to help resolve any difficulties – including communicating with your team.





## Speaking with your doctors

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.

Keeping a symptom diary or using a health tracker App, may be helpful for you, to write down or record any information you may find helpful for your appointment. It can be easy to forget things just before or during a consultation, so this may be useful – for example, a list of current medicines, current symptoms and / or any questions you may have.



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 discuss 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 decide on what choice to take, if any.

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## 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 Neuroendocrine Cancer under control. You might be told that things have improved, for instance if surgery has successfully removed all or part of your cancer 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 cancer has continued to grow or spread despite treatment. You may even be told that new tumours have been found.

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.

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