



When you are first diagnosed

Being diagnosed with Neuroendocrine Cancer can be a lot to take on board - not least the different words and terminology used - it's like entering a whole new world. A world of tests, appointments and various discussions that can feel very bewildering, exhausting and / or confusing... and while we cannot tell you that we know how you feel right now or how you may feel as time goes by - we are here to help when and where we can.

Receiving your diagnosis

Being told you have Neuroendocrine Cancer may have come as a shock - not only if you have been feeling well and had been having tests as part of a routine health-check or other reason, but also because it may be something you have never heard of before. On the other hand, it may have come as some kind of relief - particularly if you have been feeling unwell - to find out that there is a reason why, even if the name is not something you're familiar with.

The emotions you may experience, at this time, the confusion and/or information needs you may have may be varied and variable. You may feel anger, particularly if there have been delays in diagnosis, or you had been told your symptoms were due to something else - maybe even psychological. Disbelief, fear, anxiety are also common and are completely normal responses to hearing you have cancer.

A vital aspect of ongoing care, following diagnosis, is ensuring that you are seen by the right people, in the right place, at the right time - a key aim of the NHS.

For those with Neuroendocrine Cancer this is about the involvement of a specialist Neuroendocrine Cancer Team. This "NET" MDT (multidisciplinary team) - is a team of healthcare professionals from various disciplines e.g. medicine, surgery, oncology, etc. who have expert knowledge and experience in diagnosing, treating and supporting the care of those with Neuroendocrine Cancer.



For some of you there may be added uncertainty about this if the word cancer is not mentioned. The words 'lesion', 'tumour' or even 'carcinoid' may be used instead. This may leave you with all sorts of questions and concerns about what you've been told - some uncertainty about the diagnosis and what it may mean for you and your life moving forward. And so you may feel either overwhelmed with information you're not quite ready to hear, to fully understand, or you may find yourself struggling to get the information, or clarity of information, you feel you need.

Being faced with trying to get, or take in the information you may need to make decisions about your care can be difficult - both practically and emotionally. This leaflet is about the following days, weeks and months - about how you may feel, what you might experience, what might help and where that support and information can be found. You may find some days and weeks easier to deal with than others - good communication is key.

When you are first diagnosed with cancer, you may be introduced to a Clinical Nurse Specialist (a CNS) or care coordinator or navigator - keep hold of their contact details, they can provide vital support and information, especially through these early days. They can also help you navigate through trying to juggle work or study, travel arrangements - particularly if you have to go elsewhere for certain tests or treatments, and talking with family.

Psychosocial support is also an essential part of personalised care and can help you to deal with what may feel like the biggest challenge you have ever faced.

This challenge may feel more difficult because you have been given a rare cancer diagnosis - one that may not be diagnosed, treated or behave in the same way as other cancers you may be more familiar with. Psychosocial support is centred around what your needs are - when you need it.

Specialist NET MDT involvement

Once you are diagnosed with Neuroendocrine Cancer, it's vital to get the best possible information and advice from the right team of people - that is a "NET or Neuroendocrine Cancer MDT".

Referrals to specialist Neuroendocrine Cancer MDTs vary slightly across the UK – as there is no currently agreed single pathway. However, you can be referred, or ask to be referred, by your GP, A&E staff or hospital doctor. There are a number of specialist Neuroendocrine Cancer MDTs across the UK. A list is available on the NCUK website.

Dealing with "rare"

Most people have heard of breast, lung, prostate or bowel cancer, as these are the 4 most common cancers diagnosed across the UK, but few may have heard of Neuroendocrine Cancer. You, and those close to you, may not be sure what this diagnosis may mean for you - and even some healthcare professionals may not be certain about what it is and how it is best treated. Which is why being linked in to a specialist "NET MDT" is so important. You may not need to travel to see the "NET MDT", especially if recommended care and treatment is safely available closer to home,



but there may be times when being seen by the team is necessary, for example, to access certain tests, scans and/or treatments.

Neuroendocrine Cancer, can behave differently to other cancers - because of this, different ways of dealing with and/or treating it may be required. Whilst chemotherapy and/or radiotherapy may be appropriate for some types of Neuroendocrine Cancer, other treatment options are available and have been proven to be as, if not more, effective. However, this may lead others to question your diagnosis, as it doesn't meet the usual expectations of cancer care and treatment. But, with specialist "NET MDT" involvement, you can be assured that the care and treatment options discussed with you, will be appropriate for you.

You may already have had your own experience of cancer - on either a personal or family/friend/colleague level. That experience can affect how you may feel now and things that may have helped then, may be helpful to you now. However, your previous experience may not have been positive and while its hard to put poor or difficult experiences behind us, dwelling on what wasn't so good then, may not be helpful right now. Remember, that just as no two experiences are the same - no two people and no two cancers are the same either - especially when it comes to "rare".

Living well with Neuroendocrine Cancer is possible but may require adjusting expectations.

As mentioned Neuroendocrine Cancers can behave and be treated differently to other cancers. Finding out more about your diagnosis, the tests and treatments that may be involved, can help. Having a clear understanding of the aims and implications of treatment can be useful in helping you to make informed decisions about your care. It can also help to restore a sense of control.

Managing uncertainty

As human beings, we tend to like a sense of order, it helps us make sense of the world - dealing with uncertainty and unpredictability can be difficult and take a lot of emotional energy. Knowing what is going to happen next, having a clear plan - for example confirming your next appointment date, knowing what the wait time for results is likely to be, who you can contact if you have concerns or questions - can all help in reducing uncertainty and anxiety.

There is a lot of information about 'coping with cancer', this can vary from source to source and may not always feel relevant to you. Always check this information for reliability and accuracy.

“No decision without me” - partnership in care

It is important to be able to talk through your understanding, concerns and questions with your specialist care team. This will help you work together, so that any and all decisions about your care are fully informed and your wishes, concerns and choices are known and respected. Your specialist team may not always have all of the answers, but knowing your concerns can help them to work with you to address any uncertainty you may be feeling.

Information

Everyone takes in information in different ways: it can sometimes feel confusing when medical terms and explanations are used - when simple, straightforward wording is what you need. 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. At other times, discussions may feel too brief and not detailed enough to answer questions you might have.

Take the time you need, write down and ask the questions that are important to you. You can set the pace and don't be afraid of asking the same question more than once if you need to, to ensure your understanding.

Mental Health and Neuroendocrine Cancer

If you already live with anxiety, depression or a mental health diagnosis let your mental health support team and your Neuroendocrine Cancer team know so that together you can work out how best to support you. And if you have a clinical nurse specialist - use him or her! They often link in with all members of your specialist team as well as with local care and support services - so can be a vital resource, of both support and information, for you. Talking with your specialist nurse, a counsellor or therapist may help you to deal with difficult or uncomfortable feelings.



Talking

We each have our own way of dealing with a difficult situation - talking can help. So if you have someone you can talk openly with, who won't judge or try to leap in and fix how you're feeling - that can really help. This may be a partner, close friend or healthcare / counselling professional.

You may need time to work out what you might want and need - time to 'get your own head straight' first. Or you may prefer to talk things through with others right away.

It sometimes feels easier to offer, rather than ask for, help - asking for help isn't a weakness - it takes strength and can be a show of trust in those close to you. It can also help them to understand what you are going through.

Be kind to yourself

We often have very high expectations of how we should behave in, or respond to, a particular situation. When we don't live up to these expectations, we can be very hard on ourselves. Don't do this! You are dealing with something that is life-changing - and sometimes need to take care of ourselves first, to be able to carry on and be there for others.

Many people with Neuroendocrine Cancer look well no matter how they may be feeling.

If you don't look ill, it may be that others, including employers, may underestimate the impact that cancer and/or its treatments may be having on you. They may expect you to feel as well as you look. This can be upsetting, particularly if you are feeling unwell, having a difficult time, or are struggling to find energy and/or support. Other times it can be a relief - to simply still be seen as you. For information about available support - please visit our website.

NCUK Support

Neuroendocrine Cancer UK support services and other useful resources can be found on our website. You can also call our Peer Support Helpline or complete the 'Ask the Nurse' form on our website.

Other resources for self-care and support:

- The Mental Health Foundation - www.mentalhealth.org.uk
- NHS Every mind matter: www.nhs.uk/oneyou/every-mind-matters/
- Mindfulness - www.mindful.org
- CALM (Campaign Against Living Miserably) - 0800 58 58 58 / www.thecalmzone.net
- Samaritans - 116 123 / www.samaritans.org.uk
- Shout - Text "SHOUT" to 85258 or visit: www.giveusashout.org
- 'Living Well with Pain and Illness' by Vidyamala Burch
- 'Full Catastrophe Living' by Jon Kabat-Zinn
- 'Being Mortal' by Atul Gawande



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