

NEUROENDOCRINE CANCER

HIGH GRADE

2023

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What is High Grade Neuroendocrine Cancer?

Grade is an essential assessment and measurement of how neuroendocrine cancer cells are developing, growing, dividing and reproducing.

The grade may be decided by counting the cells that are dividing (called mitotic count or MiB1) but more often a test called Ki-67 is used – often expressed as a percentage (%).

Ki67 is a protein present in cells and is involved in cell growth and division. By using this protein to stain cancer cells, an assessment can be made as to how slowly or quickly the cancer cells are likely to grow and spread. So, a result of less than 3% shows that very few cells are actively growing and reproducing, therefore the overall rate of growth would be relatively slow. The higher the percentage the quicker growth can occur.

Typically, Neuroendocrine Tumours (NETs) have a lower Ki67 than Neuroendocrine Carcinomas (NECs).



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High Grade Categories

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





GRADE 1

Where the Ki67 is less than 3% and cells are 'well-differentiated'.



GRADE 3A

Where the Ki67 is above 20% and the cells are 'well-differentiated'.



GRADE 2

Where the Ki67 is between 3 and 20% and cells are 'well-differentiated'.



GRADE 3B

Where the Ki67 is above 20% but the cells are 'poorly-differentiated'.

Both Grades 3a NET and 3b NEC are considered High Grade Neuroendocrine Cancers.

However – Neuroendocrine Carcinoma (NEC) will require a different treatment plan than used in most Neuroendocrine Tumours (NETs) – because of the rate of cell growth and the cell differentiation (well vs poorly).

Whilst some High Grade Neuroendocrine Tumours (that is 3a) may benefit from some of the specific tests and treatments used in NEC, Neuroendocrine Carcinomas may benefit more from some of the tests and treatments used in more commonly known cancers – for example chemotherapy.



So, what is different about Neuroendocrine Carcinoma?

Neuroendocrine Carcinoma is Grade 3b Neuroendocrine Cancer – it is rarely associated with Neuroendocrine Cancer-related Syndromes. In fact, less than 10% will have symptoms of a Neuroendocrine Cancer-related Syndrome e.g., Carcinoid Syndrome.

However, rare symptoms, for example, raised calcium levels (Hypercalcaemia), may occur. These particular symptoms and syndromes can occur in any form of cancer and are known as either a Paraneoplastic syndrome or an oncological emergency. You can read more about complications here.

Treatment for Neuroendocrine Carcinoma will more closely resemble 'traditional' cancer treatment, for example chemotherapy.

Are Neuroendocrine Carcinoma's genetic?

In general cancer terms Neuroendocrine Carcinoma is quite rare and it is not usually associated with a genetic condition. However, we recommend speaking to your GP, and specialist team, if there is a strong family history of (any kind of) cancer or a known cancer-associated genetic condition. They may refer you for an NHS genetic test, (if a specific test is available), which will tell you if you have inherited one of the cancer-risk genes: for example BRCA1 or BRCA2 – which are associated with the more commonly known breast, ovary and prostate cancers.





Certain types of Neuroendocrine Carcinoma may have similar risk factors to those of other more common cancers – for example, smoking, exposure to carcinogens (cancer-causing substances), alcohol excess and other identified risks.

How is it treated?

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. Treatment options will depend on the type, position and size of your cancer – and whether (and to where) it has spread. It will also depend on whether you have any other health concerns and / or illnesses and your general health and fitness.



One or more of the approaches below may be suggested:

- Surgery
- Control of your disease, by slowing or stopping further growth and / or spread
- Palliation, or easing, of any symptoms you may be experiencing.

Surgery

in Neuroendocrine Carcinoma will depend on the stage and site of disease and may not be the first-line treatment. Unless diagnosed at a very early stage where complete removal is possible, Chemotherapy, to try to establish control of growth rate may be the first-line choice of treatment.

Bypass surgery may be offered in Neuroendocrine Carcinoma to alleviate symptoms that may be caused by cancer than cannot be removed.

If you have chemotherapy as first-line treatment and have a good and sustained response to it – surgery may be considered, if complete removal is possible, and there are no other health risks or concerns.

Chemotherapy

can be given orally (in tablets) or Intravenously (through a vein) to slow tumour growth or try to reduce tumour size. This is the most common first line therapy in Neuroendocrine Carcinoma and may also be used to increase tumour cell sensitivity to radiation therapies or given in combination with radiotherapy.





Support

High Grade Neuroendocrine Cancer Support UK Facebook Group

Neuroendocrine Cancer UK (NCUK) HGNC Peer Support is the NCUK's online support group for those, living in the UK and/or under the care of the NHS, affected by High Grade Neuroendocrine Cancer – that is Grade 3 Neuroendocrine Tumour (G3NET) and Grade 3 Neuroendocrine Carcinoma (G3 NEC).





The UK has a unique healthcare service – the NHS – that aims to deliver the right care, to the right person, at the right time, in the right place – however, in rare and uncommon cancers, access to the right information, diagnostics and expert care, can vary – and for a number of reasons, from disease awareness (public and healthcare professionals) to geography (how near the right specialist may be to where you live) to resource availability.

NCUK HGNC Peer Support provides a safe place for people affected by HGNC to meet others in similar situations, with a similar diagnosis, symptoms, treatments or follow up plans, others who "get it", who understand: A chance to share thoughts, research, get support, or just to chat with others also affected by High-grade disease.

Our hope and aims are to make sure that everyone in the UK has the right access to the right support – by phone, online or face-to-face – somewhere to turn to for information, advice and friendship.

