



Glossary

A pocket glossary of terms to help you navigate through your journey with **Neuroendocrine Tumours (NETs)**

A **Adrenaline:** a hormone and neurotransmitter. Also called epinephrine (USA).

B **Benign NETs:** are those that tend to grow slowly and be confined to a limited area of the body and may generally be considered non-life threatening if they do not squeeze or replace other nearby areas of the body.

Biopsy: a medical procedure, during which a small sample of tissue is removed from a part of the body. The sample of tissue is then examined under the microscope to look for abnormal cells. Sometimes the sample is tested in other ways.

Bronchoscope: a thin, flexible fibre-optic instrument that has a light source and a viewing device or camera on the end and is used to look inside the airways.

Bronchoscopy: a nonsurgical procedure that is used to look inside a person's airways inside the lungs using a bronchoscope.

C **Carcinoid syndrome:** a group of symptoms that can occur together when NETs release hormones such as serotonin, histamine and bradykinin. These symptoms may include diarrhoea, flushing of the skin (particularly the face), wheezing, stomach pain and heart problems such as palpitations and high blood pressure, but vary from person to person.

Carcinoid tumours: carcinoid tumours or carcinoids are a type of neuroendocrine tumours (NETs). The term is used to describe gastrointestinal NETs or gastroenteropancreatic NETs (GEP-NETs).

Catecholamines: a type of neurohormone (a chemical that is made by nerve cells and used to send signals to other cells). Catecholamines are also a collective term for the hormones epinephrine, norepinephrine, and dopamine. High levels of catecholamines in the urine or blood may indicate the presence of NETs.

Chromogranin A: Chromogranin A or CgA is a protein that is secreted by neuroendocrine tissues. It may be used as a marker in blood tests or tissue samples to detect NETs. It is one of the most important tumour markers for gastroenteropancreatic neuroendocrine tumours (GEP-NETs).

Colonoscopy: a test that examines of the inside of the colon (gut). During this test a thin, tube-like instrument called a colonoscope is inserted into the anus and passed up inside the gut. The colonoscope has a very small light and video camera at the end for viewing the inside of the gut.

Computed tomography (CT): an imaging method that uses X-rays to create pictures of cross-sections of the body. CT scans are one of the main imaging techniques used for diagnosing and monitoring NETs.

D Debulking: a type of surgery that is used to remove as much of the cancer as possible to make chemotherapy or radiation possible or more effective. Debulking may be performed when it is not possible to remove all of a tumour such as when doing so may severely harm an organ.

Dopamine: a hormone and neurotransmitter released by the brain. High levels of dopamine in the urine or blood may indicate the presence of NETs.

Doppler ultrasound: a non-invasive test that can be used to estimate your blood flow through blood vessels by bouncing high-frequency sound waves (ultrasound) off circulating red blood cells. A regular ultrasound uses sound waves to produce images, but can't show blood flow.

E **Echocardiogram:** often referred to as a cardiac echo or simply an echo, an echocardiogram is a sonogram of the heart (it is not abbreviated as ECG, because that is an abbreviation for an electrocardiogram). Echocardiography uses standard two-dimensional, three-dimensional, and doppler ultrasound to create images of the heart.

Endoscope: a medical device consisting of a long, thin, flexible tube that has a light and a video camera at the end and is inserted into the body via the mouth. Endoscopes can be used to look for cancers that cause no symptoms. They can also be used to collect a sample of tissue (biopsy) for further examination.

F **Fluorodopa:** 18F-dihydroxy-phenylalanine: a radioactive substance or tracer that is used in a PET scan to detect the location of NETs. Also called flurodopa, or 18F-DOPA.

Fluorodeoxyglucose: usually abbreviated to FDG. This is a radioactive substance or tracer that is used in a PET scan to identify the presence of certain tumour types within the body.

G **Gallium-68:** a radioactive substance or tracer that is injected into the body and can be used to identify specific neuroendocrine cancer cells during a PET scan.

Gastrin: a hormone released by the pancreas that causes the stomach to produce digestive acids and enzymes. Gastrin can be used as a marker in blood tests to detect and monitor NETs.

Gastroenteropancreatic NETs (GEP-NETs): neuroendocrine tumours (NETs) which are found in both the gastrointestinal tract, and the pancreas.

Gastrointestinal NETs (GI-NETs): also called gastric NETs or GI-NETs. These are the most common type of NETs (previously called carcinoid tumours). They are found in the gastrointestinal (GI) tract, and include tumours that develop in the bowel, stomach or food pipe (oesophagus).

Gastrointestinal tract: also known as the GI tract or digestive system, it is the organ system that is responsible for consuming and digesting foods, absorbing nutrients from food and expelling waste. It includes the mouth, throat, oesophagus, stomach, small and large intestines, rectum and anus.

Gastroscopy: examination of the inside of the stomach using a flexible fibre-optic tube called a gastroscope that is passed through the mouth and oesophagus and into the gut.

Glucagon: a hormone produced by the pancreas that helps to increase blood sugar (glucose) levels and keep blood sugar levels balanced. Measuring the presence of glucagon in the blood can be used to detect and monitor NETs occurring in the pancreas.

Grade: a description of how cancer cells and surrounding tissues look under a microscope and how quickly they are likely to grow and spread. Grades are used to help plan treatment and determine prognosis. Also called histologic grade and tumour grade.

H Hormones: chemicals that are carried through the bloodstream to have specific regulatory effects on the activity of other organs or cells in the body.

Hypochlorhydria: refers to states where the production of hydrochloric acid in gastric secretions of the stomach and other digestive organs is absent or low, respectively.

Hypokalemia: means low potassium levels in the blood.

Hypotension: is low blood pressure, especially in the arteries of the systemic circulation. Blood pressure is the force of blood pushing against the walls of the arteries as the heart pumps out blood.

I **Insulin:** a hormone produced in the pancreas that regulates the amount of sugar (glucose) in the blood. The lack of insulin causes a form of diabetes. Functioning tumours in the pancreas may make extra amounts of insulin.

Irradiation: also called total body irradiation (TBI). This treatment method gives radiotherapy to the whole body. It uses high-energy radiation to destroy cancer cells and shrink tumours.

Islets/Pancreatic islets: also called islets of Langerhans, are tiny clusters of cells scattered throughout the pancreas. Pancreatic islets contain several types of cells, including beta cells, that produce the hormone insulin. Insulin helps cells throughout the body absorb glucose from the bloodstream and use it for energy.

L **Linear accelerator:** a machine that uses electricity to form a stream of fast-moving subatomic particles. This creates high-energy radiation that may be used to treat cancer.

Lung function tests: tests that look at how well the lungs work, such as by measuring how much air a person can exhale after taking in a deep breath. Also called pulmonary function tests.

Lung NETs: an uncommon form of lung cancer caused by NETs. There are two grades (grade 1 and grade 2) of lung NETs depending on how quickly they grow.

M **Magnetic resonance imaging (MRI):** an MRI scan uses a large magnet and radio waves to look at organs and structures inside the body. It is one of the main imaging techniques used for diagnosing and monitoring NETs.

Malignant NETs: those that are often growing faster or more uncontrollably, perhaps affecting the surrounding tissues or have moved from one area of the body to another (metastasised).

Metabolically active tumour: a term used to describe tumours that are actively growing and using the body's energy resources.

Metastasis: a process that describes how cancer cells spread from one part of the body to another.

MIBG scan: an imaging test that uses the radiopharmaceutical metaiodobenzylguanidine (MIBG) to help locate and diagnose certain types of cancer in the body.

N Neuroendocrine tumours (abbreviated to NETs): tumours that arise from cells of the endocrine (hormonal) and nervous systems. They most commonly occur in the gastrointestinal (digestive) system but they are also found in the pancreas, lung and the rest of the body.

Neuroendocrine cancer: a malignant tumour that starts in neuroendocrine cells. Malignant means that it can spread, or metastasise, to other parts of the body.

Neuroendocrine cells: cells that are distributed throughout a network in the body and make up the neuroendocrine system. Neuroendocrine cells release hormones into the blood that then regulate specific body functions, such as metabolism, growth and reproduction.

Neuroendocrine system: made up of your Foregut, Midgut and Hindgut — this is the part of your body which includes the digestive system. It's also the area of your body which includes the organs that produce hormones. It helps to regulate metabolism, growth and development, tissue function, as well as playing a part in dictating mood. NB The field of medicine that deals with disorders of endocrine glands is endocrinology.

Neurotensin: a peptide neurotransmitter found in various parts of the brain. It is involved in vasodilation, hypotension, and pain perception. Levels of neurotensin in the blood can be used to detect and monitor NETs.

Noradrenaline: a chemical made by some nerve cells in the adrenal gland. It can act as both a neurotransmitter and a hormone. Also called norepinephrine (USA).

NT proBNP: a protein that can be measured in the blood and used to help detect and evaluate the risk of heart failure.

O **Octreotide scan:** an imaging test used to find certain tumours, including NETs. Radioactive octreotide is injected into a vein and travels through the blood, then a radiation-measuring device (gamma camera) detects the radioactive octreotide, and makes pictures showing where the tumour cells are in the body. It can also be called somatostatin receptor scintigraphy or SRS.

P **Palliate:** To make (a disease or its symptoms) less severe without removing the cause, e.g. “treatment works by palliating symptoms”.

Pancreatic NETs (pNETs): Tumours that form in hormone-making cells (islet cells) of the pancreas. These include functioning and non-functioning tumours.

Pancreatic polypeptide: a hormone produced by the pancreas. Levels of pancreatic polypeptides are high in the blood of people with pancreatic NETs (pNETS). Blood levels can therefore be used to diagnose and monitor pNETs.

Pellagra: is a disease that occurs when a person does not get enough niacin (one of the B complex vitamins) or tryptophan (an amino acid).

Positron emission tomography (PET): a PET scan is an imaging technique that can show how body tissues are working, as well as what they look like. It can help to diagnose and assess the severity of a cancer. In this scan, a radioactive tracer may be injected, swallowed or inhaled, depending on which organ or tissue is being studied by the PET scan.

Primary tumour: the original, or first, tumour in the body. Cancer cells can spread from a primary tumour to other parts of the body and form secondary tumours. The place where a primary tumour starts in the body is called the primary site.

Prognosis: a medical assessment regarding the probable cause and outcome of a disease.

Proliferative index: a measure of the number of cells in a tumour that are dividing (proliferating).

R **Radiofrequency ablation (RFA):** uses heat made by radio waves to kill cancer cells. RFA is given using a probe (electrode) that is injected through the skin into the tumour. The electrical current from the probe heats the cancer cells to high temperatures, which destroys them.

S **Scintigraphy:** an imaging test that produces two-dimensional images of the distribution of radioactivity in tissues after the internal administration of a radiopharmaceutical imaging agent. Radioactive imaging tests include octreotide scan, bone scintigraphy and MIBG scan.

Serotonin: a hormone and neurotransmitter that is found in many tissues of the body. Symptoms of gastrointestinal NETs (GI-NETs) may be caused by an excessive release of serotonin.

Small bowel capsule endoscopy: a way to record images of the gastrointestinal (digestive) system. It involves swallowing a small capsule about the size and shape of a pill. The capsule contains a very small video camera that takes pictures of the inside of the gut.

Somatostatin: a hormone that stops the release of other hormones, such as gastrin, insulin and glucagon. Symptoms of gastrointestinal NETs (GI NETs) may be caused by an excessive release of somatostatin.

Somatostatin analogues: somatostatin is a protein made naturally in the body. It slows down the production of many hormones, including gut hormones and growth hormone. A somatostatin analogue is a synthetic version of the somatostatin protein, which mimics the actions of the natural hormone, slowing down the emptying of the stomach and bowel, and controlling the release of hormones from the pancreas. Somatostatin analogues may reduce symptoms of NETs by stopping the body from releasing too many hormones from the pancreas.

Sonography (also known as an Ultrasound): a procedure that uses high-energy sound waves (ultrasound) to look at tissues and organs inside the body. Ultrasound scans are one of the main imaging techniques used for diagnosing and monitoring NETs.

T **Tumour:** a swelling of a part of the body, generally without inflammation, caused by an abnormal growth of tissue, whether benign or malignant.

U **Ultrasound (see Sonography)**

V **Vasodilation:** Refers to the widening of blood vessels, which decreases blood pressure.

VIPomas: A type of pancreatic tumour that causes changes in secretion of vasoactive intestinal polypeptide (VIP). VIP causes dilation of blood vessels throughout the body and secretion of fluid and salt in the intestinal tract, resulting in diarrhoea.

X **X-ray therapy:** A type of radiation therapy that uses high-energy radiation from X-rays to kill cancer cells and shrink tumours.



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