Neuroendocrine Cancer UK

What is Secondary Neuroendocrine Cancer (metastatic disease)?

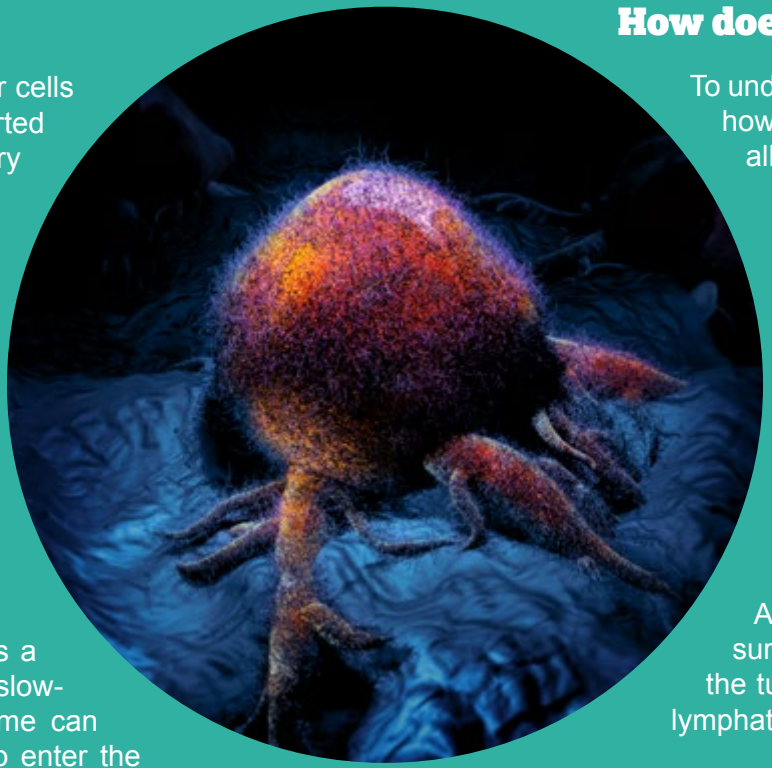
What is secondary cancer?

Secondary cancer is a term used to describe cancer cells that have spread, from the place where they started (primary site), to another part of the body (secondary site).

If cancer has spread to one or more sites, these secondary sites of disease, are called metastases.

Metastases are formed of the same kind of cancer cells as seen at the primary site – so if a small bowel neuroendocrine cancer cell goes to the liver, the metastasis formed is still a small bowel neuroendocrine cancer (as it is made up of cancer cells from the primary tumour and not cells from the secondary site).

The spread of neuroendocrine cancer is not always a sign of rapid or aggressive cancer. If a very small, slow-growing cancer is present then the passage of time can increase the risk of a cancer cell breaking away to enter the blood or lymphatic circulation. Some primary sites can be so small they may not be visible on even the best of scans. If you have secondary cancer and the primary site cannot be clearly identified by scans or other tests, you may be told you have a cancer of unknown primary (CUP).



How does secondary cancer happen?

To understand how cancer spreads we need to understand how cancer cells develop and what is in the body that allows it to travel elsewhere.

In terms of cancer development, normal cells have a set of rules that regulate growth and behaviour, in cancer the control signals go wrong and the rules are forgotten!

Cancer develops when the body's normal control mechanism stops working. Cancer cells do not die and instead grow out of control, forming new, abnormal cells. As these cells grow they form a mass of tissue, called a tumour.

As tumours form and grow, cancer cells can grow into surrounding structures and cells may break away from the tumour and enter either the blood stream and/or the lymphatic system.

Information about primary neuroendocrine cancer is available in a separate factsheet.

Normal cells:

- Develop and grow in a controlled manner
- Do what they are supposed to do, then die off as they are replaced by new cells
- When they become damaged - try to repair themselves or will die and be replaced if they can't
- Do not spread to other parts of the body
- Do not infiltrate (grow into) surrounding tissue - if they grow too big they tend to push against rather than through

Cancer cells:

- Have an uncontrolled development and growth rate
- Do not always do what they are supposed to, do not die off but continue to grow alongside new abnormal cells
- Do not try to repair themselves or die, but continue to grow producing further abnormal cells
- Can spread to other parts of the body, by either growing into surrounding tissue or entering the blood or lymphatic system
- Will grow into surrounding tissue rather than push against it when they grow too big

Blood circulatory system - all cells in the body need a system to provide them not only with oxygen and nutrients to survive, but also one that allows them to offload carbon dioxide and waste. This system is the bloodstream.

Blood is made up of blood cells and plasma. Plasma leaks out of the blood vessels, bathes your tissues and supplies the cells of your body with nutrients. Most of this plasma then drains back into the blood vessels.

A lot of the blood from the organs of the body flows through the liver on its way back to the heart and lungs, and that blood flows through the lungs. If a cancer cell enters the blood stream it is highly likely to travel to and settle into either the liver and/or the lungs – making these two of the most common sites for secondary disease.

Lymphatic system - is part of your immune system, which helps protect you from infection. Lymph is formed by plasma, and contains waste products from cells – including germs, toxins and damaged/abnormal cells, along with some fats and fat-soluble vitamins. Lymphatic vessels contain lymph (like blood vessels carry blood) with lymph nodes acting as filters.

These nodes contain cells that fight infection so anything that doesn't belong in your body, including any damaged and abnormal cells are removed in the lymph nodes.

Other parts of the lymphatic system include:

Bone marrow - is the spongy material at the centre of many of your bones. It makes all the new blood cells you need, including those that are needed to fight infection. Bone marrow health is essential for general health – and may be affected by certain anti-cancer treatments.

Thymus - is a gland that sits behind your breastbone. In children, to the age of puberty, it is responsible for producing T-lymphocytes – one of our infection fighting blood cells. As we get older it shrinks and other parts of the lymphatic system take over its job. The thymus also contains neuroendocrine cells and though rare is a potential primary site for neuroendocrine cancer.

Spleen - sits on the left-hand side of your body, behind your stomach. It filters blood, much like lymph nodes filter lymph – and although it has a key role to play in how our bodies fight infection, it is possible to live well without it. If a cancer cell enters the lymphatic system, the lymph nodes will try to destroy it.

How is secondary neuroendocrine cancer diagnosed?

Secondary cancer may be present at the time that neuroendocrine cancer is discovered – indeed this is quite common and true for more than half of those diagnosed.

For many, the primary disease may have been present for a number of months or even years, with no signs or symptoms, until the disease has spread elsewhere. It may not be until symptoms, caused by the secondary tumour, occur that a suspicion that something is wrong occurs.

There are a number of tests that can be carried out to confirm a diagnosis of primary and / or secondary neuroendocrine cancer.

The type of tests you may have will be based on the type of neuroendocrine cancer you are thought to have or are known to have – and whether there is/was any evidence of secondary disease at the time of first diagnosis.

Can it be cured?

As with more common cancers, early diagnosis offers the best chance of cure. For secondary neuroendocrine cancer there is no cure – however, this does not necessarily make this a terminal diagnosis.

Incurable neuroendocrine cancer, depending on grade, general health and symptoms can be managed as a chronic disease – one you can live with - with expert input and life-long support.

Incurable does not necessarily mean life-shortening. Yes there may be some limitations - but living long and well is possible.

How is secondary neuroendocrine cancer treated?

Treatment will depend on the type (grading, functionality), position and size of your primary neuroendocrine cancer.
As well as the extent of your secondary cancer - where and how widely it has spread and overall how much cancer is present is important to confirm.

It may also depend on whether you had secondary cancer at the time of diagnosis – or whether it has developed since diagnosis – and whether you have already had treatment.

If so, what effect did the treatment have - on both you and the cancer.

Other factors include whether you have any other health concerns and / or illnesses and your general health and fitness and the aims, expectations and hopes of treatment options.

Treatment options may include:

- Monitoring or surveillance
- Removal of all or part of the cancer
- Control of disease, by slowing or stopping the growth of cancer
- Palliation, or easing of, symptoms

Follow up and ongoing care

There are expert agreed guidelines regarding how and when follow up should occur, however, in practice this varies and often with good reason – follow up should be expert informed & evidence based.

Neuroendocrine Cancers vary - not just by appearance, grading, stage and function - but also between individuals.

Not all cancers are the same - care and treatment plans as well as hopes for the future will depend on a number of factors - having secondary cancer may or may not alter your life expectancy - but having an expert team and the support you need around you can really make a difference.

There is global consensus agreement that all neuroendocrine cancer patients should be reviewed by a specialist neuroendocrine cancer MDT to ensure best care.

Further information on all of the areas covered in this Factsheet are available on our website.

Neuroendocrine Cancer UK
(Formerly NET Patient Foundation)

Neuroendocrine Cancer UK

Neuroendocrine Cancer UK exists to support and inform patients and families from diagnosis, enabling access to the best care and treatment, whilst stimulating Neuroendocrine Cancer research, increasing national awareness and influencing improvements in outcomes.

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