What is a neuroendocrine carcinoma (NEC)
There are many different types of tumors originating from neuroendocrine cells. These cells are located throughout the body. Some of the tumors that originate from these cells are called Neuro Endocrine Tumors (NET grade 1 or grade 2). These NETs are well-differentiated or intermediate-differentiated (see table).

A neuroendocrine carcinoma (NEC grade 3) is classed as malignant or poorly differentiated. The grade of differentiation tells us something about the growth speed. A poorly differentiated tumor usually grows fast. The growth speed of a tumor indicates which treatment is possible and what the chances of survival are.

Research
By means of tissue samples (biopsy) the grade of differentiation and the growth rate (or how fast the tumor cells are dividing) can be established. Scans are used to look for any secondary tumors or metastases and their location.

Primary tumors and metastases
The place in the body where the cancer originated is called the place of the primary tumor. Cells of the primary tumor can break off and spread throughout the body, via blood vessels and lymph fluid. If these cells continue to grow in another place we call this metastases.

<table>
<thead>
<tr>
<th>Grade 1 NET Neuroendocrine tumor</th>
<th>Grade 2 NET Neuroendocrine tumor</th>
<th>Grade 3 NEC Neuroendocrine carcinoma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slow growing</td>
<td>Medium differentiated</td>
<td>Fast rate of growth</td>
</tr>
<tr>
<td>Well differentiated</td>
<td>Functional</td>
<td>Poorly differentiated</td>
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<tr>
<td>Functional</td>
<td>Non functional</td>
<td>Small cells SCNEC</td>
</tr>
<tr>
<td>Non functional</td>
<td></td>
<td>Large cells LCNEC</td>
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Small cells & large cells
NEC are divided into small cell (SCNEC) and large cell (LCNEC) carcinomas. The majority of NEC are small cell (SCNEC). The abbreviations stand for:

- Small Cell cancer: SCNEC (Small Cell Neuro Endocrine Carcinoma)
- Large Cell cancer: LCNEC (Large Cell Neuro Endocrine Carcinoma)

SCNEC generally develop in the lungs. But a small number of SNEC can develop in other parts of the body. The name for SNEC originating in the lungs, is SCLC or small cell lung cancer. SCLC occurs quite frequently in The Netherlands so doctors do have a lot of experience with this type of cancer.

LCNEC are much rarer and about a half of them develop primarily in the lungs. Other tumors can originate in other parts of the body. It needs to be noted that the primary tumor in cases of LCNEC can often go undetected.

Treatment
Treatment is tailored to give the most effective results for each individual person. It is thus of vital importance that treatment is given in hospitals with expertise in this type of cancer. Recovery from NEC is possible if the tumor is still localized and has not spread. By local we mean that there are no other tumors than the primary tumor.

If recovery is no longer possible, then there are still a number of treatments available. These treatments are aimed at reducing symptoms, prolonging life and improving the quality of life. Which kind of treatment is most appropriate depends on the individual situation. In addition, it is important for patients to consider which treatment they do or do not want to undergo.

NEC in the lungs
NEC often start growing in the lungs. As long as the tumor is only growing in the lungs, an operation is possible. Lung cancer is usually treated by a combination of chemotherapy and radiation therapy. This type of treatment is certainly used in the case of secondaries or metastases in the glands behind the sternum (the so-called mediastina lymphatic glands). In some cases recovery is then still possible.

NEC outside the lungs
NEC that do not start growing in the lungs are rare. In these cases not much is known about what the best possible treatments are. Thus treatment is tailored to give the most effective results for each individual person. This could be: an operation with or without extra radiotherapy or chemotherapy, or a combination of chemotherapy and radiotherapy.

The choice of a NEC treatment depends on:
- the condition of the patient
- the place where NEC originated (primary tumor)
- the size of the tumor
- the stage of the disease (are there secondary tumors and where?)
- the location and the number of secondary tumors

The most common treatments for NEC are:
- surgery (if possible) sometimes followed by chemotherapy
- surgery (if possible) sometimes followed by radiotherapy
- a combination of chemotherapy and radiotherapy
- only chemotherapy
Expertise
NEC that do not primarily grow in the lungs are very rare and extremely malignant. It is thus of great importance to see a specialist who has knowledge and experience in the treatment of cancer. Pulmonologists (lung specialist) all have their own specialisms. It is advisable to find a pulmonologist who is specialized in the treatment of cancer.

Specialist nurses
In hospitals where many NEC patients are treated, specialist nurses are present. You can easily approach them with all your questions. Specialist nurses can also give support and advice about symptoms such as pain, shortness of breath, insomnia and anxiety.

Questions for your specialist
It is important to be open in your discussions with the specialist (nurse). It is quite understandable that it is not always easy to remember all of the information. Therefore make a list of all your questions so you can discuss these during the next visit. A doctor does not mind at all, if you come with a list of questions.

Points to discuss with your specialist:
- Where the primary tumor is
- Are there secondary tumors in the lymph glands or organs?
- How far has the tumor advanced and what implications does this have for my situation?
- How much experience do you have in the treatment of NEC?
- Do you have contact/consultation with a NEC specialist? If so, with whom?
- Is other research needed before treatment can be started?
- What choices in treatment do I have?
- Which treatment do you recommend, in what order and why?
- What are the risks and side effects of the proposed treatment?
- Are there any current trials of new medicines or treatments for NEC? In which hospital?

Discuss with your doctor who you can contact if you have questions or if there are new problems.

More tips about questions you may wish to discuss with your specialist can be found on the web-site of the NET-groep.

Extra help
Once a specialist has told that you that you have a NEC tumor it can come as quite an emotional shock. Everyone reacts differently to bad news. Some people get sad or angry and want to talk with everyone about it. Others retreat and want to deal with it on their own or share it with their loved ones. There are social workers and psychologists who are specialized in helping cancer patients. If you need this kind of help then your specialist (nurse) or GP can refer you to them.
Think zebra
The zebra is the international symbol for neuroendocrine cancer (NET and NEC). This is because, during their training, doctors learn that when you hear hoof beats this must be a horse. However this can sometimes be from the far less common zebra. In addition to this, each zebra has a unique pattern of stripes. Thus each and every zebra is different, so is NEC!

The NET-groep foundation
The NET-groep advises and supports patients as well as their partners, children, friends. You are most welcome to come with your questions and worries. We appreciate it when people become members. Enrollment is free via the website or telephone. With more and more members the NET-groep can better represent the interests of patients.

The NET-groep:
- has an informative web-site www.net-kanker.nl
- organizes informative meetings with professionals
- produces information material (films and brochures)
- has an open Face book site with constantly updated news, accessible without a Facebook account
- Hosts a private group for patients on Face book (accessed by invitation only)

Board of advisors
The NET-groep has a Board of Advisors of specialists who are of (inter) national importance in the development of treatments for both NET and NEC. The names of the specialists and the hospitals where they work can be found on the home-page of the NET-groep. Through the knowledge and experience of these specialists the NET-groep is able to keep you updated on the latest developments around NEC.

Financing NET-groep
The NET-groep activities are financed by voluntary contributions from patients and their families and relatives, from funds and (pharmaceutical) companies. The NET group only accepts donations and subsidies when they are given with no intention of profit making. We can hereby avoid a conflict of interests.