Lungekreftforeningen

For those who have RET-positive lung cancer

Causes, symptoms, treatment and research

Contents

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Lung cancer is one the world's most common forms of cancer and can affect anyone. Each year, 2 million people are diagnosed with lung cancer. In Norway, more than 3500 people are affected by lung cancer yearly, which makes it the third most common form of cancer, and lung cancer accounts for about 10 per cent of all new cancer cases in Norway.

Malignant tumours originating in the cells of the lung tissue are referred to as lung cancer. Lung cancer can develop in all parts of the lungs, but it most often appears in the lung's upper lobe.

Types of lung cancer

Lung cancer is roughly divided into two types, small cell and non-small cell. Non-small cell lung cancer is the most frequent, accounting for roughly 90 per cent of all cases. Small cell lung cancer makes up less than 10 per cent of all lung cancers.

Non-small cell cancer is divided into two main groups, based on the original cell where it arose:

- Squamous cell carcinoma: The cancer cells originate in the mucous membranes. The tumour often grows in a central area in relation to the large bronchial branches. This is the second most common form of lung cancer.
- Adenocarcinoma: The cancer cells originate in gland tissue. The tumour often grows on the outer edges of the lung. This is the most common type of lung cancer, and the type that is becoming more prevalent.
- Large cell carcinoma: These cancer cells are large and show no specific microscopic features.

RET-positive cancer

Mutations in the RET gene occur in 1-2 per cent of all lung cancer patients, generally in adenocarcinoma non-small cell lung cancer. These genetic mutations are only found in cancer cells, and patients with this type of cancer are treated with targeted therapy.

Facts about RET

The genetic alterations (mutations) linked to lung cancer have usually arisen in cancer cells during a patient's lifetime. These are not present in the body's healthy cells. This is also the case for RET-positive lung cancer. Genetic mutations occurring during a lifetime are referred to as somatic mutations*. This type of mutation is not hereditary*, which means that there is no predisposition to the disease in the family. Somatic genetic mutations may be caused by environmental factors, but they often occur spontaneously without any evident cause.

Chromosomes contain genes, and each gene in the body contains information needed to form proteins. Proteins have special tasks and functions in the body. The RET gene codes for a protein located in the cell membrane and is involved in the communication between cells. In cancer, different types of RET mutations affect the function of the protein. If a base of the gene has been switched, this is called a point mutation. Some mutations lead to the production of abnormal proteins that activates the development, growth and spread of cancer cells. A fusion gene is created when part of one chromosome moves to another chromosome such that two previously independent genes are joined. A RET fusion event is when a RET gene is fused with another gene, which then produces a higher number of RET proteins than normal. This activates the development, growth and spread of cancer cells. Uncontrolled cell growth will then form a tumour.

* You can find more information on the terminology page

Symptoms

The most common symptoms of lung cancer are coughing and shortness of breath, but these symptoms are also common for many other diseases. In lung cancer, the symptoms do not improve over time. It is therefore important to see a doctor if coughing and shortness of breath last longer than what is common for a respiratory infection. Possible symptoms of lung cancer:

- Cough, especially a persistent dry cough that suddenly changes
- Shortness of breath
- Bronchitis or a cold that does not improve, even with antibiotics
- Repeated respiratory infections
- Wheezing or feeling out of breath
- Hoarseness and trouble swallowing
- Coughing up blood
- General weakness and fatigue
- Significant weight loss for no apparent reason
- Pain in the chest and upper part of the abdomen, headache, dizziness, and trouble swallowing may be signs of metastases (the spread of cancer cells). Spreading to the bones may result in pain and fractures. **A referral for an x-ray would be necessary for such symptoms affecting the chest, arms, legs or back**. If the x-ray suggests lung cancer, the patient will be referred to a specialist.

Patient care pathway

A standard patient care pathway describes how assessment, treatment, communication and dialogue with the patient and family members, distribution of responsibilities, and specific trajectory schedules are all organised. The purpose of a patient care pathway is to ensure that cancer patients receive a well-organised, comprehensive and predictable trajectory without unnecessary delays in assessment, diagnostics, treatment and rehabilitation. The patient is given a patient care pathway coordinator who will be the patient's contact person and who will be responsible for calling the patient in for appointments. The patient can also contact the coordinator for questions. A patient care pathway for lung cancer ensures that all hospitals treating lung cancer will have regular decision-making meetings with a multidisciplinary team (MDT) to ensure quality assurance of assessments and therapies. Participants in meetings for assessing lung surgery should include pulmonologists, thoracic surgeons(), nuclear medicine radiologists, and patient care pathway coordinators.

A patient care pathway has been designed for diagnostics, treatment and follow-up of lung cancer. See **www.helsedirektoratet.no** for more information on patient care pathways.

Assessment

If the patient is diagnosed with lung cancer, doctors will try to determine the stage of the disease. The stage indicates how advanced the disease is, whether it has spread, and how it should be treated. It is generally easier to cure lung cancer when the disease has not yet spread.

The assessment should lead to a choice of treatment based on the diagnosis of the type of lung cancer, the location of the tumour and its extent, as well as the patient's level of function.

Methods used to determine the diagnosis will vary depending on the case.

How is lung cancer diagnosed?

Step 1 is radiological examinations. A CT can of the lungs and abdomen is essential. Afterwards, the pulmonologist will determine whether to also perform a PET-CT scan, MRI scan, or other examinations.

- X-ray of the lungs
  A chest x-ray may indicate a tumour.
- CT scan of the lungs and abdomen
  With the aid of a CT scan, doctors can get a very accurate picture of the size, location and spread of the tumour as well as possible spreading to other organs.
- MRI of the brain, chest or bones
  An MRI scan provides precise images with the use of a powerful magnetic field. May be relevant in certain cases.
- PET scan
  A PET scan provides images that can show tumours and spreading of the cancer (metastases), which must normally be confirmed by tests. Before the PET scan, the patient is given a radioactive glucose solution intravenously, and they must rest in a dark room prior to the examination. During the examination, the patient is slowly led through a scanner where images are taken of their entire body. Cancer cells, as well as infections, need a large supply of energy and have a high rate of metabolism. The injected glucose collects in the cells requiring a large supply of energy. It is easier to see the affected tissue on these images through the glucose solution.

Step 2 Tissue or cells samples are taken from the tumour for biopsy to determine whether they are benign or malignant, and if possible to identify the type of tumour.

- A tissue or cell sample for a biopsy is taken from different places in the body where cancer is suspected. The choice of the source of samples and the method of of taking

samples will vary according to the patient.

- Bronchoscopy: During a bronchoscopy, the doctor guides a bronchoscope, which is a flexible tube about the thickness of a pencil, through the patient's nose or mouth down through the trachea and into the bronchi and its branches. The aim of a bronchoscopy is to see the extent of the tumour and to take tissue samples of tumours that are accessible to the bronchoscope in the airways. This procedure involves the use of a small forceps for tissue samples. A small brush is used for taking cell samples.
- EBUS: An endobronchial ultrasound examination (EBUS) combines a bronchoscopy and an ultrasound. The doctor will first insert a thin bronchoscope to administer anaesthesia, and will then insert a slightly thicker EBUS bronchoscope with an ultrasound head on the end that can be used to take cell samples.
- CT-guided biopsy or ultrasound-guided biopsy for tissue samples from the lung or metastases to other areas in the body. The doctor will first apply a local anaesthetic to the skin and soft tissue and then remove tumour tissue from the lung or other places in the body, such as the liver or leg, using a thin needle that is pushed through the skin.
- Ultrasound-guided pleural tapping: With the aid of an ultrasound, the doctor can take samples of fluid in the pleural sac of the lung (pleural effusion) through the chest wall. Sometimes, samples from the pleural sac membrane (pleural biopsy) may be taken prior to pleural tapping.

Biomarker test:

Tumour cells from all patients with non-small cell lung cancer are always tested for PD-L1, a protein associated with the response to immunotherapy. For patients with adenocarcinomas, tests are also done to identify various genetic mutations, such as BRAF, KRAS, EGFR, ALK, ROS1, RET, and others. Genetic mutations can be examined in different ways, such as sequencing or staining (immunohistochemistry) the protein that the gene codes for. Tissue or cell samples are analysed in a laboratory that specialises in pathology. When such genetic mutations are detected, specialised, targeted therapies can be initiated to attack a specific characteristic of the tumour.

Stage

Patients diagnosed with lung cancer will often already have an advanced disease (spreading) at the time of diagnosis. This is also true of patients with RET mutations. New therapies are constantly being developing for lung cancer. Even patients who cannot be completely cured of lung cancer may benefit from therapies to reverse the disease and keep it stable.

Some patients who are diagnosed in earlier stages will have been diagnosed by chance after a CT scan of the chest for other reasons.

Checklist for consultations on diagnosis and treatment

Once you have undergone the initial examinations and been diagnosed with lung cancer, it is a good idea to bring a checklist along to a consultation with your doctor. Make sure to have everything explained to you as precisely as possible so that you can better understand the findings and consequences. We have collected a few tips for the checklist:

Questions about the diagnosis:

- Is the diagnosis certain or are there still uncertainties?
- Where exactly is the tumour located?
- How large is the tumour?
- What is the stage of the disease? Localised, locally advanced or extensive?
- Has the tumour spread outside the lungs?
- Should I have more tests done to confirm the diagnosis?
- Were there any results on biomarker tests?
- Are there currently any clinical trials that may be relevant to me?

Questions about treatment:

- What is the prognosis?
- What is the best treatment for me?
- Are there other treatment options that should be considered?
- What side effects should I be aware of?
- Which examinations and measures should I expect going forward?
- Should I be treated at a clinic or a hospital specialising in lung cancer?

Causes and risk factors associated with RET-positive lung cancer are unknown

Genetic mutations leading to the lung cancer may be caused by environmental factors, such as smoking, but they often occur spontaneously without any evident cause.

RET-positive lung cancer and metastases

Sometimes cancer spreads from one part of the body to another. Lung cancer may, for instance, spread to the brain, liver or bones. This would still be considered lung cancer, so we refer to it as "metastases". Some patients experience symptoms of metastases, while others do not.

Treatment

There are several treatment options for patients who have RET-positive lung cancer. You may be offered immunotherapy as well as drugs aimed specifically at RET mutations, and/or surgery, radiation and chemotherapy. You should discuss the different options with your doctor. The type of treatment selected largely depends on the stage of the disease, as well as the age and general condition of the patient.

Several drugs have been specially developed to attack the gene mutation that is the cause of your type of cancer.

Patients with lung cancer are discussed at a multidisciplinary meeting (MDT) if the cancer is detected early and surgery may be an option.

Surgery or radiotherapy may cure non-small cell lung cancer in the early stages (localised and locally advanced). Chemotherapy and immunotherapy alone are not curative, but they may increase the possibility of a cure when provided together with surgery and/or radiotherapy.

Drug therapy

Targeted therapy

Drugs have been developed that specifically target the RET mutation, and new drugs are underway. Some of these have been approved for use in Norway. Targeted therapy will often be the first choice when available. Targeted treatment may also be available through clinical trials, and it is recommended to investigate the possibility of clinical trials before starting therapy and before changing therapies. Some patients may benefit from radiotherapy during targeted therapy to stabilise the disease.

When all available targeted therapy has been exhausted, a combination of chemotherapy and immunotherapy will often be the next choice of systemic therapy.

Several drugs that are specifically aimed at RET mutations are currently under development. These may become available for use after their registration, depending on the available data.

Regardless of the type of targeted therapy you receive, you will undergo radiological examinations and have blood tests taken before and during your treatment to monitor the effect and blood cell levels, and to see if your liver and kidneys are functioning properly.

Your doctor will explain how to take the RET-inhibitors – how many times a day, with or without meals, and any food or other drugs you should avoid taking at the same time.

Usually, the therapy will be continued as long as it is effective unless you experience severe side effects. Do not stop the treatment on your own – talk to you doctor first.

Surgery

Surgery with a curative aim is relevant when treating earlier stages of lung cancer when the cancer is only in the lung and in the lymph nodes of the same lung, or in just a lymph node between the lungs. Surgical removal of tumour tissue in the lungs is done with the intent of curing the patient. Surgery for lung cancer is a good option if the tumour can be completely removed. At the first checkup after surgery (approx. 1 1/2 months), the doctor will determine whether additional treatment is needed, such as chemotherapy, immunotherapy or radiotherapy.

Radiotherapy in localised lung cancer

Radiotherapy is used to damage the DNA of the irradiated cells, thereby killing the cells. Radiotherapy is used both to cure a patient of cancer and to limit or alleviate symptoms in patients who cannot be cured.

There are three types of radiotherapy with a curative aim:

1) Stereotactic radiotherapy is a very precise, targeted and high dose of radiation that is administered a few times, with 3-8 treatments approx. every other day, while fractionated radiotherapy is administered 30-33 times. This is given for curative purposes, also instead of surgery.
2) Many treatments with radiotherapy (30-33) with or without chemotherapy for curative purposes for those who have locally advanced cancer.
3) If the patient is too weak to tolerate the two above-mentioned radiotherapies, or the disease is too extensive for curative treatment, but the patient is still in good shape with a good general condition, it may be determined to administer a milder dose of radiotherapy to keep the disease in check or to alleviate the symptoms. This will be determined in consultation with the patient.

Radiotherapy combined with chemotherapy for locally advanced cancer (spreading to the lymph nodes between the lungs)

Combined chemotherapy and radiotherapy is given with a curative aim. Many (30-33) small doses of radiation are given 5 days a week with a break on weekends. In addition, two courses of chemotherapy are administered, one at the start and one halfway through the treatment. If the patient has PD-L1 above 1%, they can receive immunotherapy for one year afterwards. Treatment is always assessed individually, partly based on the side effects.

Treatment of metastases

Spreading tumours (metastases) can be treated with radiotherapy if they cause discomfort, threaten important organs or if it is believed that it could help stabilise the disease. This is often done using radiotherapy, including stereotactic radiotherapy, which provides a very precise, targeted and high radiation dose. Radiotherapy is often administered simultaneously with drug therapy.

Brain metastases can be treated with surgery and stereotactic radiotherapy directed at a certain area or the entire brain.

Radiotherapy of bone metastases can provide effective pain relief.

Symptoms and side-effects during treatment for RET-positive lung cancer

If you have RET-positive lung cancer, you may experience symptoms of both the lung cancer and side effects of the treatment. It is wise to talk to your doctor about all signs and symptoms or side effects – especially if you start to feel worse.

Common signs and symptoms of lung cancer include:

- Persistent cough, coughing up blood
- Chest pain
- Shortness of breath
- Recurrent infections (such as bronchitis or pneumonia)
- Fatigue and weakness

Many experience an intense fatigue that makes it difficult for them to engage in normal activities, and that affects their quality of life.

Those who are given targeted therapy for RET-positive lung cancer may also experience side effects directly related to the therapy and that resemble some of the signs and symptoms described above, such as:

- Anaemia
- Abdominal pain, diarrhoea, nausea, vomiting, dry mouth, mouth sores
- Altered sense of taste
- Intense fatigue, fever
- Drug-induced liver damage (increased ALT and AST)
- Shortness of breath, cough
- Muscle pain
- Headache
- Changes in sodium balance
- Reduced kidney function

Talk to your doctor if you experience any of the symptoms or side effects mentioned here, or if your physical condition worsens.

Treatment resistance or resistance in cancer cells

Although more than 80 per cent of patients respond to RET inhibitors, most RET inhibitors stop working after a while as the cancer cells develop resistance and begin dividing again. Some patients have a good effect of RET inhibitors for a considerable time, while others unfortunately develop resistance early on.

When resistance occurs, the patient can switch to another type of therapy. In addition, new RET inhibitors are constantly being researched and developed, and the patient may benefit from participating in a clinical trial, if possible.

Several resistance mechanisms may occur in the same tumour. Because this can happen, it can be useful to be able to take another tissue biopsy if the disease progresses. If this is difficult for the patient, a blood test where traces of DNA from cancer cells can possibly be found would be helpful. Some cancer mutations have been reported using this technique.

Chemotherapy

Chemotherapy drugs or cytostatics are drugs that kill cells or inhibit cell growth and cell division. Chemotherapy is often used in combination with immunotherapy.

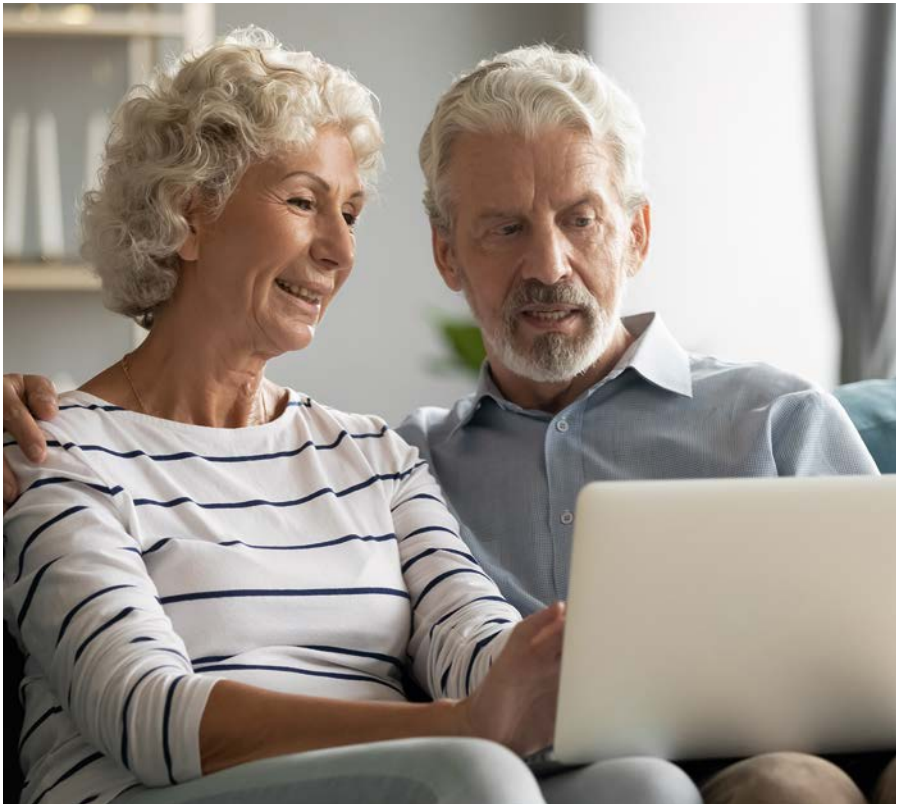
Immunotherapy

Immunotherapy is cancer treatment that utilises the body's own immune system to attack the cancer. In the case of lung cancer with proven RET mutations, immunotherapy, possibly combined with chemotherapy, is recommended when the available targeted drugs have already been tried.

If the cancer progresses while you are on this therapy, it may be better to try other drugs. This is known as moving from one line of therapy to another. The good news is that new drugs are continually being tested in clinical trials.

Some advice on how best to cope with treatment

- Be aware of any changes related to your health: It may be useful to keep a journal where you can write down your feelings, symptoms and side effects. These are things you can discuss with healthcare personnel, which can help you feel you have better control over your life.
- Share your experiences: Let your doctor know about any side effects. Do not stop taking your medications – talk to your doctor instead.
- Learn more: If you would like to learn more, ask questions and find out as much as you can about RET-positive lung cancer and its treatment. Obtain information from reliable sources.



Clinical trials

All potential new drugs must be carefully tested to see if they work as they should and can safely be used by humans. Testing is conducted in what are called "clinical trials". Ask your doctor about clinical trials that may be relevant to you.

Clinical trials may be a good option for patients who need treatment for progressive cancer, as it has been shown that participation in clinical trials may result in a better prognosis. Patients who participate in a clinical trial are always closely monitored through tests, hospital visits and other follow up. In a clinical drug trial, patients are usually divided into groups for comparison in order to ensure clear results. Neither you nor the doctor will know whether you are receiving the drug to be tested in the study or whether you have been randomly placed in the control group.

Your doctor may ask you if you wish to participate in a clinical trial. Participation costs nothing and is entirely voluntary.

In clinical trials for cancer, the comparison drug will normally be the best treatment, or "best standard of care".

If you are considering taking part in a clinical trial, you should find out as much as possible about the study before deciding whether to join. Learn about the following:

- What are the researchers trying to learn?
- Are there potential side effects linked to the drug being researched?
- What do I have to do?
- Where do I have to meet up?
- What are my rights and duties as a participant?
- What is the alternative if I do not wish to participate?

Participants in a clinical trial must always be given information about the drug through a consent form (informed consent). This must provide information on the effects and side effects, as well as the possible risks of participating in the clinical trial. Treatment logistics and sampling must also be included in this information.

You can find an overview of ongoing clinical trials at **www.clinicaltrials.gov** (search for RET + lung cancer), or go to **www.helsenorge.no/kliniske-studier** where you will find a list of all clinical trials in Norway.

Current research

RET mutations

Several new drugs are being developed and tested that target RET mutations. Much of the research into RET-positive lung cancer focuses on treating lung cancer in the same way as other chronic diseases: with lifelong drug therapy and other therapies. New drugs are being researched in clinical trials that include patients who have developed resistance.

Improved screening

Treating lung cancer in the earlier stages will give better results, which is why there is a strong interest in being able to detect lung cancer before symptoms appear. It has been proven that CT screening increases life expectancy for lung cancer patients, and such a study has already begun at Akerhus University Hospital (Ahus). Researchers are investigating better screening techniques, such as genetic testing, to understand who may be at higher risk of developing lung cancer. So far, there is no evidence of this.

Advances in treatment

Work is being done to find ways to improve the effect of different types of treatment in combination, such as surgery or radiotherapy together with immunotherapy, while at the same time reducing side effects of these.

Liquid biopsies

Researchers are studying whether DNA released from cancer cells in patients' blood samples can help identify molecular changes that can be used in planning treatment.

Patient story

Thankful for targeted therapy

"There have been many difficult moments, but I have always been determined that this would turn out well," says Ellen Brandt. Ellen has lung cancer with metastases, but four tablets daily have kept the cancer stable.

Since 2021, Ellen (age 60) has received targeted therapy with RET inhibitors, which she is very thankful for, but the road to get here has been anything but easy.

"Imagine how fortunate patients with RET-positive lung cancer are now. They can start this therapy right away!"

Called for ambulance herself

Back in 2016, Ellen had been experiencing pain in her right side for six months. She went to see her doctor, but was told that a CT scan was not necessary. As autumn approached, the pain became so bad that she had to call an ambulance.

"It got to a point where I felt I had to take action. I actually had to fight to be heard."

At the hospital, a CT scan was performed, and shortly after, Ellen was diagnosed with lung cancer that had spread to her bones.

"It was a huge shock. In retrospect, I feel I should have stood up for myself more, but I've learned from this experience, and today, I've become both determined and ready to take action for myself and my own disease."

Tough rounds of treatment

At the time Ellen was diagnosed, targeted therapy was not yet a reality.
She was started on several rounds of radiotherapy and chemotherapy, which ultimately resulted in an allergic reaction in the winter of 2017.

"At that time, you couldn't get first-line immunotherapy either, so I was put on maintenance treatment with chemotherapy. I was given a total of 11 rounds of chemotherapy

before the tumour started growing again. Only then was I able to get immunotherapy."

In early 2018, Ellen was given immunotherapy, which was effective, and the metastases disappeared. She was also given stereotactic radiotherapy for the tumour in her lung.

"I had great hope that this would actually be curable. I actually had a few months without treatment until early 2019 when the tumour started growing again."

Ellen was put back on immunotherapy, and received several rounds of both this and maintenance treatments with chemotherapy, without the desired effect. In 2020, it was determined that the cancer had spread to her brain, spleen and liver.

During her treatment, genetic testing of tumour was performed, and Ellen was told that she had a RET mutation.

Access to RET inhibitors

"I got a second opinion at the Thorax Clinic in Heidelberg, Germany, and they strongly recommended that I try RET inhibitors. When I got home, I had to discuss the issue with many doctors and hospitals to get access to this treatment, which at that time was not yet approved in Norway. Finally, I was granted access through the health trust."

After starting targeted therapy with a RET inhibitor, Ellen experienced an almost immediate effect. Already after three months the tumours began to shrink.

"I started on RET inhibitors in the summer of 2021, and since then, the cancer has stabilised."

Ellen has had few side effects. Her only problems have involved regulating her metabolism. But due to the tough treatment prior to this, she notices that she now quickly becomes tired and that her balance has become worse.

"I have to say that I'm doing really well and can do whatever I like. I sing in a choir, do line-dancing, and I do strength training in a pool. I recommend participating in activities that are positive for you."

Ellen has a short perspective on her own disease. She attends checkups and follows her doctors' recommendations.

"It's important to keep your spirits up. I think that if the drug I'm on stops working, then there will be other drugs I can try. My goal is to keep living as well as possible, and I feel I can do that, which is why I also feel fortunate.

Terminology

AST/ALT (also known as transaminases): Enzymes produced in liver cells. These are released into the bloodstream when liver cells are damaged, and they are used to measure liver damage.

Line of treatment (first-line, second-line, etc.):
First-line treatment is the first drug or treatment given to a patient for a specific disease (usually regarded as the best treatment for this disease). Second-line treatment can be given if the first drug is not effective enough for the patient.

Biopsy: A procedure that involves taking a tissue sample from the body in order to look for signs of disease. The tissue sample is examined for any changes or growth patterns.

CT scan: computer tomography is cross-sectional photography of relevant areas of the body using X-rays.

Fatigue: Another word for intense exhaustion that does not improve after rest.

Gene: A piece of the body's DNA (genetic material), which determines the body's characteristics, for example hair colour, eye colour or proteins that regulate cell growth.

Genetic mutation: An abnormal alteration of the DNA sequence in a gene. A somatic mutation is a mutation occurring in a gene that is not hereditary and that normally only occurs in certain parts of the body. These mutations are usually caused by environmental factors, but they can also occur spontaneously. A germline mutation occurs in cells that have developed into egg or sperm cells, which can then be passed on from parents to offspring. Gene mutations have various effects on our health depending on where they occur and what function the mutated gene originally had.

Hereditary: Something passed from parent to offspring through the genes. Characteristics or diseases children inherit from their parents.

Brain metastases: When the cancer has started in one place in the body, such as the lungs but spreads to the brain. This is still considered lung cancer, not brain cancer.

KRAS inhibitors: Anti-cancer drugs that act on and block (inhibit) the growth of cancer cells caused by RET mutations.

Cancer: A group of diseases caused by the uncontrolled division and growth of abnormal cells in parts of the body.

Metastases: When cancer spreads from one part of the body to another.

Molecular testing: A lab test that analyses certain changes in a gene or chromosome that could cause a certain disease or condition.

MRI scan: produces digital images of internal organs with the aid of a very

strong magnetic field and radiofrequency pulses.

Targeted therapy: Targeted drugs that only work on specific cancer cells by affecting how they send signals or interact with each other. This can stop cancer cells from dividing and growing.

Neuropathy: Nerve damage that may be caused by drugs, tumours or surgery. The symptoms vary depending on which nerves have been affected. You may experience pain, extreme sensitivity, numbness or weakness. Symptoms are often most noticeable in the hands, feet or lower part of the legs. The nerves that control digestion and blood pressure may also be affected, which can lead to constipation, dizziness or other symptoms.

NSCLC: Non-small cell cancer. Approx. 85% of all lung cancer cases are NSCLC. KRAS-positive lung cancer is one form of NSCLC and comprises approx. 17% of all NSCLC cases.

PET-CT: Positron emission tomography (PET or PET-CT) is a diagnostic examination that enables the production of physiological images of the body, i.e. images that show activity in cells and tissues through the detection of positrons. Before the examination, the patient is given a weak radioactive glucose solution. During the examination, the patient is slowly led through a scanner where images are taken of their entire body. Cancer cells need a large supply of energy and have a high rate of metabolism, so the glucose collects in these cells. It is easier to see the affected tissue on these images through the glucose solution.

RET: RET is a gene that codes for a protein located in the cell membrane and that is involved in the communication between cells. High activity can contribute to the development, growth and spread of the cancer.

RET mutation: Mutations (gene alterations) occur when cells divide. If the mutation occurs in the RET gene, it may lead to an expression of an abnormal RET protein. This can lead to uncontrolled cell growth and the development of cancer.

RET fusion: Displacement of parts of the DNA strand can cause the RET gene to fuse with another gene, which in turn leads to the increased production of RET protein. This can contribute to cell growth and division as part of the cancer development.

Central nervous system: Part of the nervous system that consists of the brain and spinal cord.

Somatic (mutation): Non-hereditary genetic mutations that occur after birth, during a lifetime.

Tumour: A mass or lump caused by abnormal tissue growth. These can be benign (not harmful) or malignant (cancer).

Translocation: Where a piece of DNA moves from one place to another. A RET gene translocation refers to the rearrangement of the RET gene.

Norwegian Lung Cancer Society

The Norwegian Lung Cancer Society is a patient organisation for those who have or have had lung cancer, and for family members of lung cancer patients.

We provide advice and support, and we protect the interests of lung cancer patients. Together, we work to improve treatment and rehabilitation for lung cancer patients. We work to spread knowledge of lung cancer prevention, and to promote the issue of lung cancer before health authorities and politicians.

The Norwegian Lung Cancer Society has 900 members. We have local organisations, contacts in the county and peer support persons throughout the country. More detailed information about us and our peer support services can be found on our website: **lungekreftforeningen.no**

Contact us:
E-mail Secretariat: post@lungekreftforeningen.no
Phone Secretariat: **93470121** – the phone line is open Monday–Friday, 09:00–15:00

Peer support services:
Living with a serious illness involves experiences that can make us feel alone. Family members may also feel alone with the uncertainties and concerns this entails. The Norwegian Lung Cancer Society therefore aims to provide a community for people in the same situation. We have peer support persons who are patients, as well as family members who have gone through the process of the disease, and who have been trained to provide support to others who have found themselves in the same situation.

You can contact the Norwegian Lung Cancer Society's peer support persons directly. See the list of our peer support persons on our website:
www.lungekreftforeningen.no/likepersontjenesten
You can also send an e-mail to **likeperson@lungekreftforeningen.no**

Join our community – become a member of the Norwegian Lung Cancer Society:

lungekreftforeningen.no/stott-oss/bli-medlem

We partner with:

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The brochure was developed with support from Takeda, MSD, Roche and AstraZeneca.

November 2023

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