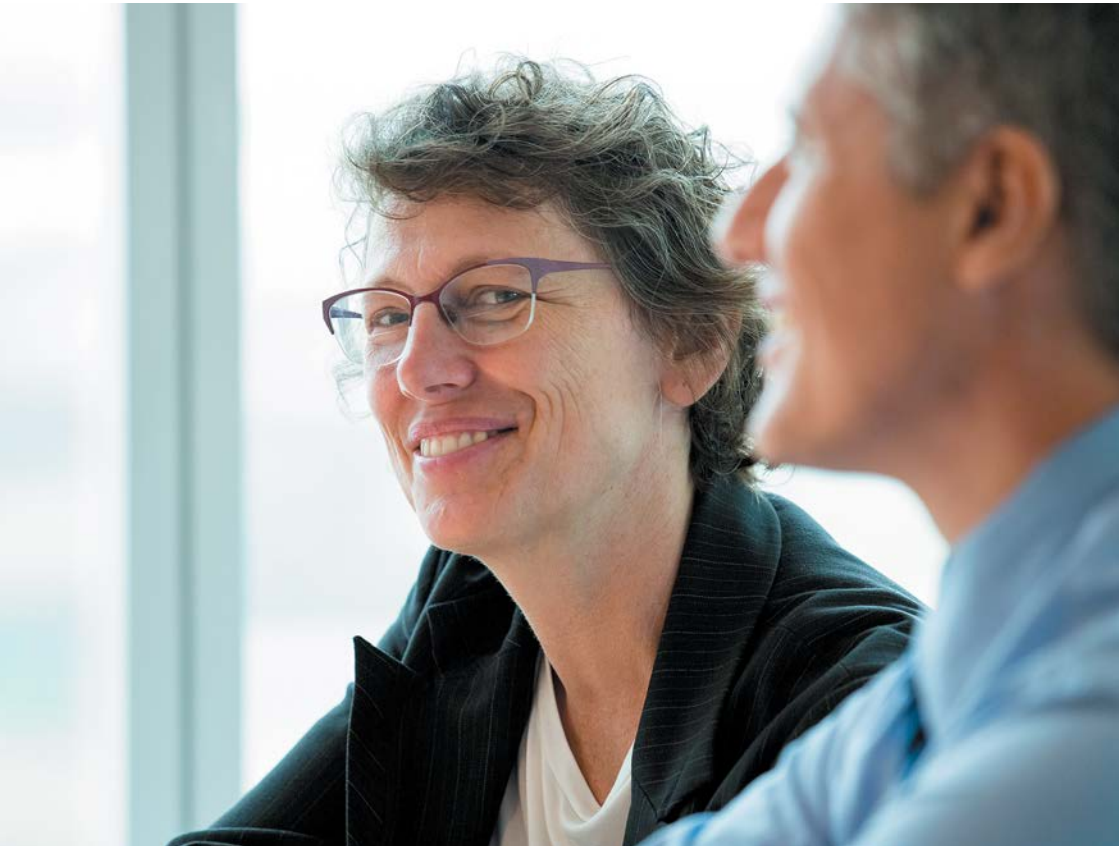
Lungekreftforeningen



For those who have ROS1-positive lung cancer

Causes, symptoms, treatment and research

Contents

ROS1-positive lung cancer

Lung cancer is one of the most common forms of cancer in the world, along with colon cancer (both sexes), prostate cancer (men) and breast cancer (women).
Lung cancer can affect anyone, but it is more common among smokers. It is more frequent among people over the age of 50, but it can occur at any age.

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 around 10 per cent of all new cancer cases in Norway. New, targeted treatment in the last several years have enabled many people to live much longer with lung cancer than before.

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.

Causes and risk factors

- The risk of lung cancer increases with the number of cigarettes smoked and the number of years a person has smoked. Passive smoking is also a risk factor.
- Asbestos is considered a risk factor for the development of lung cancer.
- A smaller number of lung cancer cases are possibly due to exposure to radioactive radon gas in the bedrock.
- Other risk factors include air pollution, including diesel exhaust, as well as nickel and chromium exposure.
- New research, such as the study presented in 2022 at ESMO, Europe's largest congress for medical oncology, shows that air pollution can lead to lung cancer in people who have never smoked.

The risk of lung cancer is especially high for smokers who have also been exposed to asbestos or radon gas.

There is no evidence that any of these environmental factors are specific risk factors for developing ROS1-positive lung cancer.

Facts about ROS1

Genetic alterations (mutations) linked to lung cancer generally arise during a person's lifetime. This is the case with ROS1-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. We do not know why ROS1 mutations occur.

A mutation of this type leads to changes in the growth factor receptor genes, so that growth signals are permanently being sent to the tumour tissue. This growth signal is constantly switched on, which means that the fine-tuned regulation of cell division in normal cells is overridden. This will cause uncontrolled cell division, which will result in the development of a tumour, as well as the rapid growth and spread of the tumour.

* You can find more information on the terminology page.

Small cell and non-small cell lung cancer

Lung cancer is roughly divided into two forms, small cell and non-small cell. Non-small cell lung cancer is the most frequent, accounting for around 85 per cent of cases. Small cell lung cancer is the most aggressive type of lung cancer as it often spreads quickly to other organs and accounts for roughly 15 per cent of lung cancer cases.

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

- Squamous cell carcinoma: A tumour originating in the mucous membranes that line the inside of the respiratory tract. 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: A tumour that originates in the glands that line the lung tissue. The tumour often grows further into the lung tissue. This is the most common type of lung cancer, and the type that is becoming more prevalent.
- There are also other smaller, less common subgroups.

ROS1-positive lung cancer

Around 1-2 per cent of all patients with non-small cell lung cancer tumours have a mutation in the gene for a receptor called ROS1 (c-ros oncogene 1). This means that there are mutations in the genes of the cancer cells that cause them to grow rapidly.

The vast majority of people who have this gene mutation have the most common form of lung cancer, adenocarcinoma. The gene mutations are only in the cancer cells, and patients with such mutations are given targeted therapy where the aim is to block the mechanism in the cancer cells that causes them to divide.

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 knees and upper part of the abdomen, headache, dizziness, chest pain, hoarseness 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 arms, legs or back. If the x-ray suggests lung cancer, the patient will be referred to a specialist.

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 difficult it will be to treat. It is generally easier to cure lung cancer when the disease is detected early.

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. The following diagnostic methods may be used:

- Medical history, including occupational and smoking history, and a clinical examination
- Heart and lung function tests

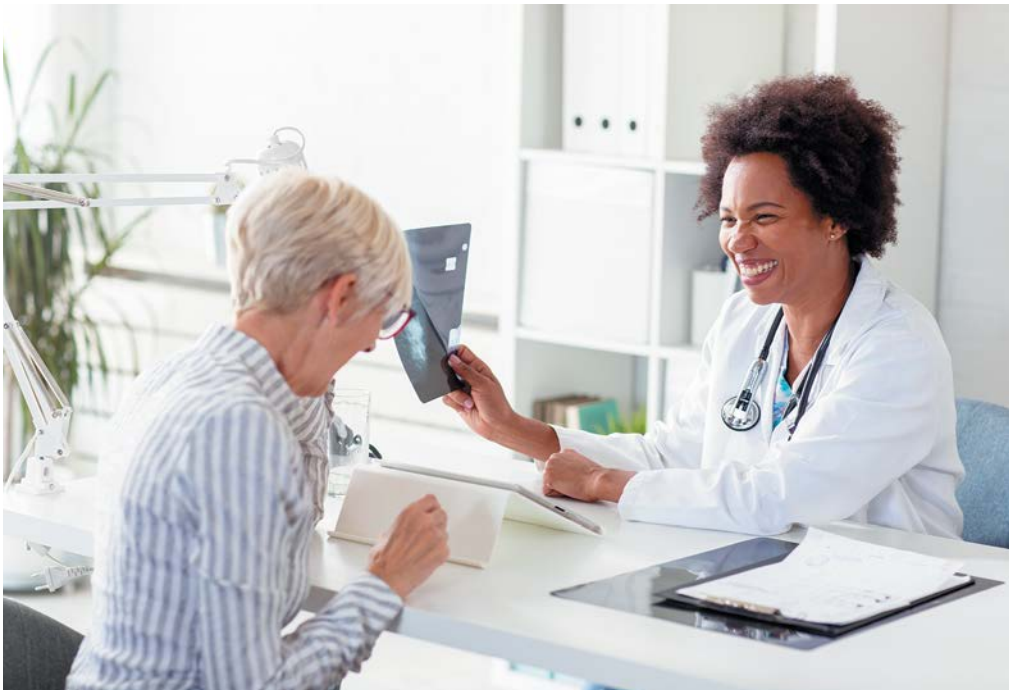
- Comorbidity (other diseases the patient has), such as COPD or cardiovascular diseases
- Blood tests
- Radiological examinations. These may include:
  - CT scan: A CT scan can show areas of the lung that are hidden by other structures in the chest, or that are not visible on the X-ray. With the aid 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 scan: An MRI is used for creating detailed images of the brain and bones. These images are captured with the use of a powerful magnetic field.
  - PET scan: A PET scan produces images of tumours and metastases. 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 the entire body. Cancer cells need a large supply of energy and have a high rate of metabolism. Therefore, these cells contain a lot of glucose, making the cancerous tumours in various parts of the body visible.
  - Skeletal scintigraphy: A skeletal scintigraphy or bone scan is used to check for metastases in the bones. Radioactive substances are injected into a vein in the arm. These substances will primarily gather in places where the metabolism rate is high, which is in cancer cells.
- Bronchoscopy: During a bronchoscopy, the doctor guides a bronchoscope, which is a flexible tube about the thickness of a pencil, through the nose or mouth of the patient, down through the trachea and into the bronchi and its branches. The aim of this examination is to take tissue samples or biopsies by "washing" (rinsing the lungs), or by using a small brush.
- Fine-needle biopsy: In a fine-needle biopsy, the doctor takes cell samples from the lung using a long, thin needle that is pushed through the chest wall. This method is used to determine whether the tumour is benign or malignant, and if possible to identify the type of tumour.
- Mediastinoscopy: A mediastinoscopy is used to examine the space between the lungs – the mediastinum – and to take tissue samples. This procedure is done under general anaesthesia.
- EBUS: An endobronchial ultrasound examination (EBUS) combines a bronchoscopy and an ultrasound. The doctor inserts an ultrasound probe at the end of a bronchoscope tube and then takes tissue samples.
- Sputum culture test: A sputum culture test involves an analysis of sputum or mucus coughed up from the lungs. This contains cells that have loosened from the mucous membranes of the bronchi or other parts of the lung. It may therefore by possible to find tumour cells in this.

Biomarker testing

Tumour cells from all patients with non-small cell lung cancer are tested for various mutations and biomarkers (PD-L1 Expression, EGFR, ALK, ROS1, etc.).

The test is done by taking a small tissue sample (biopsy) of the tumour tissue. The tissue sample is examined at a laboratory that specialises in pathology. The laboratory uses the biomarker test to determine whether certain genes in the tumour have mutated. When such genetic mutations are detected, specialised, targeted treatments can be initiated that attack a specific characteristic of the tumour.

Many patients who are diagnosed in earlier stages are accidentally diagnosed after having a chest CT scan 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 what it means and how to deal with it.

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?
- Has the tumour spread outside the lungs?
- Should I have more tests done to confirm the diagnosis?

Questions about treatment:

- What is my prognosis?
- Will I be undergoing additional examinations?
- What is the treatment plan?
- Should I be treated at a clinic or a hospital specialising in lung cancer?

Treatment

There are several treatment options for patients who have ROS1-positive lung cancer. You may be offered surgery, medication directed at your type of cancer (targeted therapy), and/or traditional cancer treatment such as radiotherapy 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 an operable lung cancer are discussed at a multidisciplinary team meeting (MDT). Here the options for surgery or other therapies are assessed.

Surgery or radiotherapy may eventually cure non-small cell lung cancer in the early stages. Patients who cannot undergo surgery may be given the option of radiotherapy. Chemotherapy alone is not curative, but it can increase the possibility of a cure when provided together with surgery and/or radiotherapy.

Surgery

Surgery with a curative aim may be a treatment option in earlier stages of lung cancer. 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. This treatment option is only used if the tumour is still limited to one area.

Radiotherapy

Radiotherapy is used to damage the DNA of the irradiated cells, thereby killing the cells. For non-small cell lung cancer, radiotherapy can be offered after surgery, as curative treatment instead of surgery, or as part of a combined chemotherapy and radiotherapy for a disease with spreading to local tissues (in the lungs).

In many cases, stereotactic radiotherapy is used. Stereotactic radiotherapy is a medical treatment that uses a very precise, targeted and high dose of radiation.

Patients with metastases may be offered palliative and life-prolonging treatment with radiotherapy in addition to 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.

Drug therapy

Targeted therapy – ROS1 inhibitors
First-line targeted therapy (therapy that is administered first) is the standard treatment for ROS1-positive, non-small cell lung cancer with metastases. Some patients will also benefit from second-line targeted therapy (therapy recommended for treating a disease that has progressed during first-line therapy), or therapy in subsequent lines. The choice of second-line treatment will depend on mutation status and previously administered therapy.

Tyrosine kinase inhibitors (ROS1 inhibitors), inhibit the activity of ROS1, and thus also the growth and spread of cancer cells. ROS1 inhibitors are taken daily in the form of tablets or capsules.

Several ROS1 inhibitors are now available or under development. Most ROS1 inhibitors are given as first-line therapy. In some cases, it may be best to administer another ROS1 inhibitor in subsequent lines of therapy, but this will be assessed by a doctor in each individual case.

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

Your doctor will explain how to take the ROS1 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 your doctor first.

Resistance
Although more than 50 per cent of patients respond to ROS1 inhibitors, most ROS1 inhibitors stop working after a while as the cancer cells develop resistance and begin dividing again. Unfortunately, resistance may develop as early as in the first three months after starting therapy, but in some patients these drugs will be effective for many years.

Once resistance occurs, it may be appropriate to switch treatment to a combination of chemotherapy and immunotherapy. Depending on which ROS1 inhibitor is used for first line therapy, it may be useful in certain cases to switch to a different ROS1 inhibitor.

There is much research being done on what happens in cancer cells when resistance occurs, and new drugs that target various resistance mechanisms are being developed. Currently, this is not standard treatment, but patients may benefit from participation in a clinical trial.

Sometimes resistance develops because ROS1-positive cells develop multiple mutations. These may be mutations other than ROS1 mutations. In some cases therefore, drugs that target other mutations may be effective for continued treatment, even if the tumour did not originally have this exact mutation.

Several of these resistance mechanisms may be present simultaneously in the same tumour. It may therefore be useful to do a new biopsy if there is progression. This is often difficult for the patient, in which case it would be much better to do a blood test to determine traces of DNA from cancer cells. Some cancer mutations have been reported after using this technique.

Sometimes, it may be beneficial to continue therapy with ROS1 inhibitors even if the cancer has progressed. When a patient does not experience symptoms and the progression seen on the CT or MR scan is minor, the doctor may consider continuing treatment with the same ROS1 inhibitors while carefully monitoring the patient's condition, as there is a risk that the tumour growth will spike when the ROS1 inhibitor is discontinued. Sometimes a patient may experience oligoprogression during therapy. This means that the cancer growth is under control in most metastases, but there may be progression in a few of the metastases. In this case, ongoing treatment with the ROS1 inhibitor can be continued with simultaneous local radiation therapy directed at the progressing metastases. The patient may then have a continued response to the same ROS1 inhibitor.

Chemotherapy
Chemotherapy drugs or cytostatics are drugs that kill cells or inhibit cell growth and cell division. Chemotherapy is recommended and used after surgery for early stages of non-small cell lung cancer, either alone or together with radiotherapy, and may be relevant in later treatment for those who have an extensive stage of the disease.

Immunotherapy
Immunotherapy is cancer treatment that utilises the body's own immune system to attack the cancer.

For ROS1-positive lung cancer, chemotherapy combined with immunotherapy is recommended for later lines of treatment after all relevant ROS1 inhibitors have been tested.

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.

Symptoms and side-effects during treatment for ROS1-positive lung cancer

If you have ROS1-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)
- Exhaustion and weakness
- Weight loss

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

Those who are given targeted therapy for ROS1-positive lung cancer may also experience side effects directly related to the therapy, including:

- Diarrhoea/nausea/abdominal pain
- Skin rash
- Higher risk of infections
- Reduced appetite
- Dizziness

Talk do you doctor if you experience any of the symptoms or side effects mentioned here, or if your physical condition worsens. Several of the side effects will go away with supportive treatment.

ROS1-positive lung cancer and the brain

Sometimes cancer spreads from one part of the body to another. Lung cancer may, for instance, spread to the brain. This would still be considered lung cancer, however, so we refer to it as "brain metastases". Some types of cancer spread faster to the brain than others. Non-small cell cancer with ROS1, ALK or EGFR mutations are more likely to spread to the brain than other non-cell small cancers. Some patients experience symptoms of brain metastases, while others do not.

Cancer that has spread to the brain may cause symptoms such as:

Headache, muscle weakness, nausea, mood swings, behavioural changes, seizures, difficulties with coordination, fatigue, or problems with reading or speaking.
Contact your doctor immediately if you experience any of these symptoms.

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 may 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 ROS1-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".

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 being tested in the study or whether you have been randomly placed in the control group.

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

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:

- 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?

You can find an overview of ongoing clinical trials at **www.clinicaltrials.gov** (search for ROS1+ lung cancer), or go to **www.helsenorge.no/kliniske-studier** where you will find a list of all clinical trials in Norway.

Lifestyle – tips and advice

General health advice such as eating healthy and getting enough sleep and exercise is important for everyone, also patients with lung cancer. We do not have any special dietary advice for lung cancer patients, but for many patients, it can be challenging to get enough nutrition while undergoing treatment. Advice from a dietician or personnel with experience with cancer patients and nutrition can be beneficial. Lung cancer patients are advised to stop smoking for many reasons. Smoking can reduce your appetite. Quitting smoking will make chemotherapy and radiotherapy more effective and it reduces the risk of developing other types of cancer in patients that have been cured of lung cancer. When it comes to exercise, patients should do what they feel up to doing. It is pointless to force yourself to do strenuous exercise during this tough treatment, but it is a good idea to engage in some movement and physical activity.

Additional tips on how to live with lung cancer can be found on the Norwegian Lung Cancer Society's website: **www.lungekreftforeningen.no**

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. Among other things, 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, pathologists, 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.

Current research

Improved screening

Treating non-small cell 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. Researchers are investigating better screening techniques, such as genetic testing, to understand who may be at higher risk of developing lung cancer.

Advances in radiotherapy and surgery

Work is being done to find ways to improve the effect of surgery and radiotherapy, while simultaneously reducing the side effects of these procedures.

Liquid biopsy

In recent years, a great deal of research has been done on liquid biopsies. A liquid biopsy involves taking a blood test to identify DNA that has been shed from the patient's tumour cells. This may help find molecular changes that can be used to plan treatment, and it may replace or supplement a tissue biopsy. Such biopsies may be useful at the time of diagnosis and perhaps even more so if the cancer progresses in order to ensure more targeted therapy. Research is also being conducted to learn whether lung cancer can be detected in blood samples at earlier stages of the disease.

Much of the research into ROS1-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.

Patient stories

Helen is given targeted therapy

Everything turned around for Helen Lillebostad (aged 53) when she was able to start targeted therapy. Within four weeks, the tumour in her lung had shrunk, and there were no longer any signs of spreading to the head or other parts of the body.

Violent cough and back pain

Helen has had asthma all her life and in the spring of 2021, she initially thought that her asthma had become worse, which caused her to start coughing more and more. Like her GP, a pulmonary specialist concluded that her asthma symptoms had worsened when examining Helen during a consultation in May.

"I could feel that something was not right in my body, but it's probably just human nature to look for natural explanations for why you feel ill."

Her medication was adjusted without effect. In June, Helen contacted her GP again and was given a course of anti-inflammatory medicine to help with the asthma. She was to take the medicine for one week, but by the end of the week, Helen went back to her GP feeling worse.

"I told my GP that something was very wrong. I was coughing violently and could feel this stabbing pain in my back. It just couldn't be asthma. I thought maybe I had a bad case of pneumonia."

Helen's GP took her seriously and sent her for an immediate x-ray at the hospital in Molde. Three days later, she received a phone call telling her that they found something in her lungs.

Difficult news

After the CT and MRI scans, the doctors established that this was lung cancer that had spread to both the bones and brain.

"It had crossed my mind that t could be cancer, but I wasn't prepared for the news. That day I had no one with me at the hospital, so I sat there alone and listened to the information from the doctors. I just remember asking 'is it game over now?'. That's what I was thinking – that no one survives lung cancer."

Several examinations followed, including biopsies and genetic testing of the tumour.

"It felt like forever waiting for the results. That was almost the worst part, feeling the uncertainty of this difficult situation."

One week later, Helen received her results. She had non-small lung cancer with a ROS1 mutation.

Could not tolerate the therapy

Later that summer, she was admitted to hospital and started on several drugs. The first month, she was given Crizotinib (Xalkori), which her doctors believed would work well for her, but as it turned out, this had a harmful effect on her liver and kidneys. After a while, she needed pauses in her treatment, and altogether she went without drugs for a month. New CT and MRI scans then indicated that her cancer had spread even further. She also had some fluid around her heart.

In mid-November, she had a renal artery stent inserted due to kidney failure.

"At that point, I was feeling really down. I had told my doctor that I didn't want to be revived if my heart were to stop. Everything seemed so dark and hopeless that I just wanted it to end quickly. My family and I did what we could to prepare. I wrote letters to my children and we took new family photos. We were visited by a palliative care team, hospital chaplain and cancer coordinator."

New hope with new drugs

In late October, Helen was started on a new drug, Lorviqua (lorlartinib), which is a targeted, tyrosine kinase inhibitor.

"At that point, everything was uncertain. I asked the doctors if they thought I would live to become a grandmother to my second grandchild who was expected in January, but they weren't able to answer me."

After four weeks with the new drug, new scans were performed and the results were very promising.

"Everything in my brain was gone, the primary tumour had shrunk and all the smaller tumours in my body were gone. It was amazing, like getting a new gift of life!

Helen tolerated the therapy well, and towards Christmas, she started feeling much better. She began reducing other medications she was using, such as morphine and anti-nausea drugs.

Family support

Helen lives with her husband on a small island outside Molde called Bolsøya. They have children and grandchildren living nearby, which she appreciates. Family means everything to her.

"My husband has been exceptionally supportive of me, and having the chance to spend time with my children and grandchildren is the world's best medicine."

Helen has been determined to be open about her disease and talks willingly about it if someone asks her how she is.

"Many people know that I am seriously ill. Some are in awe of how healthy I seem, in spite of it all ..."

One little tablet ...

Now she takes one tablet of lorlatinib daily. CT and MRI scans performed in the spring and summer of 2022 show that everything remains stable.

"Although I would like to cancer continue to shrinking, I'm thankful that nothing has started growing again. It's amazing that this little tablet I take each day keeps me alive!"

"It's amazing that this little tablet I take each day keeps me alive!"

She doesn't spend too much time thinking about the future, as the uncertainty is what bothers her the most.

"I'm doing well, actually, but of course I do have certain moments where I think 'is there any point? I'm going die from it anyway!'. But then I pull myself together. I'm just happy for each day I'm given. And I am overjoyed that I get this time together with my grandchildren. And of course, I still live in the hope that there will be new medicines.

"The fact that I had ROS1 turned out to be good news!"

"The fact that I had ROS1 was good news, because it meant that I could be given a targeted drug that works on this particular mutation. I am so grateful for that!" says Karin Tverå Hansen Juvik (age 66) from Trondheim.

Large tumour

Around the same time Karin retired from her job as head teacher in February 2021, she began experiencing an itching cough.

"It didn't bother me too much. It just felt as though I was coming down with a cold. Later in the spring it went away and I felt better, but when summer was over, it was as though someone had pulled out the plug. The energy that I usually had was completely gone and even going for a short walk was exhausting."

Her GP quickly sent her to the hospital for an assessment, and shortly after, the tumour in her lung was discovered.

"When the doctors at St. Olavs Hospital took the biopsy, they found a large tumour. It also appeared that the cancer had spread. All this was completely foreign to me. I had always been healthy and had never once thought that I could get lung cancer!"

ROS1

A genetic test was performed on Karin's tumour, which showed that she had a ROS1 genetic mutation. In the midst of all this tragic news, this was some good news.

"I was put on a targeted drug and the x-ray two weeks later showed that the tumour

had already shrunk. Two months later, new scans were performed and there were only traces left of the tumour. It is amazing that the drug was so effective!"

Knowledge is important

Karin's husband and three sons have been a strong source of support for her, also because they worked hard to learn as much as possible about the type of cancer she had and possible treatment methods.

"Now that I'm in better shape and have more energy, I want to learn more and keep up to date on what's happening in research and new drugs. Among other things, I participate in an international forum on Facebook where others with the same mutation share patient stories, information about drugs and side effects, and the treatments they've tried. It helps me to read about other people's experiences. This is an especially serious disease, but we have to have faith!"

Karin also shares the knowledge she acquires with her doctors.

"There are enormous developments in research now with new drugs on the market all the time. Naturally we're thankful for that, but at the same time, I don't think we can expect doctors to be completely updated on everything all the time. That said, I am very happy with both the way I've been met and the treatment I've received at St. Olavs."

Second opinion

For extra security to make sure that Karin is getting the right treatment, the family has asked for a second opinion at the University of Colorado Hospital in the United States.

"There they have many ROS1 patients and are doing a lot of research on this mutation. They confirmed that the treatment I'm receiving in Norway is good, which is incredibly reassuring."

After a few months of treatment, the Decision Forum approved a newer targeted drug that prevent spreading to the brain more effectively. Karin switched to this drug. The plan is for her to continue on this drug for many years.

"Now I go for checkups every other month. Everything looks good and I'm not worried about the future at the moment."

Wishes to contribute

"I have more or less returned to the life I lived before I got sick. I am physically active and go out walking one to two hours a day, and I feel that I am becoming more fit. I generally do what I want based on my capacity and energy.

Karin also wishes to contribute to the Norwegian Lung Cancer Society. Among other things, she has participated in the Society's national conferences and various seminars, and has helped to establish a local organisation in Trøndelag county.

"Through the Norwegian Lung Cancer Society, I have met other lung cancer patients in settings other than during treatment, which has been pleasant, secure and inspiring. It's nice to know that you're part of a community."

Terminology

ALK: A gene that ensures the production of a protein in the body called ASL receptor tyrosine kinase.

ALK mutation: An ALK mutation (genetic alteration) occurs when the ALK gene is damaged and attaches itself to another gene.

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

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.

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

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

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

EGFR: A gene that ensures the production of a protein in the body called the epidermal growth factor receptor. A mutation of the EGFR gene may cause EGFR-positive lung cancer.

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

Fatigue: Another word for intense exhaustion.

Gene: Basic units made up of DNA sequences (genetic material) that determine such things as hair colour and eye colour.

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. 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. Genetic mutations have various effects on our health depending on where they occur.

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

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.

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.

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. ALK-positive lung cancer is one form of NSCLC and comprises approx. 4% of all NSCLC cases.

ROS1: ROS1 is a receptor tyrosine kinase (codes for the ROS1 gene), with structural similarities to the anaplastic lymphoma kinase (ALK) protein.

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

Targeted therapy: A type of cancer treatment that targets specific genes and proteins and disrupts the way specific cancer cells send signals or interact with each other. This can stop cancer cells from dividing and growing.

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

Tyrosine kinase inhibitors (TKI): Drugs that block chemical messengers (enzymes) called tyrosine kinase. Tyrosine kinase helps to send signals to cells that trigger growth. The inhibitors block the signals, which stops cells from dividing and growing.

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 800 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.

Join our community – become a member of the Norwegian Lung Cancer Society:
www.lungekreftforeningen.no

Contact us:

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

We partner with:

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The content of this brochure was quality assured by Vilde Drageset Haakensen, specialist in oncology and senior consultant at the Department of Oncology, Oslo University Hospital.

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