



# For those who have Lung Adenocarcinoma

Causes, symptoms, treatment and research

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# Lung adenocarcinoma

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 3,000 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 they most frequently appear in the upper lobe of a lung.

## 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 also 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.

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

## Small cell and non-small cell 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 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, accounting for about 15 per cent of lung cancer cases.

Non-small cell cancer is divided into three 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.
- Large cell carcinoma: These cancer cells are large and show no specific microscopic features.

### Gene mutation

About 60 percent of all patients with non-small cell lung cancer tumours have adenocarcinoma. With adenocarcinoma, the cancer cells are analysed for possible gene mutations, and it is currently routine procedure to examine whether any of these mutations are present: EGFR, ROS1 and ALK. These genetic mutations occur almost only in adenocarcinomas.

### EGFR:

Around 10 per cent of all patients with non-small cell lung cancer tumours have a mutation in the gene for a receptor called EGFR. This means that there are mutations in the genes of the cancer cells that cause them to grow rapidly. EGFR stands for epidermal growth factor receptor. Since 2013, Norwegian treatment guidelines have recommended that all non-small cell, non-squamous cell lung cancer patients be tested for EGFR mutations.

EGFR mutations appear to be more common among non-smokers, and about half of non-smoking women with lung cancer have an EGFR mutation. 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 to stop them from dividing.

### ROS1

Patients with ROS1 account for around 1-2 per cent of all cases of non-small cell adenocarcinomas, which corresponds to just 10 patients per year.

## ALK-positive

Around 2 to 5 per cent of patients with adenocarcinoma of the lungs have a genetic mutation called ALK in their cancer cells. ALK stands for anaplastic lymphoma kinase. Genetic mutations involving the ALK gene appears to be more frequent among younger non-smokers with an advanced stage disease, but it can occur at any age and also among smokers. These genetic mutations are only found in cancer cells, and patients with this type of cancer must be treated with targeted therapy.

The ALK gene controls the production of the ALK receptor tyrosine kinase, a protein that is part of the signalling pathway controlling cell growth and cell division. ALK-positive lung cancer occurs when parts of the ALK gene are damaged and bind to another gene, which in turn results in a fusion of these two genes. This is sometimes referred to as a rearrangement or translocation. A genetic mutation of this type halts the signal that would normally have told cells to stop growing. This will cause uncontrolled cell division, which leads to the development of a tumour.

## 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 torso and upper part of the 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 the patient's occupational and smoking history, as well as 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:
  - X-rays: A chest x-ray enables doctors to see the tumour determine exactly where it is located in the lung.
  - Ultrasound: With an ultrasound examination (sonography), doctors can determine where the tumour is located, its extent or whether it has encroached upon nearby lymph nodes.
  - CT scans: A CT scan can show areas of the lung that are hidden by other structures in the chest, or structures 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:
  - 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 pictures 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.
  - Skeletal scintigraphy - bone scan (rarely used).

- **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 this examination is to take tissue samples or biopsies by “washing” (rinsing the lungs), or cells samples using a small brush.
- **Fine-needle biopsy:** In a fine-needle biopsy, the doctor removes cells 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 be possible to find tumour cells in this.

### **Biomarker test:**

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 in 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 more 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 an adenocarcinoma, either with or without mutations.

You may be offered surgery, traditional cancer treatments such as radiotherapy and chemotherapy as well as drugs targeting your type of cancer (genetic mutations). You should discuss the different options with your doctor. Clinical trials may also be an option. The treatment selected largely depends on the stage of the disease, as well as the age and general physical condition of the patient.

Several drugs have been specially developed to attack the gene mutation that is the cause of your type of cancer (if a mutation has been identified).



Patients with operable lung cancer are discussed at a multidisciplinary team meeting (MDT). Here the options for surgery or other therapies are assessed.

Surgery or radiotherapy can lead to a cure for 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.

Patients with adenocarcinoma without ALK, EGFR, or ROS1 mutations should be assessed for combination treatments with immunotherapy along with chemotherapy, or alternatively, immunotherapy as a monotherapy for high PD-L1 expression.

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## What is PD-L1?

PD-L1 stands for Programmed cell death ligand 1. A high PD-L1 expression on tumour cells can bind themselves to the Programmed cell death protein 1 in immune cells and prevent them from fighting and neutralising cancerous tumours. There are several drugs that block this binding that are available for treating various types of cancer.

PD-L1 inhibitors are drugs that help the immune system fight cancer cells.

## Surgery

Surgery with a curative aim can 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 removed as completely as possible. This treatment option is only used if the tumour is still limited to one area. Other measures may be implemented before surgery.

## Radiation therapy

Radiotherapy is used to damage the DNA of the irradiated cells, thereby killing the cells. This is intended to kill the tumour cells. For non-small cell lung cancer, radiotherapy can be offered after surgery, as curative treatment instead of surgery, or as part of combined chemotherapy and radiotherapy for disease with spreading to local tissues. This would increase the probability of a cure.

In many cases, stereotactic radiotherapy is used. Stereotactic radiotherapy is a medical treatment that uses a very precise, targeted and high dose of radiation. It can be used if there are small tumours in the lung.

If the disease has metastasised, the patient 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 – EGFR inhibitors**

First-line targeted therapy (therapy that is administered first) is the standard treatment for EGFR-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 or protein kinase inhibitors (EGFR inhibitors) inhibit the activity of the epidermal growth factor receptor protein, thereby stopping the cancer cells from growing and spreading. EGFR inhibitors are taken daily in the form of tablets or capsules.

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

Regardless of the 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.

Learn more about the treatment of EGFR-positive lung cancer in our brochure “*For those with EGFR-positive lung cancer* “. You can ask to have this sent by contacting the Norwegian Lung Cancer Society.

### **Targeted therapy – ALK inhibitors**

First-line targeted therapy (therapy that is administered first) is the standard treatment for ALK-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 the mutation status and previously administered therapy.

ALK-inhibitors, also known as tyrosine kinase inhibitors (TKI) or protein kinase inhibitors, inhibit the activity of the protein ALK receptor tyrosine kinase, thereby inhibiting tumour growth. ALK inhibitors are taken daily in the form of tablets or capsules. Several drugs that are specifically aimed at inhibiting ALK are currently under development. Various ALK inhibitors can be given as first-line or later line treatments, depending on the existing data. Regardless of what 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.

Learn more about the treatment of ALK-positive lung cancer in our brochure *“For those with ALK-positive lung cancer”*. You can ask to have this sent by contacting the Norwegian Lung Cancer Society.



### **Targeted therapy – ROS1 inhibitors**

Patients with mutations in the ROS1 gene can also be treated with specific tyrosine kinase inhibitor tablets. This form of therapy may have side effects, but it is usually tolerated well.

Learn more about the treatment of ROS1-positive lung cancer in our brochure “*For those with ROS1-positive lung cancer* “. You can ask to receive this by contacting the Norwegian Lung Cancer Society.

### **Chemotherapy**

Chemotherapy, or cytostatics are drugs that kill cells or inhibit cell growth and cell division. Chemotherapy is used and recommended following surgery for early stages of non-small lung cancer either alone or together with radiotherapy. This is also used parallel with radiotherapy for locally advanced disease, and in patients with stage IV lung cancer (with metastases), chemotherapy is often used together with immunotherapy.

### **Immunotherapy**

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

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

For patients with non-small cell lung cancer, extensive stage disease, immunotherapy is part of a standard treatment, either alone or combined with chemotherapy. Immunotherapy is also used for patients with locally advanced non-small cell cancer, or following rounds of radiotherapy and chemotherapy.

## **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. These tests are done in clinical trials.

Clinical trials may be a good option for patients who need treatment for progressive cancer, as it has been shown that participation itself 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 randomly been placed in the control group.

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

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

- What are the researchers trying to learn?
- Are there potential side effects linked to the drug?
- 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](http://www.clinicaltrials.gov) or you can search for or go to [www.helsenorge.no/kliniske-studier](http://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 ruin your appetite and reduce the effect of cancer treatment. 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](http://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 multi-disciplinary team (MDT) to ensure quality assurance of assessments and treatments. 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](http://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. This 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.

### Drug therapy for lung cancer

There are many clinical trials that involve testing new drugs. These may be drugs targeted at specific mutations or subgroups of patients, or there may be trials for all patients with lung cancer. This can give lung cancer patients access to new and promising drugs. As these are often new drugs, patients will be closely monitored to identify potential side effects.

## Patient story

# Per Otto lives with non-small cell lung cancer

“No one thought I would survive the summer of 2015. Even I had to face the fact that life was coming to an end,” says Per Otto Nilsen (age 73).

But then he was given the opportunity to take part in a study on immunotherapy. After only a few treatments, Per Otto noticed that his physical condition had improved.

### **Few days from x-ray to treatment**

Per Otto had been noticing a lump on his neck for two or three months before he finally worked up the courage to visit his GP in late 2014. His doctor thought it was probably just a lymph node and that there was no need for concern. Fourteen days later another lump appeared under the arm, this time the size of a golf ball. Per Otto's GP sent him for an X-ray immediately, which showed changes in his lungs. After that everything moved quickly, and a few days later he was starting his first course of chemotherapy. He was diagnosed with stage 4 non-small cell lung cancer, with adenocarcinoma without an EGFR mutation.

“Naturally I was shocked. Although, in addition to the lumps, I had felt some back pain and noticed that in the last six months I had some shortness of breath, I never expected that this could be cancer.

### **Immunotherapy changed everything**

Per Otto did not tolerate the chemotherapy well. After each of the three rounds of chemotherapy he received, he became so ill that he ended up in an isolation ward each time. The doctors did not dare to give him more chemotherapy and decided that he should try radiotherapy. In the spring of 2015, he received several sessions of radiotherapy, while at the same time his weight plummeted and he felt that he was getting weaker and weaker. He wrote a last will and testament leaving everything to his children.



“When they asked if I wanted to participate in a study on immunotherapy, I had nothing to lose. I was one of the first to receive the immunotherapy nivolumab, which at the time had shown good results for melanoma. After just a few treatments, I noticed that my condition had improved, I was gaining weight, and my shortness of breath eased. When a CT scan showed positive signs, and my hope also returned.”

### **Treatment free for several years**

Per Otto was given immunotherapy for two years, a total of 50 treatments. That was why he was excited when he learned he could discontinue the therapy in 2017.

“I haven’t had any treatment for several years. At first I was very nervous before each check-up, but now I’m no longer anxious. Now I go for check-ups every six months and everything looks stable. The doctors can see that there are some remains, but they can’t say whether this is cancer or scar tissue.”

With all the treatment Per Otto has received, he notices that his body is not quite the same, although he is not struggling with any serious long-term side effects.

“I have trouble with steep slopes, and the same problem with stairs. I still have some shortness of breath, but the doctors have said that it’s nothing dangerous and that it is good for me to walk a lot. So I often go for walks and do what I can to keep in shape.



# Carina lives with non-small cell lung cancer



Carina Aarstad (aged 57) had two relapses after she was diagnosed with lung cancer in 2016. Successful treatment with immunotherapy has given her new hope.

“I choose to focus on the future and allow myself to dream a bit. I think it is important not to shut out the future, because I want to be around for as long as possible.”

Carina describes getting her lung cancer diagnosis as living in a vacuum, where everyone around her continued with their normal lives, while she herself was staring death in the eye. Carina was diagnosed with non-small cell lung cancer with adenocarcinoma, without any known mutations. After surgery and chemotherapy in 2016, she felt that she had been given the gift of life again. From the time she was diagnosed, she has used the internet and Google searches, contacted many people in a similar situation, and acquired as much knowledge as possible about her own situation.

“There is a lot to be said about using Google in a crisis like this, and I’m aware that it is discouraged, but it has helped me gain control over myself, my illness and everyday life. Having a kind of ownership of this disease has, in a way, given me a sense of security.”

## Changed her view of cancer

With two relapses behind her, the last few years have been characterised by both ups and downs. Before her first relapse in 2017, Carina was very anxious that the cancer would return. When she relapsed, she was crestfallen.

“It was tough. I had been working to regain my physical condition after the first tough round of treatment, and felt that I had done everything I could to prevent it from happening, but it did anyway. I was depressed and feeling really down. Fortunately, I

was able to see senior consultant Åslaug Helland at Radiumhospitalet, who said that she thought I should try radiotherapy. She told me that lung cancer would become a chronic disease on a par with cardiovascular disease and diabetes, and the fact that I had now relapsed could mean that I would continue to need treatment now and then. That changed something in me, and made me feel more safe. I no longer felt I had a death sentence hanging over me. I truly wish all lung cancer patients could have such a reassuring doctor!”

When relapse number two came in 2018, Carina returned to Åslaug and joined the COMIT study where she received radiotherapy and immunotherapy. After two years of immunotherapy, she received her last dose in November 2020. A recent PET scan Carina took in 2021 showed that everything was stable. The doctors only saw a small growth of 1 mm from the previous year, which was not enough to worry Carina.

“It’s just a little spot, so I’m not worried about that,” says Carina.

### **Fitness training is a large part of life**

Physical activity has been a large part of Carina's life, both before and after her cancer diagnosis.

“I love fitness training and have continued training while I’ve been ill. Fitness training gives me a sense of accomplishment and helps me get my old life back. I am also very fond of hiking in the mountains, and I’ve added a few mountain peaks to my hikes as well. Being able to reach a few tall peaks gives me an incredible feeling of accomplishment, even if it takes longer. I believe that I am where I was before I got sick, but I realise that I need to stop more often to take a breather.”

### **Thinking ahead**

Today, Carina is on disability benefits, as the illness made it difficult to return to the job she had. It was also too difficult to apply for jobs due to her lung cancer diagnosis. However, that doesn’t mean she doesn’t have plans. She is looking at the possibility of becoming a dog trainer, perhaps starting a dog day care, or becoming a medical yoga instructor.

“I’m constantly thinking ahead. Although I feel like a shadow has come into my life, I try not to let it overshadow everything.



# 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 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.

**Cancer:** A group of diseases caused by an 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 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 can occur in cells that have developed into egg or sperm cells, and this can be passed on from parents to offspring. Gene mutations have various effects on our health depending on where they occur.

**Hereditary:** Something passed from a parent to offspring through the genes. Characteristics or diseases that are inherited by children 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](http://www.lungekreftforeningen.no)

## Contact us:

E-mail Secretariat: [post@lungekreftforeningen.no](mailto:post@lungekreftforeningen.no)

Phone Secretariat: **93470121** – the phone line is open Monday through 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 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](http://www.lungekreftforeningen.no/likepersontjenesten)

You can also send an e-mail to

[likeperson@lungekreftforeningen.no](mailto:likeperson@lungekreftforeningen.no)

We partner with:



**KREFTFORENINGEN**

# Community Unity Security

**The content of this brochure has been quality assured by Åslaug Helland, senior consultant at Radiumhospitalet.**

For sources and references, see: [www.lungekreftforeningen.no/referanser-diagnosebrosjyrer](http://www.lungekreftforeningen.no/referanser-diagnosebrosjyrer)

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