Lungekreftforeningen

For those who have EGFR-positive lung cancer

Causes, symptoms, treatment and research

Contents

EGFR-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 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 it most often appears in the lung's upper lobe.

Causes and risk factors associated with EGFR-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.

General risk factors for lung cancer:

- 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.

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

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 about 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 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.

Mutations in the EGFR gene

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 lung cancer patients be tested for EGFR mutations.

The vast majority of people who have this gene mutation have the most common form of lung cancer, adenocarcinoma. 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.

Facts about EGFR

Genetic alterations linked to lung cancer generally arise during a person's lifetime. This is also the case with EGFR-positive lung cancer. Genetic alterations 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 don't know why EGFR mutations arise, but they appear to be more common among women and patients who have never smoked. They are also more prevalent in South East Asia than in the West.

A mutation of this type leads to changes in the growth factor receptors (EGF receptors) that tell the cells to continuously divide. This growth signal is constantly switched on, which means that the fine-tuned regulation of cell division in normal cells is overridden. This will lead to uncontrollable cell division, which results in the formation of 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 arms, legs or back. If the x-ray indicates 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. 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 treatments. 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 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.

Which methods should be used to determine the diagnosis will vary depending on the case. The patient's general physical condition, medical history and other diseases will affect both the assessment and choice of treatment.

How is lung cancer diagnosed?

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

- 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 and bones An MRI scan provides precise images 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 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.

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

- Tissue samples can be taken from different parts of the body. 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 the bronchoscopy is to determine the extent of the tumour and to take tissue samples with a small forceps or to take cell samples using a small brush.
- EBUS: An endobronchial ultrasound examination (EBUS) combines a bronchoscopy and an ultrasound. The doctor inserts an ultrasound probe at the end of a broncho-scope tube, and then takes tissue samples.
- A CT- or ultrasound-guided tissue biopsy from the lung or metastases. The doctor will take a sample of the tumour tissue using a thin needle that is inserted through the skin.
- Ultrasound: 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.

Biomarker test:

Tumour cells from all patients with non-small cell lung cancer are tested for various mutations and biomarkers (PD-L1 expression that is important for immunotherapy, and genetic mutations such as EGFR, ALK, ROS1, etc.). 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.

Patients diagnosed with ALK-positive lung cancer will often already have an advanced disease at the time of diagnosis. Many patients who are diagnosed in earlier stages are accidentally diagnosed after having a chest CT scan for other reasons.

It is important to keep in mind that there are several treatment options that can slow down or stop the spread of ALK-positive lung cancer.

Further assessment

Heart and lung function tests can provide important information prior to other treatment, such as surgery.

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? Localised, locally advanced or extensive?
- 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 EGFR-positive lung cancer. You may be offered surgery, traditional cancer treatments such as radiotherapy and chemotherapy as well as drugs targeting your type of cancer: You should discuss the different options with your doctor. The 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 multidisciplinary team meetings (MTD).

Surgery or radiotherapy may cure early stage lung cancer (localised and locally advanced). 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 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. At the first checkup after surgery (approx. 1 1/2 months), the doctor will determine whether there is a need for additional treatment, such as chemotherapy, immunotherapy or radiotherapy.

Radiotherapy for localised lung cancer.

Radiotherapy is used to damage the DNA of the irradiated cells, thus killing the cells. There are two types of radiotherapy with a curative aim. Stereotactic radiotherapy is a very precise, targeted and high dose of radiation that is administered a few times, 3-8 treatments approx. every other day.

Fractionated radiotherapy consists of many (approx. 33) smaller doses of radiation administered 5 days a week with a break on weekends.

If the patient is too weak to tolerate the two above-mentioned radiotherapies but is still in good shape with a good general physical condition, it may be determined to administer a few doses to keep the disease in check. This will be decided 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. The patient is given many (approx. 33) smaller doses of radiation administered 5 days a week with a break on weekends. In addition, two courses of chemotherapy are administered, one at the start and one at the end of the treatment. If the patient has PD-L1 above 1 %, they can receive immunotherapy for one year afterwards.

Treatment of metastases

Radiotherapy can be used to stop the growth of metastases. Such radiotherapy may include stereotactic radiotherapy that provides a very precise, targeted and high dose of radiation, or a fractionated, flat dose. The type of radiotherapy is determined partly by the location of the tumour. Radiotherapy is often administered parallel 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 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 a different 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 radiological examinations done and blood tests taken before and during your treatment to monitor the effect and blood cell levels, and to check if your liver and kidneys are functioning properly.

Your doctor will explain how to take the EGFR 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.

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

If you have EGFR-positive lung cancer, you may experience symptoms of the lung cancer and side-effects of the treatment. It is a good idea to talk to your doctor about all signs and symptoms or side-effects – especially if you start feeling 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)
- Feeling tired and weak

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 EGFR-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:

- Intense exhaustion (fatigue)
- Nausea and vomiting
- Diarrhoea and constipation
- Shortness of breath/cough

Other potential side effects include: a low white blood cells count, swelling/inflammation, liver problems, nerve damage (neuropathy - may be experienced as a tingling or burning sensation in the hands or feet), heart arrhythmia or confusion.

You should talk do your doctor if you experience any of the symptoms or side effects mentioned here, or if your physical condition worsens.

Resistance in the cancer cells (the treatment stops working)

Although more than 50 per cent of patients respond to EGFR inhibitors, most EGFR 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 3 months after starting therapy, but in some patients these drugs can 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 EGFR inhibitor is used in the first line, it may be useful in certain cases to switch to a different EGFR 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 if there is one available.

Sometimes resistance develops because EGFR-positive cells develop multiple mutations. These may be mutations other than EGFR mutations. Therefore, in some cases, 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 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, it may be better to take a blood test to find traces of DNA from the cancer cells. Some cancer mutations have been reported using this technique.

It may sometimes be beneficial to continue therapy with EGFR inhibitors even if the cancer progresses. 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 EGFR inhibitors and carefully monitor the patient's condition, as there is a risk that the tumour growth will spike when the EGFR inhibitor is discontinued. 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 EGFR inhibitor can be continued with simultaneous local radiation therapy directed at the progressing metastases. The patient may then have a prolonged response to the same EGFR inhibitor.

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.

Immunotherapy

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

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

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.

EGFR-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 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 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 will 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 EGFR-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. These tests are done in 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 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** (search for EGFR + 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 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**

Current research

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 to plan treatment.

Much of the research into EGFR-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 research in clinical trials that include patients who have developed resistance. New drugs are also being developed for rare variants of EGFR mutations that do not respond as well to the existing EGFR inhibitors. Furthermore, there is research on different combinations of EGFR inhibitors with other drugs that may potentially increase the effect of EGFR inhibitors.

Maintenance treatment with EGFR inhibitors following surgery

The results of recent research also indicate that treatment with a specific EGFR inhibitor can be used as maintenance treatment following surgery for early stage EGFR-positive lung cancer. Patients who were given this treatment relapsed much later than patients who did not receive the treatment. It is still uncertain as to whether this treatment will increase life expectancy and it has not yet been established as standard treatment.

Patient story

Living with non-small cell EGFR-positive lung cancer

Since 2013, Kari Grønås (age 59) has been participating in two clinical trials, and her cancer has stabilised with the use of EGFR inhibitors.

The future looked bleak for Kari when she was diagnosed with lung cancer around Christmas in 2012. The cancer had spread to her lymph glands, kidneys, bones and brain. Despite the metastases, she had few symptoms, which was atypical of lung cancer.

"For almost six months, I had been seeing a physiotherapist for what we thought was a torn hamstring muscle. However, a CT scan showed that it was something else entirely, and I was referred elsewhere. Soon after, I was told I had lung cancer."

This was an EGFR-positive non-small cell lung cancer, a diagnosis Kari was well aware of as her sister had been given the same diagnosis with the same mutation three years earlier.

"I was carefully examined and was screened for hereditary factors twice, but the doctors found no connection. The fact that I got the same diagnosis as my sister increased our shock and grief. When I was told I had lung cancer, my sister was very ill and died six months later."

Included in a clinical trial

After receiving the diagnosis, Kari was given stereotactic radiotherapy to both her brain and bones. But in early February 2013, she was offered the chance to participate in a clinical trial at Radiumhospitalet.

"I was given Giotrif, a second-generation EGFR inhibitor. This drug made me feel better almost immediately." After two months, new scans were performed indicating that the tumour in her lung had shrunk to half its size and that the tumours in her kidneys were gone. On blood tests, doctors saw that the cancer marker had fallen from about 300 to 10, and was almost down to the normal level of 5.

Admittedly, there were some side effects, but on the whole everything went in the right direction.

"At first, my sense of taste and smell changed, but this passed. I was troubled by itchy skin and many sores, including my mouth and eyebrows, as well as an inflammation of the nail roots. I also had a lot of gastrointestinal problems. Later, I was diagnosed with lactose intolerance, which means that I now have better control of my stomach issues. Whether this is a side effect of the medication, they haven't said."

New clinical trial after four years

Kari was on Giotrif for four years. She took one tablet daily and was closely monitored. This close follow-up was due to her participation in a clinical trial, which she feels has been positive and has made her feel secure.

"One of the advantages of participating in a clinical trial is the close monitoring. This gives me an enormous sense of security. At first, I attended checkups every other month, and after six months, I had checkups every third month."

In 2017, during another PET scan, doctors detected a possible recurrence of the cancer. A biopsy of the lung tumour confirmed this suspicion.

Shortly after, Kari was offered the chance to participate in another clinical trial. At that time, researchers had opened up for additional participants in a study on the EGFR inhibitor Tagrisso, which led Kari to begin taking this drug.

"Tagrisso has been very effective. I have now been taking the drug for four years and am doing fine. There are also fewer side effects, which is an added bonus."

Kari is still in this clinical trial. She attends checkups every three months and her last PET scan in autumn 2021 indicated that everything remained stable. Blood tests also showed that the cancer marker was as low as it had ever been, and as long as the disease is in check, she can continue to use Tagrisso.

Long-term side effects from radiotherapy

The radiotherapy Kari was given earlier in the disease led many years later to a couple of tough surgical procedures. In November 2020, it was discovered that she had a bleed

in an area of the brain that was irradiated, which meant that she needed brain surgery. The good thing was that no cancer cells were found in her brain. An area of one arm had become so weakened by the radiotherapy that she incurred a fracture, and late in the summer of 2021, she underwent surgery for a new shoulder joint.

Learned to live with it

Kari is a pharmacist and has extensive knowledge of pharmaceutical developments. The fact that she has been able to continue working helped her learn to live and cope with her cancer diagnosis. Currently, she is working part time in addition to her appointment as a board member of the Norwegian Lung Cancer Society, as well as other board appointments.

"I am very pleased that I can continue working. I would encourage others to do the same if they have the opportunity. It's wonderful to have something else to think about, and to do things that are interesting. Life offers so much more than illness."

When it's time for a new checkup, Kari still feels worried.

"It's like sitting for an exam every time. As though my whole life is under assessment. The days I have checkups are difficult. So it's always lovely when I can leave the doctor's office knowing that everything is stable and looks good.

Although being diagnosed with lung cancer was a huge upheaval, I have learned to live with my disease and I don't let lung cancer control my life. That said, I've been very fortunate as I have felt healthy enough to do what I like. Although my physical condition is not what it once was, I can generally do what I want. I am also very grateful that I have a family who supports me, but who also continue to live their lives without getting too caught up in my disease. This has helped me normalise my life without too much focus on the fact that I'm ill.

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.

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.

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 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 can occur in cells that have developed into egg or sperm cells. 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 parent to offspring through the genes.

Characteristics or diseases inherited by children from their parents.

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: **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 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:

KREFTFORENINGEN

Community

Unity

Security

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, and Janna Berg, pulmonologist at the Department of Medicine, Vestfold Hospital Trust.

For sources and references, see: www.lungekreftforeningen.no/referanser-diagnosebrosjyrer

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