Lungekreftforeningen

For those who have pleural mesothelioma

Causes, symptoms, treatment and research

Contents

For those who have mesothelioma

Pleural mesothelioma is a very rare disease. In recent years, this form of cancer has affected around 60-80 men and 15 women in Norway.
The cause of pleural mesothelioma is exposure to asbestos fibres, which are inhaled into the lungs.

Most people who develop pleural mesothelioma have been exposed to asbestos in a work context, and the gender imbalance is due to the fact that more men than women have been exposed to asbestos through their work. It often takes a long time, usually 20 to 40 years, from the exposure to asbestos until the patient develops cancer. Because it takes such a long time from exposure to asbestos until the disease appears, it generally affects people over the age of 65. In rare cases, a genetic predisposition may contribute to the development of the disease.

Facts about pleural mesothelioma

Malignant pleural mesothelioma (MPM) is a type of cancer arising in the pleura or membranes of the lungs, and it is most often caused by asbestos exposure earlier in life.

Pleural mesothelioma is a form of cancer that is often diagnosed at an advanced stage.

In 2003, the Scandinavian Centre for the Treatment of Malignant Pleural Mesothelioma was established. This centre is located at Rigshospitalet in Copenhagen and accepts patients from the Nordic region that have operable malignant pleural mesothelioma.

Symptoms

The most common symptoms of pleural mesothelioma is shortness of breath, chest pain, weight loss, fatigue and coughing. These are symptoms that are also common in other diseases. In the case of pleural mesothelioma, 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 pleural mesothelioma:

- Shortness of breath
- Pain in the chest or chest region
- General weakness and fatigue
- Significant weight loss for no apparent reason

Assessment

It may be difficult to diagnose pleural mesothelioma. A tissue biopsy can give a definitive answer, and sometimes several tissue biopsies must be performed to make the diagnosis. The tissue sample will also show which of the two main types of pleural mesothelioma cancer is present: Epithelioid or sarcomatoid (or possibly a mixed type). Further analyses will determine whether it is operable, which is only possible in certain cases of limited stage disease.

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:
  - CT scan: 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: MRI scan are used to create 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 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.
  - 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 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 by using a small brush.

- Fine-needle biopsy: In a fine-needle biopsy, the doctor takes 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 by possible to find tumour cells in this.
- CT-guided biopsy: A needle is inserted into the chest wall to take tissue samples from the tumour in the pleura (lung membrane) just inside the chest wall. A CT machine is used to guide a targeted removal of a tissue sample.

Checklist for consultations on diagnosis and treatment

Once you have undergone the first 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 what to do.

We have collected a few tips for the checklist:

Questions about the diagnosis:

- Is the diagnosis certain or are there still uncertainties?
- What is the stage of the disease?
- Has the cancer 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 malignant pleural mesothelioma?

Treatment

There are several treatment options for those who have pleural mesothelioma. Currently, there is no standard treatment for this form of cancer. This means that each individual patient must be examined and assessed individually before a treatment method is chosen.

You may be offered surgery or traditional cancer treatment such as radiotherapy and chemotherapy. Immunotherapy may be an option. 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.

Patients with operable pleural mesothelioma will be discussed at a multidisciplinary meeting (MDT). Here the options for surgery or other therapies are assessed.

Surgery
Certain patients with a limited stage of pleural mesothelioma may be eligible for surgery. This is done at the Scandinavian Centre for the Treatment of Malignant Pleural Mesothelioma at Rigshospitalet in Copenhagen. At Rigshospitalet, surgery is performed to remove parts of the pleura, the thin membrane surrounding the lungs (partial pleurectomy) and the adjacent tumour in the chest cavity (decortication). To be eligible for surgery, the patient must be in a good general physical condition.

Radiotherapy
Radiotherapy is used to damage the DNA of the irradiated cells, thus killing the cells. Radiotherapy can have a good pain-relieving effect on pleural cancer, and it is also beneficial for reducing the production of fluid from the pleural membrane.
If the disease has metastasised, the patient may be offered palliative and life-prolonging treatment with radiotherapy in addition to drug therapy.

Chemotherapy
Chemotherapy, or cytostatics are drugs that kill cells or inhibit cell growth and cell division. It is recommended that patients who are being considered for surgery are treated with 3 to 6 rounds of chemotherapy.
Chemotherapy may be appropriate for inoperable patients, and it can alleviate symptoms and delay the progression of pleural mesothelioma.

Immunotherapy
Immunotherapy is cancer treatment that utilises the body's own immune system to attack the cancer disease. Recent studies have shown promising results of

immunotherapy for patients with pleural mesothelioma, but as of 2022, this treatment has not been introduced to Norway.

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 being tested in clinical trials.

Symptoms and side-effects during treatment for pleural mesothelioma

With pleural mesothelioma, you may experience symptoms of the cancer disease as well as the side effects of treatment. It is a good idea 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)
- Feeling tired and weak
- Weight loss

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 immunotherapy for pleural mesothelioma may also experience side effects that are directly related to the treatment, such as:

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

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

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 want to learn more, ask questions and find out as much as you can about malignant pleural mesothelioma 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.

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 malignant mesothelioma), or you can visit **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 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** for more information on patient care pathways.

Current research

There have been no treatment breakthroughs for patients with inoperable pleural cancer for many years. Fortunately, this has changed with the arrival of new and promising results with immunotherapy. This has increased the interest in research on the disease. In Norway, there is currently research on combining immunotherapy with cancer vaccines for mesothelioma. Several types of immunotherapy drugs are being tested in clinical trials.

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.

Patient story

Developed pleural mesothelioma after exposure to asbestos

A long working life as a machinist at sea and on land involved repeated exposure to asbestos for Jarle Frøystadvåg. He was diagnosed with pleural mesothelioma at the age of 63.
"I had never been ill and had always been in good health. So it was a huge shock to get such a serious diagnosis, to say the least!"

Around Christmas time in 2020, Jarle noticed that he was a little short of breath, but a course of penicillin from his GP made him feel better for a short while. When the shortness of breath returned, he underwent a private health examination which set further examinations in motion.

"Everything moved quickly after that doctor's appointment. I was sent for an X-ray at the hospital where the radiographer immediately requested a CT scan, breath tests and blood tests after the images were ready. The CT images showed that something was wrong, the pulmonologist was contacted and I was soon asked if I had been exposed to asbestos.
And I had been.

A biopsy confirmed the diagnosis of pleural mesothelioma, and the doctors were certain that this was due to asbestos exposure."

Asbestos in the workplace

Jarle had worked as a machinist for over 40 years. During his working life, he had repeatedly been exposed to asbestos.

"In older boats that were built before the 1980s, asbestos was used for insulation around the exhaust pipes. When the engines heated up, this led to a lot of dust and to my exposure to asbestos through the ventilation system when I had been on duty in the engine room."

Started on chemotherapy

In March 2021, Jarle started chemotherapy at Volda Hospital. Every three weeks until October of the same year, he received courses of three types of chemotherapy. Against all odds, he remained in good physical condition, and new CT images showed that the cancer was kept in check.

"My wife, who is a nurse, had read about the options for immunotherapy. Although the doctor at the local hospital was sceptical, I was determined that I wanted to try them. So an application was sent to request my participation in a clinical trial for immunotherapy at Ullevål Hospital."

At Ullevål, the NIPU study was initiated. This was a phase 2 study that included patients with pleural mesothelioma who had experience a recurrence after chemotherapy. Jarle was first told that he was not a candidate because his tumour was stabilised. But in October, the tumour started growing again, and he was included in the clinical trial.

Tough start to the clinical trial

"In December, I was started on my first round of therapy, and managed two rounds before Christmas. I've always considered myself to have two sets of batteries that keep my energy levels up, but this time I hit the wall. I was left lying on the sofa, couldn't breathe, lost my appetite and was completely exhausted. I also developed neuropathy and fatigue, as well as gingivitis. For the first time in my life, I felt down for the count. It was a tough time."

However, his physical condition improved during the winter. After a few months, Jarle was able to take his boat out for cod fishing again. After a while, he was able to ride an electric bicycle and often goes out for walks.

Immunotherapy has been effective

Since he started the study, Jarle has travelled from Ulsteinvik to Ullevål every fortnight for treatment. He has been given two types of immunotherapy and is gradually feeling better. At his appointments in May, June and July 2022 he was told that his tumour was regressing.

"Pleural mesothelioma is practically incurable, so I'm not too sure about the future,

but I do have a strong belief in immunotherapy. I am a living example of its effect." After almost a year in the study, I can only praise Ullevål Hospital. I have been given wonderful care, everyone involved has been great, the information has been good, and I have felt secure and supported the entire time. My wife, Mette, who has stood by me the entire time has been an incredibly important supporter. At the same time, it has been a difficult road, but when you get a serious disease you have to make the best of it. I have tolerated the treatments well and my mental health is good. Now the tumour has regressed and everyone is pleased!"

Chose to be open

"I'm the type of person who likes to chat with people. When I became ill, I realised early on that I wanted to be open about my disease to friends and acquaintances. For me, this was a good decision, so people don't have to talk about me and my illness behind my back."

Since pleural mesothelioma is a diagnosis that affects few people, Jarle had no one to talk to with the same diagnosis for quite some time. After he joined the NIPU study, he came into contact with other pleural mesothelioma patients who had also been diagnosed after exposure to asbestos during their working life.

"Becoming acquainted with others in the same situation has been important for me. We have given each other a lot of support! I feel an enormous gratitude for my participation in the study. I would not be where I am today had I not been included.

Terminology

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.

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

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.

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.

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.

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

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

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, 09:00–15:00

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

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