For those who have cervical cancer

Causes, symptoms, treatment and research

gynkreftforeningen

Each year, 1700 Norwegian women are diagnosed with a form of gynaecological cancer, and around 300 of them have cervical cancer. The average age at the time of diagnosis is 45.

Today, around 22,000 women in Norway are living with a form of gynaecological cancer or have undergone treatment for this.

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300
women in Norway are diagnosed with cervical cancer each year

Cervical cancer originates in the cervix or cervical canal. One important factor in the development of the vast majority of cervical cancer cases is the HPV virus (human papillomavirus). The HPV vaccine that is important for preventing cervical cancer is offered to both girls and boys in Year 7 at school, and it reduces the risk of contracting HPV. Cervical cancer often develops over a span of several years. At an early stage, this form of cancer often has no symptoms. With early detection, there is a good chance of recovery, and the cancer can be detected early with a cervical screening test (smear test). In Norway, all women between the ages of 25 and 69 receive a letter from the Cancer Registry of Norway's Cervical Cancer Screening programme (NCCSP) with a reminder that it is time for a new smear test.

Treatment of cervical cancer has been centralised to centres for gynaecological cancer at the four regional hospitals in Tromsø, Trondheim, Bergen and Oslo.

Cervical cancer is prevented through vaccination and screening. New studies by the Norwegian Institute of Public Health show indicate that by 2039, cervical cancer will be all but eradicated in Norway, thanks to high vaccination coverage and screening examinations.

This is HPV

HPV stands for human papillomavirus, of which there are more than 100 different types. Some are completely harmless, while others can cause cell alterations and cancer. Some types of HPV are transmitted through sexual contact. More than 70 percent of sexually active people become infected with HPV during their lifetime, and for most people, the infection goes away on its own. Some types are completely harmless, while others cause genital warts. High-risk HPV viruses can cause a persistent infection that can lead to cervical cancer in the long term. This usually takes between 10 to 30 years.

There are also other forms of cancer that are caused by HPV, such as cancer of the vagina and external genitalia in women, cancer of the penis in men, as well as cancer of the throat and rectal canal in both sexes. It is unknown why some infected persons develop cancer and others do not. Anyone who is sexually active may be infected by HPV, regardless of the number of sexual partners. There is currently no routine testing for HPV infection, and the infection cannot be treated. It is therefore important to accept the invitation to participate in the Cervical Cancer Screening programme, which is sent to all women from the age of 25. Severe cell changes (precancerous lesions) in the cervix can be detected in samples from the cervix and treated through surgery, where the outermost cone-shaped tissue of the cervix is removed (conization).

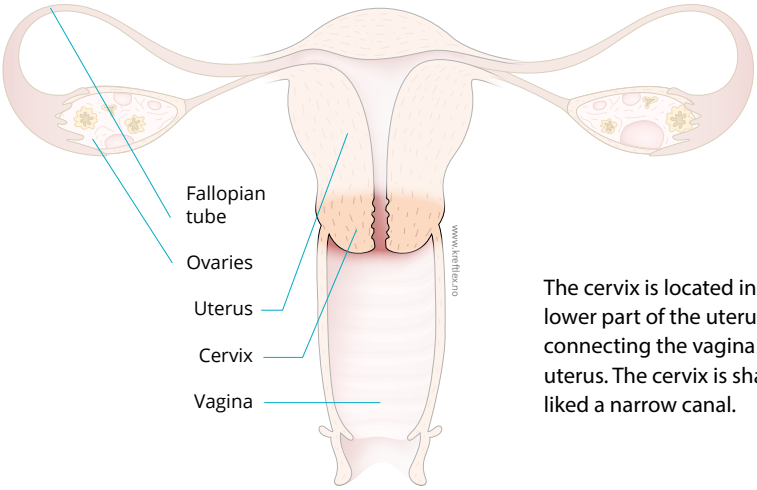
SOURCE: NORWEGIAN INSTITUTE OF PUBLIC HEALTH

Symptoms

Early stages of cervical cancer have few or no symptoms. The symptoms vary from person to person, and depend on how far the disease has progressed.

- ○ Bleeding disorders/irregular menstruation
- ○ Bleeding after sexual intercourse or physical activity
- ○ Bloody and foul-smelling discharge
- ○ Pelvic pain, abdominal pain or pain in the lower back
- ○ Bleeding after menopause when menstruation has ceased

If symptoms persist, you should not wait to contact your doctor. This applies even if you have recently taken a smear test that did not detect any abnormalities.



The cervix is located in the lower part of the uterus, connecting the vagina and uterus. The cervix is shaped liked a narrow canal.

Causes and prevention

More than 99 percent of cervical cancer is due to a long-term HPV infection. Most sexually active women are exposed to HPV, but only 10 percent will develop a long-term infection. Among those with a long-term infection, around 1 percent will develop cervical cancer.

Regular cervical screening and HPV vaccination are the two most important measures for preventing cervical cancer.

- It is essential to follow the Cervical Cancer Screening programme when you get a reminder from the Cancer Registry of Norway, and have a smear test done every three years. This will reduce your risk of cervical cancer.
- The HPV vaccine reduces the risk of contracting HPV. It is given to both girls and boys in Year 7 at school. Adults can also get the vaccine. This must be prescribed by a doctor and administered by a doctor, medical secretary, public health nurse or other nurse.
- Smoking is also a risk factor, as smoking has an effect on the immune system of the cervix.
- In addition to a long-term HPV infection, there are other factors that can increase the risk of cervical cancer:
- Chlamydia infection
- Use of oral contraceptives over a lengthy period
- Weakened immune system
- Women who gave birth before the age of 17, and who have had three or more children have a higher risk
- Prior radiation therapy of the pelvis

Assessment

Smear test and HPV test

Gynaecological examination, smear test and an HPV test are all important in the assessment of cervical cancer. A sample of the cervix is extracted during a gynaecological examination, where a small brush is used to collect cells from the surface of the cervix. For women under the age of 34, the sample is examined for cell changes, while for women ages 34 and older, the sample is examined with an HPV test. If this is positive, the sample is examined for cell changes. It usually takes three to four weeks to get the results of a smear test. If the test is normal, women are recommended to take a new smear test after three years. If the sample is HPV-negative, a new test is recommended after five years.

If the smear test shows that you have cells changes (CIN 1 or LSIL), this usually means that you have an HPV infection. If you test positive for HPV, you will either be referred to a gynaecologist for a more thorough examination, or you will be recommended to take another test after a certain period of time. CIN 1 often resolves on its own and is therefore only treated if it persists for a long time.

If the smear test shows that you have moderately or severely abnormal cells (CIN 2 or 3, or HSIL), the doctor will refer you directly to a gynaecologist. In order to check your cervix more thoroughly, the gynaecologist will examine your cervix with a microscope (colposcopy) and take tissue samples (biopsy). If moderate to severe cell abnormalities are found in the tissue sample, it is recommended that you undergo a minor gynaecologist surgical procedure called a conization. In this procedure, a small part of the cervix is removed. Conization is standard treatment for CIN 2 and 3.

If cervical cancer is detected or suspected in a tissue sample or a visible tumour on the cervix, you will be referred directly to a patient care pathway for cervical cancer (see more information about patient care pathways further down in the brochure).

Colposcopy

A colposcopy is performed if there severe cell abnormalities or there is suspicion of cervical cancer. Here, the doctor uses a microscope that resembles binoculars (colposcope) to examine the cervix. This enables the doctor to see abnormal areas of the cervix and take small tissue samples (biopsies).

Conization

If the tissue samples show that you have severe cell abnormalities, a conization will be performed. This means that the outermost part of the cervix will be removed. A conization is performed if there are no visible tumours present during the gynaecological examination or in an MRI scan.

Additional examinations

- CT scan of the lungs, abdomen and pelvis to determine whether the disease has spread
- MRI of the pelvis to see how deep it has infiltrated the cervical wall and any surrounding organs
- PET-CT
- Blood tests

Treatment

Treatment of cervical cancer is determined by the stage and size of the tumour. If the disease is detected at an early stage, the tumour can usually be surgically removed.

Stage I: The tumour is only present in the cervix.

Stage II: The tumour has spread outside the cervix to the supporting tissue around it, or to the upper part of the vagina.

Stage III: The tumour has infiltrated the pelvic wall or the lower part of the vagina.

Stage IV: The tumour has infiltrated the bladder, into the rectum, or has spread to other parts of the body.

Any spreading to the lymph nodes will be assessed separately.

Surgery

Conization

Conization is performed during the early stages of cancer development (high-grade cell changes) in the cervix. This is a surgical procedure where a small, cone-shaped wedge of the cervix is removed. Usually, cancer cells can only be detected through a microscope. Conization is usually performed using a loop electrosurgical excision procedure or a laser, and is often done with a local anaesthetic. The surgery normally takes five to fifteen minutes.

Simple hysterectomy

A simple hysterectomy is a procedure where only the uterus and cervix are removed.

Radical hysterectomy

A radical hysterectomy (Wertheim-Meigs operation) is the most common surgical procedure for cervical cancer. Here, the uterus, cervix and surrounding tissue, as well as the upper part of the vagina, are removed. Pelvic lymph nodes are also removed. This procedure is used when the tumour is only present in the cervix. Usually, this procedure will be

performed as an open surgery (laparotomy). Only certain patients will undergo keyhole surgery (laparoscopy or robotic surgery).

Radiation therapy following surgery may be necessary, depending on the results of the surgery. You will be informed of whether or not you need radiation therapy a few weeks after the surgery. Radiation therapy after surgery is done to reduce the risk of recurrence. If the lesion in the cervix is still present and has not spread after radiation therapy, a radical hysterectomy may be considered.

Radiation therapy and chemotherapy

Treatment with chemotherapy has different purposes:

- Full recovery
- Reduce the tumour to a size smaller than before surgery or radiation therapy
- Kill cancer cells that may be found elsewhere in the body after surgery or radiation therapy
- Keep the disease at bay and reduce symptoms caused by the tumour

In cases where the tumour is large or has deeply infiltrated the cervix, or has spread to the lymph nodes (Stages Ib2–IV), the patient will receive a combination of radiation therapy and chemotherapy. Radiation therapy is also used when the tumour has spread outside the cervix, often in combination with chemotherapy.
In radiation therapy, a combination of external and internal radiation is used. Chemotherapy is administered weekly during the external part of radiation therapy, which will help increase the effect of radiation therapy.

Once the disease has spread outside the pelvis (Stage IVb), chemotherapy is usually administered, sometimes in combination with Bevacizumab, a substance that inhibits abnormal blood vessel formation to the tumour. Radiation therapy can also be used to alleviate symptoms or to impede tumour growth.

Side effects

Different types of chemotherapy can give different types of side effects, which vary from person to person.

Common side effects of chemotherapy during active treatment include:

- Nausea
- Fatigue
- Hair loss
- Weakened immune system

Radiation therapy leads to reactions in the mucous membranes, skin and urinary tract to a greater or lesser extent during and after gynaecological radiation therapy. Many find that their skin reddens in the irradiated area. Some may look sunburned and their skin may become sore. Learn more about this in the section Late effects.

Fertility-sparing surgery (trachelectomy)

Fertility-sparing surgery is offered to some young women who have a strong wish to preserve their ability to have children. The tumour must be no larger than 2 cm and limited to the cervix. It must not have spread to the lymph nodes, and these are often removed during a keyhole surgery prior to the trachelectomy. The trachelectomy itself, where a larger part of the cervix is removed, is done through the vagina. In some patients, a type of band called a cerclage will be inserted around the remaining part of the cervix to keep it closed. If the woman later gives birth, the baby must be delivered by Caesarean section. Only when the final results of the surgery are available will you receive a final answer as to whether any type of post-treatment is necessary.

Targeted therapy

In 2020, Avastin® (Bevacizumab), which is a monoclonal antibody, was approved for the treatment of advanced cervical cancer and for recurrence of cervical cancer. Avastin is a targeted therapy.

Treatment of recurrence

In the event of a recurrence of cervical cancer after radiation therapy, where the goal was to ensure a full recovery, it may be necessary to undergo a surgical procedure. Here, an extensive operation may be necessary, where other pelvic organs (e.g. the bladder or rectum) must be removed.

Check-ups

Normally, check-ups are recommended every three to six months for two years, and thereafter every six months for a total of five years. Follow-up after completion of treatment must be adapted to the individual, depending on age and general condition and on the risk of recurrence where curative treatment can be offered. It is the doctor who is responsible for treatment at the hospital and who will outline a plan for follow-up and check-ups afterwards.

Follow-up visits for patients treated for cervical cancer are generally scheduled as follows:

- First year: check-up every 3 months
- From the 3rd to the 5th year: about every 6 months
- After 5 years: yearly check-ups

Examples of different dilator kits. Both can be requisitioned via NAV, and all doctors with Norwegian authorisation can order or requisition these kits.

Late effects

Both the body's cells and organ functions may be affected by cancer treatment. Side effects and late effects will vary from person to person, depending on the type of treatment, your age and general condition, and on any other illnesses you may have.

Infertility

Both surgery to remove the uterus and radiation therapy will result in infertility. After surgery, some women may also experience difficulties in emptying their bladder, as there may be nerve damage. These problems are often temporary.

Radiation-induced injuries

Gynaecological radiation therapy may result in dry, sore and irritated mucous membranes in the genital area. This may lead to bleeding, increased discharge, foul-smelling discharge, swelling, infection and pain. Radiation therapy may made the vagina less elastic and it may cause the walls of the vagina to stick together if you do not use a dilator or have sexual intercourse. The vagina may also be shortened.

It is common to experience pain during intercourse and vaginal dryness after radiation therapy for cervical cancer. You may also feel less sexual desire and have less interest in sex due to the side effects of radiation therapy. Women who have undergone radiation therapy to the vagina have a higher risk of adhesions due to damage to the mucosa. To prevent the vaginal walls from sticking together after radiotherapy, you should use a vaginal dilator kit if you do not resume sexual intercourse the first few months.

The purchase of sexual assistive devices for this purpose is covered by NAV. NAV has a separate form for this, and any doctor with Norwegian authorisation can order or prescribe a dilator kit and other assistive devices from authorised suppliers who have an agreement with NAV.

Dry vaginal mucous membranes may be remedied by hormone tablets, vagitories, or special lubricants.

Talk to your doctor, a sexologist, or a counsellor to learn more about the medical aids and devices you can use.

Radiation-induced injuries to the bladder

The bladder and urinary tract are located close to the radiation field. Radiation therapy may irritate the mucous membranes of the bladder, causing problems that resemble cystitis, with frequent urination, burning, pain and bleeding. Usually, these problems will gradually improve. However, the bladder may become more stiff and less elastic, which may lead to a frequent urge to urinate, burning, pain, and the feeling that you cannot empty your bladder.

Radiation-induced injuries to the gastrointestinal tract

Some women may experience gastrointestinal problems, often in the form of diarrhoea, gas pain or food intolerance. Around 15 percent experience persistent diarrhoea, either mild or severe, and intestinal bleeding may occur. Around 5 percent develop a fistula of the bladder or intestines, or intestinal stenosis, which will require surgery. There is ongoing research on methods of improving radiation therapy to reduce radiation to healthy tissue. This would ensure a higher targeted dose to the tumour while reducing side effects.
A clinical dietician can provide good advice.

Lymphoedema

Around five percent of women treated for cervical cancer will develop lymphoedema. This is especially the case for patients who have had lymph nodes in the pelvic region removed during surgery. Your doctor can refer you to a physiotherapist with expertise in the treatment of lymphoedema. Radiation therapy after surgery increases the risk of lymphoedema.

Menopause

After radiation therapy to the pelvis, younger women may enter an artificially produced menopause, because radiation to the ovaries halts hormone production. In cases where the ovaries are removed or put out of action, this will lead to an abrupt menopause in women who have not yet entered this phase.

This is a process that normally occurs over a long period of time, where the woman gradually loses hormones produced in the ovaries.

- Less oestrogen results in less moisture in the mucous membranes, which may make sexual intercourse painful.
- If your body is no longer producing testosterone, this may affect your sex drive. Many will notice reduced libido and with less interest in being sexually active. You may experience fewer sexual dreams and lack of interest in sex, but will still feel the need for intimacy.

Studies show that women who have had their ovaries removed can continue to enjoy a sex life similar to other women in the same age group. It is important to find the right hormone treatment adapted to the individual. Counselling and therapy, preferably with a partner, can also be helpful.

Fatigue

Fatigue is a frequent side effect of radiation therapy or chemotherapy. Around 10 to 35 percent of cancer patients experience fatigue. This is a feeling of exhaustion that does not improve with sleep or rest. There is no quick and effective cure for this. Many patients find that this gradually subsides after a shorter or longer period.

Fatigue that lasts more than six months after the end of treatment, when there are no longer signs of active disease, is called chronic fatigue. Those who experience fatigue may also feel depressed, have trouble concentrating, have trouble with short-term memory, and will generally have little energy.

Fatigue that arises within a limited period of time and subsides when treatment is finished is called acute fatigue.

Rehabilitation

Municipal health services are responsible for providing rehabilitation where you live. Most municipalities offer multidisciplinary services, with an occupational therapist, physiotherapist, nurse and social worker. Should you need assistive devices or adaptations to your home, the municipality can help you with this.
Although municipalities and health trusts are still developing local and regional rehabilitation services, many patients have found it helpful to participate in a rehabilitation programme with other cancer patients spanning several weeks. Such programmes provide a good atmosphere and group dynamics.

By participating in a rehabilitation programme after cancer treatment, you can meet others who are in a similar situation. These programmes also offer better insight and tools to help you adjust to your "new life". Most patients find that life is not quite the same as before. Rehabilitation programmes are also for patients who had cancer many years ago, and who are still struggling with the long-term effects of treatment.

At www.helsenorge.no, you can find more information about rehabilitation services and how to apply. Search for "rehabilitering kreft" ("rehabilitation cancer") and your region or health trust.

Many municipalities have local cancer coordinators who have an overview of the services and opportunities in your local area. Here you can find an overview of municipal cancer coordinators:

www.kreftforeningen.no/tilbud/kreftkoordinator-i-kommunen/

See our website for an overview of rehabilitation services
www.gynkreftforeningen.no/2022/01/rehabiliteringstilbud/

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 cervical cancer ensures that all hospitals treating this specific type of cancer will have regular decision-making meetings with a multidisciplinary team (MDT) to ensure quality assurance of assessments and treatments. The multidisciplinary team who assess and treat cervical cancer consists of gynaecologists with specialist training in gynaecological oncology, oncologists with radiotherapy expertise, radiologists, pathologists and a care pathway coordinator.

Learn more about patient care pathways for diagnostics, treatment and follow-up of cervical cancer.
See www.helsedirektoratet.no/pakkeforlop/livmorhalskreft

CURRENT RESEARCH

The results of two significant studies in immunotherapy were published in 2021. In one study (Keynote 826), patients with advanced or recurrent cervical cancer received chemotherapy with or without pembrolizumab, which is a known immunotherapy drug. The study showed that this drug delayed recurrence (10.4 months with pembrolizumab versus 8.2 months without pembrolizumab), and also prolonged survival among patients in the group receiving the checkpoint inhibitor pembrolizumab. This study was published in the New England Journal of Medicine this autumn, and the medical community has submitted the method for assessment upon introduction to Norway.

In Norway, we have participated in a similar study (Beatcc/ENGOT-Cx10) that ended by including patients last year, and we look forward to learning of the results. The second study was called EMPOWER and has so far only been published at an international conference. Here, patients with recurrent cervical cancer received treatment with either checkpoint inhibitors or non-platinum-based chemotherapy. Patients lived longer when receiving immunotherapy (12.0 months of immunotherapy versus 8.5 months of

chemotherapy). It must be said that only about 15–20 per cent of patients will benefit from the treatment. However, for those who do benefit, immunotherapy can have a long-lasting effect and provide a good quality of life during treatment. The medical community is looking forward to the published study and hope that the results will contribute to a change in practice here in Norway.

Other studies on immunotherapy are also continuing here in Norway:

HPV16 vaccine in combination with immunotherapy for patients with cervical cancer

This study is looking at the effect of giving patients with advanced cervical cancer a combination of the immunotherapy drug atezolizumab and an HPV16 vaccine.

There are certain criteria for including patients in the study. They must have a persistent, recurrent or metastatic (metastasis means that the cancerous tumour has spread to other parts of the body), unresectable (cannot be removed surgically) cervical cancer that can no longer be treated with chemotherapy, radiation therapy or other standard form of treatment. The tumour must be HPV16 positive. Patients in the study are given an HPV16 vaccine and regular immunotherapy for a maximum of 48 weeks. The study hopes to find that the cancer will regress in 30 percent of the patients. This study will probably end by the spring of 2022.

Immunotherapy in combination with radiochemotherapy for cervical cancer

The aim of the study is to find out whether immunotherapy with Keytruda pembrolizumab can delay recurrence and prolong survival compared with radiochemotherapy alone. The study includes patients in whom the cancer has spread through the pelvis or lymph nodes. The study is important for clarifying whether the immunotherapy can be used at an even earlier phase of treatment.

CLINICAL TRIALS AND APPROVAL

Clinical trials

Clinical trials must always be conducted before a new drug or treatment method can be approved for use. In these trials, drugs are tested on patients with the disease in question. Participation in a clinical trial is not a right, and it is always voluntary. Participants in clinical trials are given the opportunity to test new medicines, which will contribute to better knowledge and research progress. Generally, the physician responsible for the patient's treatment will have an overview of relevant clinical trials, and can therefore request that the patient is considered for participation in the trial at the hospital conducting the study.

Occasionally, a patient will come across a clinical trial. Patients can also contact the physician in charge of the study directly. Patients participating in a clinical trial must always fit the criteria set by the researchers for the study, such as the appropriate age, diagnosis and prior treatment.

An updated overview of current clinical trials in Norway can be found at helsenorge.no, or on the websites of various university hospitals.

You can also check the website of the Norwegian national centre of competence for gynaecological oncology:

www.oslo-universitetssykehus.no/fag-og-forskning/nasjonale-og-regionale-tjenester/nasjonal-kompetansetjeneste-for-gynekologisk-onkologi

Impress-Norway

IMPRESS-Norway is a large Norwegian study open to all patients with advanced cancer who have undergone standard treatment and have no remaining treatment options. IMPRESS was initiated in early 2021. It's aim is to offer extended molecular diagnostics and potential targeted treatment for several Norwegian cancer patients. This is done by taking drugs that are already approved for certain cancer diagnoses and applying these to other types of cancer, based on genetic changes in the cancer cells (molecular profile). Patients who are referred to these clinical trials undergo a screening process, where their cancer cells are examined for more than 500 genes to determine molecular or genetic alterations. If genetic alterations are identified that would have a consequence for treatment recommendations, this is discussed at a national meeting for the research group, held weekly. If the patient is eligible for another ongoing clinical trial in Norway, they will be referred to this study. If a molecular profile is identified that is suitable for a drug through the IMPRESS study, the patient may be assessed for inclusion in an IMPRESS clinical trial. A separate treatment arm will then be created for this specific combination of diagnosis, genetic alteration and drug therapy.

Expert Panel

In 2018, the Norwegian regional health authorities established an Expert Panel scheme. The aim of the Expert Panel scheme is to provide patients who have a life-shortening disease with a new and thorough assessment of treatment options, after established treatment has been attempted and is no longer effective. One important aspect of the Expert Panel is to help patients and their family members feel secure in knowing that all relevant treatment has been considered. The physician in charge of the patient's treatment can request a new assessment by the Expert Panel.

The Expert Panel will assess and advise on the following:

1. Assess whether adequate established treatment has been provided, or if further established treatment is appropriate, either in Norway or abroad.
2. Assess and advise on whether there are relevant clinical trials or experimental treatment in Norway or abroad, preferably in the Nordic region. Experimental treatment must be within approved protocols with criteria for participation and documented effect.
3. Assess and possibly advise on off-label treatment with drugs that have a documented effect. Off-label refers to marketed drugs that are used to treat diseases for which the drugs have not been approved.
4. Assess and possibly advise on undocumented treatment that the patient has obtained information about and wishes to have assessed.

Approval of new medicines

In Europe, a medicine is first approved by the European Medicines Agency (EMA), which grants European marketing authorisation for the medicine. The medicine must then be granted Norwegian marketing authorisation (MT) by the Norwegian Medicines Agency (SLV). In order for an approved drug to receive public funding as a "blue prescription", or for use in hospitals, it must be value assessed. This process can take time, and it is not always easy to gain a good overview of the process. Medicines that are to be financed by hospitals must be sent for assessment by the Norwegian Decision Forum for new health technologies with specialist health services in Norway. This is governed by the four regional health authorities. This Decision Forum is comprised of the directors of the four regional health authorities. It is these four individuals who decide which methods specialist health services can or cannot use. Once the Decision Forum has approved a drug, it can be used by the hospitals. This process takes time. Figures from 2018 show that it takes an average of 333 days from the time a drug has been granted marketing authorisation in Norway until it can be introduced for use. The National System for Managed Introduction of New Health Technologies is currently under evaluation, partly due to criticism of its use of time.

May had cervical cancer

May Slettan (age 55) had struggled for years with cervical cell abnormalities and had undergone frequent smear tests. Nevertheless, she was unprepared for the cancer diagnosis in 2016.

Before May was diagnosed with cervical cancer, she had experienced medical issues for years. She had several miscarriages in her twenties, but the pregnancy with her first child in 1987, when she was twenty-one, was normal. At the age of twenty-five, she lost a child in week 20 due to a cervical failure, and during her pregnancy with her third child, when she was twenty-seven, she had to remain in bed with a cerclage.

Losing the child she had carried has has a strong impact on her life. From age thirty-five to fifty, she had frequent visits to her GP due to cell abnormalities, and she often experienced bleeding after sexual intercourse. In 2011, she underwent a conization for the first time. All the problems she had experienced led to several lengthy sick leave periods, but in the summer of 2016, she had been given a summer job at a nursing home and felt that she was well on her way back to work. After her annual check-up with the gynaecologist, she was told she had to have a new conization. During conization, cancer cells were detected in the sample. Things happened fast.

Tough to get a cancer diagnosis

“I was totally unprepared for the cancer diagnosis. It was a shock, like being given a death sentence. My whole body went into crisis mode. Luckily, I was at work at the nursing home when the call came, and my colleagues all gathered around to support me.”

After three weeks, May underwent surgery. She was then fifty, and asked the surgeons to "remove everything" during the robot-assisted keyhole operation. In addition to the cervix, uterus and ovaries, the surgeons also removed several lymph glands.

"The operation went as expected, but it's a major procedure and I needed time afterwards to recover. It also takes some extra adjustment to cope with the menopause that kicks in after an operation like this. When I went home from hospital two days after surgery, I was told that in two weeks I could start doing everything I normally do. But for me, it took more than two months before everything felt like it was back to normal and I was no longer in pain.”

Her job as a nursing assistant at the nursing home also became difficult during this time, as it was not possible to return to heavy lifting after such a short time. Eventually, May returned to work and a normal daily life.
“I wasn't really too worried about anything else happening.”

Relapse

Throughout the following year, May regularly attended check-up with a gynaecologist. In 2017, the gynaecologist found something during examination. Several tests were taken and she was sent to St. Olav's Hospital for further testing under anaesthesia.

"At that point I had found my dream job. I was hired for a temporary position as a pastor, and planned to combine work with an education in theology. But then came the relapse, which was a huge let-down – to put it mildly." Everything was put on hold.

May received daily radiation therapy and weekly chemotherapy for six weeks. She had four internal radiation sessions.

A difficult time

"For me, this was a time I did not enjoy. It was hard to deal with everything the treatment did to my body, and I was always worried about whether the cancer would go away. It was a good idea to stay at the patient hotel, because the treatment made me so tired. This worked well for me, and I also became familiar with Pusterommet ("the breathing room"), and Vardesenteret in Trondheim, which made it possible for me to get some exercise with guidance from a physiotherapist."

After two rounds of treatment, May is cancer-free, but worries before check-ups, and the late effects of treatment still impact her life.

After the treatment was finished and May returned home, there were new problems.

"I couldn't bear to think about my genital area. I was burned from radiation therapy. I knew in my head what I should be doing, and I had attended a course led by a sexologist, but I couldn't do anything about it. I became

completely apathetic. The apathy meant that my genitals also started sticking together."

Pre-check-up worries

After the second round of treatment, May was declared cancer-free. She still worries before each check-up. When she is very tired, she feels various aches and pains, and she worries that it may be a new tumour.

Late effects of the treatment she went through has affected her everyday life. During the first six months, she experience significant fatigue, but this has improved. Radiation to the pelvis has led to some bowel problems. She experiences "urge" difficulties, which means that when she needs to use the toilet, she has no time to lose. She has also noticed changes in her urinary tract, with frequent leakage.

Involvement in the Norwegian Gynaecological Cancer Society

Prior to the Covid-19 pandemic, May was busy with her pastor training, which included living in a dormitory in Oslo where she was studying. Commuting between school and home in Ørlandet went fine until Covid hit.

"It became more and more challenging for me to be a master's student in 2020, I felt trapped, and eventually I had to apply to take a break in my studies. My goal is still to complete my education. But right now I find it extremely helpful to be involved in the Norwegian Gynaecological Cancer Society. It has given me inspiration and a sense of usefulness to be a user representative in various projects through the Gynaecological Cancer Society. I am working to make sure that more women get the information they need, whether it's about rehabilitation, long-term effects, rights or treatment."

The content of this brochure has been quality assured by Kristina Lindemann, senior consultant at the Department of Gynaecological Oncology, Oslo University Hospital.

Peer support services

Through our peer support services, those who have or have had cancer, and their family members, have the chance to talk to someone in the same life situation. The principle of peer support is that people who have been ill themselves can share their experiences with others, yet at the same time be a person who understands and provides support outside the healthcare system. We have certified peer support persons all over the country. Most are patients themselves, but some are also family members. All of our peer support persons have a duty of confidentiality.

You can contact our peer support persons directly.
See the overview of all peer support persons on our website:

gynkreftforeningen.no/likepersonstjenesten

Sources:
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About the Norwegian Gynaecological Cancer Society

The Norwegian Gynaecological Cancer Society is a patient association for women who have or have had gynaecological cancer, women who have been treated for gynaecological precancerous conditions, and women who have been diagnosed with a genetic risk of gynaecological cancer, and their family members. The Norwegian Gynaecological Cancer Society has over IOOO members. We have local chapters and peer support persons all over the country, and our association is run by volunteers – women who have or have had gynaecological cancer. Our main focus is the patient and generating knowledge about what should be improved in healthcare services with regard to treatment, rehabilitation and follow-up.

Join our community – become a member of the Norwegian Gynaecological Cancer Society:
gynkreftforeningen.no

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