

For those who have vulval cancer

(Cancer of the external genitalia)



Causes,
symptoms,
treatment
and research

Each year, 1700 Norwegian women are diagnosed with a form of gynaecological cancer. Around 110 of them have cancer of the external genitalia, or vulval cancer. Most of these women are over the age of 70, while roughly 10 percent are under 50 when they are diagnosed.

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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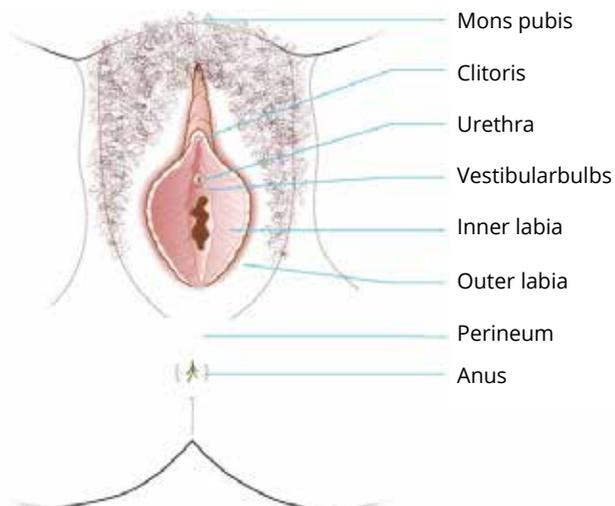
110

women in Norway are
diagnosed with vulval
cancer each year

Vulval cancer is a rare form of cancer. In older women, the conditions is often confused with the skin disease lichen sclerosus et atrophicus (a chronic inflammatory dermatosis commonly affecting the skin and mucous membranes around the genital organs – see a more detailed description in a separate section). Among younger women, there is an incidence of another type, often related to the human papillomavirus (HPV).

External female genitalia (vulva) include:

- outer labia (labia majora)
- inner labia (labia minora)
- perineum
- mons pubis
- vestibular bulbs
- Bartholin's glands
- urethra
- clitoris



Bartholin's glands (not illustrated here) located on each side of the vaginal opening, are two glands that secrete fluid.

Vulval cancer encompasses several different types, subgroups, and stages of development. The same disease will differ from patient to patient, and will require an individual treatment programme. Most cases, 85 percent, of cancer of the labia are squamous cell carcinomas (malignant tumour of epithelial cells found in the skin, mucous membranes or the glands).

Causes and prevention

Symptoms will vary from person to person, depending on where the disease is located and whether it has spread to other parts of the body. Symptoms are localised to the area around the vaginal opening.

Typical symptoms include:

- Itching, burning, soreness, pain
- Open wounds that do not heal
- A lump or nodule-like growth
- Rash
- Changes in skin colour
- Thickened patches of skin, often with pigment changes (white and dark spots)
- Bleeding wound

The symptoms of vulval cancer may be indistinct and can often be confused with other conditions, such as a yeast infection. If symptoms persist, you should not wait to contact your doctor. You can also ask to be referred to a gynaecologist.

Lichen sclerosus et atrophicus

Lichen sclerosus is a rare skin disease that attacks the mucous membranes of the female genital organs. This disease usually starts as white streaks in the skin. Eventually the skin will look patchy and shiny like cellophane. The disease causes the skin to become tight and hard, with a thin, translucent surface. The symptoms, which consist of the skin changes, develop slowly over time. Spontaneous bleeding may occur in the skin. Skin irritation and itching is often present, and sometimes soreness and burning that can impede sexual activity. Initial treatment consists of strong, local cortisone ointments, which are effective in most patients. Maintenance treatment once or twice a week is often necessary to prevent a recurrence. The disease is chronic, although the rash activity may cease and the condition will enter a more dormant phase. Cancer may develop from these skin changes, which appear as sores or nodules. The disease often develops into a precancerous condition (vulval intraepithelial neoplasia, or VIN).

The cause of lichen sclerosus is unknown. It is not an infection, and the condition cannot be transmitted through sexual contact.

Symptoms

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Assessment

Assessment of vulval cancer is often done through a gynaecological examination with a local anaesthetic. The size of the tumour is determined and lymph nodes in the groin are also examined. A tissue sample (biopsy) of the tumour is taken, along with a cell sample from the cervix. The mucous membranes of the external genital organs will also be examined using a special microscope (colposcopy).

Other examinations: CT of the abdomen, pelvis and lungs may be relevant. An MRI of the pelvis is often performed.

Vulval cancer is divided into the following stages:

Stage I: The tumour is limited to the vulva and has not spread to the lymph nodes.

Stage II: The tumour has spread to the surrounding structures (lower one-third of the urethra, vagina or anus), but without spreading to the lymph nodes.

Stage III: Spreading to the lymph nodes of the groin. The tumour is localised to the external genitalia regardless of size, or it has spread to the surrounding structures as indicated at Stage II.

Stage IV: The tumour has grown to the upper two-thirds of the urethra or vagina, has infiltrated the bladder, into the rectum, or it has spread to other places in the body.



A biopsy is a tissue sample taken from the tumour to determine whether there are any pathological changes. A diagnosis can be made once the cells are examined under a microscope.

Treatment

Vulval cancer will differ from patient to patient, and will require an individual treatment programme. Treatment of vulval cancer depends on how far the disease has spread. In many cases, the disease is detected early, which greatly improves the chance of successful treatment.

For precancerous skin conditions (VIN), laser treatment is used to remove abnormal cells. If these have developed into cancer, the surgical removal of part or all of the labia (vulvectomy) is often the most appropriate form of treatment. Radiation therapy and chemotherapy are common forms of treatment for cancer that has spread. Women with vulval cancer are treated at in the specialised unit for gynaecological oncology at one of the university hospitals in Norway.

Surgery

The extent of the surgical procedure depends on the size of the tumour and where it is located. During surgery, surgeons will remove the entire cancerous area, as well as some of the surrounding healthy tissue. Usually, some or all of the labia will have to be removed. For certain patients, it may also be necessary to remove the clitoris. The surgery is done under general or spinal anaesthesia.

In most cases, surgeons will also remove lymph nodes on one or both sides of the groin. These lymph nodes will be examined by identifying the sentinel lymph node, which is the first lymph node that could possibly receive cancer cells from the primary tumour. If the sentinel lymph node does not contain cancer cells, it means the other lymph nodes in the groin are most likely free of cancer cells. A sentinel lymph node technique involves injecting a dye that follows the lymphatic pathway and illuminates any cancer cells. If there are no signs of cancer cells, surgeons will usually only remove one or two lymph nodes. However, if the tumour is larger than four centimetres, or if metastases to the lymph nodes is suspected, all of the lymph nodes in the groin will be removed.

Radiation therapy

This may be appropriate in certain cases, also when the cancer has spread to the lymph nodes in the groin. Radiation therapy can be used as an alternative to surgery if the patient is elderly, has additional health problems, or if surgery would be too invasive, for instance, if the tumour has infiltrated the urethra, vagina or rectum. A weekly, smaller dose of chemotherapy is often administered along with radiation therapy.

Chemotherapy

Chemotherapy is rarely given, but it may be appropriate if the cancer has spread, if the cancer is recurrent, or in cases where the disease is only being treated with radiation therapy because surgery is not an option.

Side effects of chemotherapy

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

Check-ups

Follow-up after completion of treatment must be adapted to the individual, depending on the risk of recurrence, age and general condition. 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 vulval cancer are generally scheduled as follows:

- First year: check-up every 3 months
- Second year: check-up every 6 months
- From the 3rd year – annual check-ups

At each check-up, the doctor will usually perform a thorough examination and ask you how you are doing. The doctor will also feel for lymph nodes. A colposcopy will be performed (microscopic examination of the outer part of the vagina). Should there be any suspicious changes, samples will be taken of the outer part of the vagina (biopsy).

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, age and general condition, and on any other illnesses you may have.

After treatment for vulval cancer, it is common to experience gastrointestinal problems, lymphoedema, reduced libido, and vaginal dryness.

Sexual complications

Treatment for vulval cancer may result in sexual complications, such as:

- Pain during sexual intercourse
- Reduced desire for sex and ability to achieve orgasm
- Negative effect on sexual self-concept

After surgery, most women will feel swollen and sore, with discomfort in the genital area for a shorter or longer period. The external genital organs will have a different appearance than before surgery, for instance, if the labia have been removed. It may be difficult to adjust to these changes, and it may cause some concern. It can take several weeks for the wounds to properly heal. After treatment, many women experience problems, especially if much of the skin was removed during surgery. The vaginal opening may be smaller and the skin around the opening may be tighter. Some may experience thinner skin that is tender and itchy. These problems may be less pronounced over time, but not always. For some women, a vulvectomy may lead to problems with sexuality and sexual intercourse, and both the woman and her partner may have psychological reactions.

Sexual intercourse is discouraged until the wounds have completely healed. In many cases, it may be physically possible to have intercourse, but if the clitoris is removed, orgasm may be difficult to achieve.

It is not uncommon to need time to regain the energy for, and interest in sex. This is for physical, hormonal and/or psychological reasons, and may be due to the stress and strain you have been through, and that you are exhausted. Take your time, be patient with yourself and your partner, and be open about the problems. Start addressing these issues early, and talk to your partner, a sexologist, or a counsellor.

Ask your doctor about aids you can use. These may include:

- Lubricants
- Local oestrogen applied to the vagina will strengthen mucous membranes
- Testosterone replacements
- Vibrator

Early menopause

Women who have not reached menopause may experience early menopause due to radiation therapy, which may affect the ovaries. This is a process that normally occurs over a long period, 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 or uncomfortable.
- It is common to experience hot flashes, dry and sore mucous membranes in the vagina, and mood swings. You may also experience fatigue, sadness, depression, poor appetite and hair loss.
- If your body is no longer producing testosterone, this may affect your sex drive. Many will notice reduced libido and 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.

It is important to get the right hormonal treatment, adapted to your individual needs.

Radiation-induced injuries to the vagina

Many women experience pain during intercourse and vaginal dryness after gynaecological radiation therapy. Lack of sexual drive and interest in sex due to these problems is common. Women who have undergone radiation therapy to the vagina have a higher risk of vaginal adhesions due to damage to the mucosa. To prevent the walls of the vagina 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 all doctors with Norwegian authorisation can order or prescribe these devices. The form should be sent directly to the approved supplier (not via the local NAV office), and the device will be sent in a discrete package to the user within a few days.

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

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

After radiation therapy, your body will need time to heal from the wounds to the healthy tissue. The effect of radiation will continue for several weeks after treatment, and it will therefore take time for the side effects to subside.

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. If radiation damage to the bladder is confirmed, you could try hyperbaric oxygen therapy. Talk to your doctor about this.

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. If radiation damage to the gastrointestinal tract is confirmed, you could try hyperbaric oxygen therapy. Talk to your doctor about this.

Nerve damage (polyneuropathy)

Chemotherapy may in some cases cause minor damage to the nerves, especially in the fingers and feet. These symptoms may appear gradually during treatment, but will often subside once treatment is concluded. Sometimes these symptoms persist or become chronic. Such nerve damage is often described as numbness in the fingers and under the feet, or a stinging, burning sensation.

Lymphoedema

Lymphoedema is a swelling in one or both legs, as the lymphatic system is unable to properly drain fluid from the body. Some patients will experience this after surgery. This is especially true 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.

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.

Concentration

After chemotherapy (especially with Cisplatin), some patients may experience difficulties with attention, concentration, memory and problem solving. For many, this will improve over the course of a year, but some will experience persistent problems.

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. There is no specific patient care pathway for vulval cancer, but patients with suspected cancer will be referred for an assessment by specialist health services.

Learn more about patient care pathways at www.helsedirektoratet.no





CURRENT RESEARCH

There are research studies that are initiated by either pharmaceutical companies or by physicians. These include larger international studies with study centres in many different countries. Since vulval cancer is rare, there are few studies specifically aimed at this specific type of cancer. However, Norwegian patients are occasionally given the opportunity to participate in studies where experimental drugs are tested against standard treatment, such as chemotherapy. Some of these studies take place at university hospitals, which may require travel if the patient does not live nearby. You can find information on all applicable studies on the website of the Norwegian Gynaecological Oncology Research Group, which is a national centre of competence for gynaecological oncology. In addition to pharmaceutical studies, there are other studies where women with gynaecological cancer are invited to participate. This may involve quality of life studies, or studies on long-term side effects of treatment. Patients are encouraged to accept invitations to participate in such studies, as it will give us more knowledge of vulval cancer and long-term effects.

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. Its 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.

Tone is living with vulval cancer

“After more than 50 biopsies and countless surgeries, I have become my own expert. I know how important it is to have follow-up by the same doctor. My doctor must know me and my history. With my diagnosis, I have had to take responsibility for my own body,” says Tone Nikolaisen (age 43) from Stavanger.

In 2013, Tone was diagnosed with the skin disease lichen sclerosus et atrophicus. She had the typical symptoms, largely similar to that of vulval cancer: itching, burning, fissures, sores that would not heal. In addition, she had very fragile, thin, whitish skin. This did not fit with the plans she and her husband had to have a second child. The medicines she was given were ineffective, and her gut feeling was that she did not only have lichen sclerosus.

“Vulval diseases and the symptoms that come with it means that you end up between the gynaecologist and dermatologist. Unfortunately, this also means that examinations and assessments take much longer, frustratingly enough.

After a long assessment period and various diagnoses, Tone eventually became pregnant while still undergoing examinations at the hospital. There were constantly new findings. It was finally determined, after the baby was born, that she should undergo surgery. She would be having a skinning vulvectomy, which would remove the upper layer of vulval skin, which would then be sewn together



“My story touches many aspects of my life. My cancer diagnosis and lichen sclerosus makes it impossible for me to forget what I’m living with. I think it’s important to be open. I’m not ashamed.

again in a horseshoe shape. Several biopsies were taken over a six-month period. Her skin was paper-thin, with sores and fissures. Analyses of the biopsies indicated the presence of squamous cells. She suddenly also had HPV-16 related cell changes. During this period, the doctors

were clearly uncertain, because Tone received different messages.

“I was told I had cancer, that I had different types of VIN (vulval intraepithelial neoplasia), both uVIN and dVIN, which are basically different forms of VIN. uVIN is HPV-related, while dVIN is not HPV-related, but more lichen based. This was confusing, and I thought, this can't be right. No one could have all of this?!”

Tone was sent for a second opinion, which determined that she had cancer in two different places. She had it at the time of her surgery in the summer of 2017, but also six months earlier. After she was diagnosed with vulval cancer, a partial vulvectomy was performed on one side to remove the cancer.

Frequent surgeries and examinations

“After the cancer surgery, I was left with lichen sclerosus, which I'll have for the rest of my life. The main problem for those of us with this condition is that the skin almost melts together, which means it can almost fuse. I also have a HPV-16 virus that won't leave the vulva, and this is the most aggressive kind in terms of cell changes and cancer. I am constantly attending check-ups and having biopsies to check for cell changes in different areas of the skin. If there are any changes, VIN2 or VIN3, the skin has to be removed. All of these surgeries have resulted in the removal of an enormous amount of skin. Practically all of my female anatomy is gone. In 2021, I had two operations, and the year before I underwent three. That was just in the last two years.”

Because Tone's vulva is constantly changing, she stay updated on how

things look by photographing her body, and has been doing this since 2015. This way, she keeps up to date on how things look and can use the photos when talking to doctors at check-up appointment or with the surgeon before new surgeries.

“I also keep a journal on my use of medicines, and my surgeries and biopsies. Discussions can often be confusing for both me and my doctors.”

The patient knows best

After many years with surgeries and examination, she has gained a great deal of experience and knows her body well. The surgery she underwent in the summer of 2021 involved the laser treatment of a large area, with the surgical removal of two areas, just as she had felt would be necessary. The plan was to “only” laser half of her vulva, but the doctors agreed that given the duration and structure of a wound, it had to be removed along with a lump.

“But you have to get to know your own genitals and know what is normal. No one else can do that! Every night it's me, my medicines and the mirror. Now I know when something is wrong and can tell the surgeon what I think should be done.”

Over the years, Tone has had to deal with many different doctors. Now, she will only allow herself to be treated by those who know her well.

Daily challenges

“A vulvectomy is a procedure where the most sensitive parts of your body are cut away. This involves some nerve damage.

So not only do I have to deal with this, I also have had to learn to live with lichen sclerosis, which comes with its own daily challenges. Pain medications, of different types, are my best friends, closely followed by strong steroids in the form of ointments, oils, barrier creams and lots of new underpants and other leg wear. I must always make sure to avoid friction. This also means that I drive with a pillow and often have to lean back when sitting on a chair. My luxury in life is the purchase of surgical gloves, because I have to clean myself with oil after each toilet visit.”

Tone has come to terms with what her life has become, including surgeries and frequent doctor appointments. She no longer believes things can get better, but hopes that her condition does not worsen. And maybe one day, the HPV-16 virus will burn out and disappear.

Active life – with adjustments

Despite all the challenges, Tone is a working mother of two who lives an active life – with adjustments. She can keep working thanks to a flexible work schedule and an understanding boss. She is well aware of the kind of activities she can participate in with her family. Activities that could lead to wounds and tearing are not possible.

“Sometimes I go swimming – I can do that with some vaseline. Cycling is not possible. The same with jogging. This means that I can't run after the kids when they're on their bikes. Walking in the woods is also difficult, but sometimes I join them, even though I know I'll have problems afterwards.”

Tone has chosen to be open about her cancer diagnosis and life with lichen sclerosis.

“The kids feel insecure when I have to go away for surgery. I've explained to them that I have cancer, and they know that mum's private parts are ill. I have also chosen to be open with the neighbours, school and preschool, so that they can take extra good care of the kids while I'm in hospital.”

Yes to openness!

In 2017, Tone started a Facebook group for women with lichen sclerosis, where she told her story. Later, she found another similar Facebook group, and the two groups merged to become a closed group. Now they have nearly 600 members. She has also shared her story through the Norwegian Gynaecological Cancer Society, and many people have contacted her. She finds it rewarding to meet women who understand and who feel supported by her openness.

“My story touches many aspects of my life. My cancer diagnosis and lichen sclerosis makes it impossible for me to forget what I'm living with. I think it's important to be open. I'm not ashamed. I see it as my calling to be open and share my story. I know how hard it is to sit alone with these diagnoses, searching for information. It can quickly get lonely with Google as your only company. That's what I've experienced. And the most important thing of all: this is not my fault. Not any of it. It just came out of nowhere and unfortunately struck me.”

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



The content of this brochure has been quality assured by Senior Consultant Ingvild Vistad, at the Women's Clinic, Hospital of Southern Norway.

Sources:

www.kreftforeningen.no/om-kreft/kreftformer/kreft-i-de-ytre-kvinnelige-kjonnorganene/

www.kreftlex.no/Gyn-kjønnsleppekraft

www.helsenorge.no/sykdom/underliv/lichen-sclerosus/

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 1000 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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