

For those who have rare ovarian tumours or placenta cancer



Causes,
symptoms,
treatment
and research

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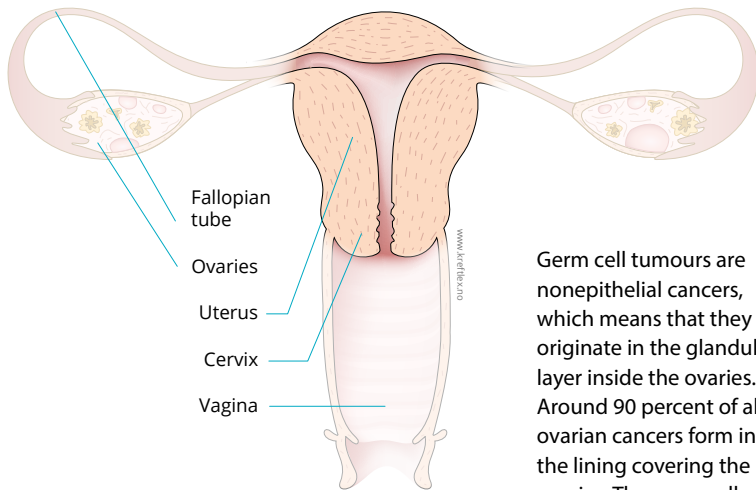
A woman with long brown hair is shown in profile, looking out of a window. She is wearing a dark blue sweater. The background is a soft, out-of-focus interior. A semi-transparent white box with text is overlaid on the lower half of the image.

Each year, 1700 Norwegian women are diagnosed with a form of gynaecological cancer.

Today, around 22,000 women in Norway are living with a form of gynaecological cancer or have undergone treatment for this. Rare ovarian tumours and placenta cancer are rare forms of gynaecological cancer. What are the symptoms and how are they treated?

Rare ovarian tumours

These are called germ cell tumours, with an incidence of five to ten patients each year. The patients are often very young, with an average age of 19. There are different types of cancerous tumours that develop from germ cells in the ovaries.



Germ cell tumours are nonepithelial cancers, which means that they originate in the glandular layer inside the ovaries. Around 90 percent of all ovarian cancers form in the lining covering the ovaries. These are called epithelial tumours.

Vulval cancer (cancer of the female external genital) and sarcomas of the genital tract are also rare gynaecological cancers. The Norwegian Gynaecological Cancer Society has created brochures for these forms of cancer.

Symptoms

- Swelling of the abdomen
- Abdominal pain (especially during physical activity)
- Irregular bleeding as the tumour produces hormones. Hormone production may also result in a false positive pregnancy test.

If symptoms persist, you should not wait to contact your doctor. You can also ask to be referred to a gynaecologist.

Causes

The cause of this form of cancer is unknown.

Assessment

- Gynaecological examination with ultrasound.
- Blood tests: Tests are performed to measure AFP, HCG, AMH and CA 125 in the blood. These are tumour markers that are often elevated in cases of rare ovarian cancers.
- Diagnostic imaging: CT scan of the lungs, abdomen and pelvis often done to assess the spread of the disease.
- Often, a biopsy or surgery will identify the type of cancer.

Treatment

Germ cell tumours are often very aggressive, fast-growing tumours that spread quickly. With the right treatment, nearly 100 percent of women with this type of cancer can be cured. Most women with ovarian germ cell tumours who are treated with fertility-sparing surgery and Cisplatin-based chemotherapy (cytotoxin) are cured and retain their fertility. Patients who have already had children may undergo surgery for the removal of the ovaries, fallopian tubes and uterus.

Radiation therapy should not be used in the treatment of patients with ovarian germ cell tumours.

Acute 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 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.

Most recurrences of rare ovarian tumours occur 1 to 2 years after treatment.

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

- The first 2 years: check-up every 3 months
- From the 3rd through the 5th year, check-up every 6 months

At these check-ups, blood tests will be taken and gynaecological examination will be performed. CT scans are conducted yearly.

Late effects of treatment

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. Below is an overview of late effects that may arise from treatment for rare ovarian tumours.

Early menopause

In women who have not yet reached menopause, the surgical removal of the ovaries, or radiation therapy, where the ovaries are within the radiation field, may trigger menopause. 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.

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 go away 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.

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.

Hearing

Treatment with chemotherapy (especially Cisplatin) may affect your hearing. You may develop tinnitus or lose the ability to hear high tones.

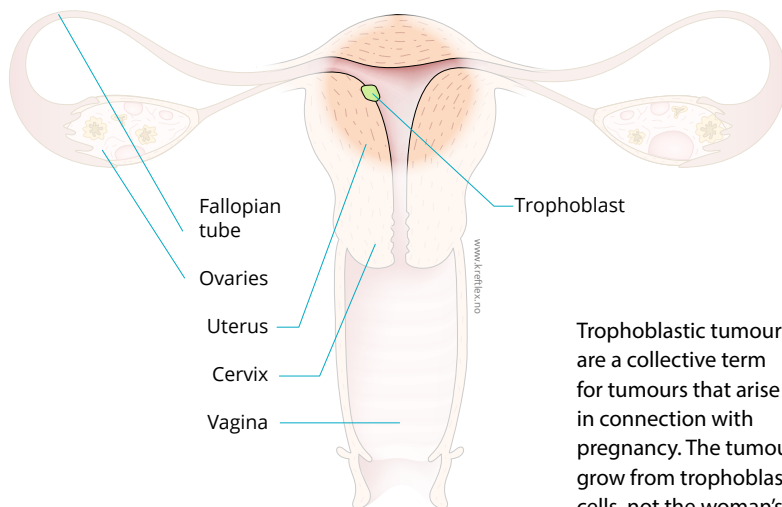


CURRENT RESEARCH

Patients with rare ovarian tumours have the opportunity to have their treatment assessed by the EURACAN network (European Reference Network on Rare Adult Solid Cancers), which can recommend alternative treatment methods and possibly include patients in studies conducted abroad.

Placenta cancer

Placenta cancer or gestational trophoblastic disease (GTD) affects young women of fertile age, and occurs in abnormal placental tissue. Gestational trophoblastic disease arises during pregnancy. The disease may appear following a normal pregnancy, ectopic pregnancy, or after a miscarriage or abortion. This type of cancer is usually found in young women of fertile age. Placental tumours produce the hormone hCG, which is present during pregnancy. Therefore, the hCG values will remain high and/or increase as the trophoblastic disease develops. Malignant trophoblastic tumours infiltrate the uterine wall and open blood vessels, which may cause vaginal bleeding.



Trophoblastic tumours are a collective term for tumours that arise in connection with pregnancy. The tumours grow from trophoblastic cells, not the woman's own tissue. Trophoblastic disease is a further development of certain changes in the placental tissue.

Symptoms

- Vaginal bleeding
- Abdominal pain
- Extreme nausea during pregnancy
- Pain in the mammary glands
- Pre-eclampsia
- Hypermetabolism
- Blood sputum (hemoptysis) due to metastases to the lungs
- Blood in the urine (haematuria)

If symptoms persist, you should not wait to contact your doctor. You can also ask to be referred to a gynaecologist.

Causes

Gestational trophoblastic disease occurs in connection with pregnancy. The disease may appear following a normal pregnancy, ectopic pregnancy, or after a miscarriage or abortion.



Assessment

Gestational trophoblastic disease (GTD) is usually identified with an ultrasound, and abnormally high levels of the hormone hCG produced in the placental tissue. In normal pregnancies, hCG is important for foetal growth. The presence of a GTD leads to an overproduction of hCG. Hormone levels can be measured in both urine and the blood. In addition to measuring hCG, a gynaecological examination is performed with ultrasound along with a CT scan to assess the extent of the disease.

Treatment

Placental tumours are often very aggressive, fast-growing tumours that spread quickly. With the right treatment, nearly 100 percent of women with this type of cancer can be cured. Radiumhospitalet has its own trophoblastic therapy unit that is responsible for treating patients with trophoblastic disease. This unit is comprised of several gynaecologists and pathologists who are specialists in the treatment of these rare tumours. They determine the type of treatment and provide patients with the appropriate information.

Treatment is determined based on the type of trophoblastic disease and on whether the disease is localised to the uterus or if it has spread to other organs. The abnormal tissue of the placenta due to trophoblastic disease is usually removed from the uterus through a minor operative procedure known as dilation and curettage (D&C). Patients who are diagnosed, but do not wish to have (more) children, the uterus may possibly be removed. Certain patients do not get well after a D&C, and they may need chemotherapy, which they are given at Radiumhospitalet.

Acute side effects of chemotherapy:

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- Fatigue
- Hair loss
- Weakened immune system

Check-ups

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

Blood tests every second week until hCG levels have normalised. Thereafter hCG measurements every month for another six months. Patients treated with chemotherapy will be followed up for one year. Contraception is recommended throughout the follow-up period, and during this time it is important that you do not become pregnant.

CURRENT RESEARCH

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Late effects of treatment

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Treatment of low-risk trophoblastic disease usually involves minimal side effects. You may experience: sore mucous membranes of the mouth and eyes, nausea, chest pain or abdominal pain, anaemia, and a weakened immune system.

Treatment for high-risk trophoblastic disease may result in hair loss, nausea and vomiting, fatigue, loss of appetite, and a low white blood cell count.

Most side effects can be managed with medicines and fluids.

Nerve damage (polyneuropathy)

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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 rare gynaecological cancers, 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

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.

Stefanie had a rare cancerous tumour in her ovary

“The cancer was discovered completely by chance. I had a routine examination in 2018, and it was thanks to the habits I developed in Austria that the tumour in my ovary was discovered so early,” says Stefanie Wüstner, age 38. In Austria, where Stefanie is from, it is common for women to have a gynaecological examination once a year.

It was the gynaecologist who found what appeared to be a large cyst and sent Stefanie for an assessment. At the time, Stefanie had no idea she had a cancerous tumour in her ovary and not a cyst. It took some time to find the right place to have the surgery to remove the cyst, but she finally underwent surgery at Ullevål University Hospital. During the surgery, the surgeons found a 7 cm cyst on her left ovary. As they removed the cyst, they also discovered new growths in her pelvis. Four weeks later, Stefanie was informed that they had removed a cancerous tumour – a so-called germ cell tumour.

Unreal message

“It was a huge shock to be told I had cancer. Everything was completely unreal. Even though this was four years ago, I still have trouble processing the entire experience.

After receiving the diagnosis, everything happened fast. Stefanie, who was then living in Northern Norway, found a flat in Oslo and started treatment at Radiumhospitalet. At Radiumhospitalet, a new gynaecological examination was performed, along with a CT scan to determine the stage of the cancer. Stefanie was then started on chemotherapy.

“I was also told that the surgery was not entirely successful. The tumour should have been removed whole, but this wasn't done.”

Tough treatment

The chemotherapy Stefanie received was strong, and she was admitted to hospital periodically. Six days admission, six days at home, a break for two to three weeks, and then another round. She was given a total of four rounds of chemotherapy.



“It was tough. Among other things, I developed sepsis after getting an infection through the venous access port. I survived, but it was traumatic.”

To manage the disease and treatment, Stefanie create her own regime.

“Even when I was very ill, I wouldn't allow myself to be too ill. No matter how bad I felt, I was always up at eight in the morning, took a shower, forced myself to eat something, like an avocado, and made sure I got exercise. I often walked up and down stairs. Although I was incredibly tired and exhausted, my mood was quite good during treatment.”

Stefanie can thank her routine of yearly gynaecologist check-ups at home in Austria for ensuring that her cancer was diagnosed so early.

During the periods when Stefanie was home, her family from Austria, her partner, and his family all took turns staying with her. She is very grateful for that. Follow-up at Radiumhospitalet also helped her feel secure and looked after.

Felt alone after treatment

Once the chemotherapy rounds were over, Stefanie was told that she was finished with treatment. She attended

check-ups with CT scans every third month during the first year, and then check-ups every six months.

Even though she went in for check-ups, she felt lost. The chemotherapy resulted in a loss of sensation in her toes, and no one had told her this could happen.

“I felt I had to manage things on my own. When I lost sensation in my toes, I found some exercises I could do and started training. I was referred to a psychologist to help me cope with everything I had been through, but was rejected because it hadn't been dramatic enough – even though it felt that way to me.”

To avoid dwelling on things, Stefanie insisted on returning to work. She is a trained veterinarian and works as a pathologist. Six months after her treatment, she was back in a full-time position.

Became a mother

In the midst of the follow-up, Stefanie became pregnant. The pregnancy progressed normally, and she felt certain that everything would go well. But after the birth, she began having new concerns.

“Everything took on a different meaning after my son was born. He is a little person I am responsible for, and that makes everything much worse. This has led the check-ups to take on a different meaning as well. If I were to relapse, it would also affect his life and my capacity to care for him. These are extra worries.”

During the days leading up to check-ups, Stefanie feels her worries piling up. She feels that the waiting time from her MRI or CT scan until the results come back are an extra burden.

“Everyone else just thinks I'm done with cancer, but it doesn't feel that way to me. Even though I'm going in for my last check-up in April 2022, I will continue to see my gynaecologist regularly.



The content of this brochure has been quality assured by Olesya Solheim, senior consultant at Oslo University Hospital. She is in charge of the treatment of rare ovarian cancer, at Nasjonal behandlingstjeneste for trofoblastsykdom [Norwegian trophoblastic disease centre].

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:

www.kreftlex.no/Gyn%20Trofoblastsykdom

Oslo University Hospital, Nasjonal behandlingstjeneste for trofoblastsykdom [Norwegian trophoblastic disease centre]

European Reference Network on Rare Adult Solid Cancers (EURACAN),

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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