

### Cancer and **SEXUALITY**

Read how cancer survivors overcame their challenges



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#### Introduction and reading tips

Cancers are known to affect our sexual experience. Many patients and partners want to seek out information and guidance when they feel they need it. The contents of this pamphlet are for you, whether young or old, living alone or in a relationship.

Rehabilitation of sexuality after cancer and cancer treatment is a demanding process for many. It can take time and it may require new ways of thinking. However, many find ways to successfully overcome their challenges.

We have collected short accounts given by cancer patients as well as their partners to shed a light on some ways of solving these new challenges.

Reading the accounts in this pamphlet may give you ideas that you can apply to your own situation.

Sex and sexuality is much more than intercourse.
Feeling close and experiencing pleasure can be a great help and resource, especially in difficult moments in life, according to the Ministry of Health's (Helsedirektoratet) strategic plan for sexual health.

This plan states that a caring and intimate environment can increase energy levels, relieve pain and contribute to relaxation. Good sexual health can even strengthen the immune system.

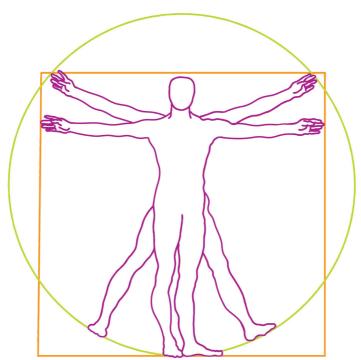
The main message in this pamphlet is this: whatever challenges you may face - there are solutions.

Enjoy!

#### The sexual body

The human body can experience pleasure through all of the senses. If a sense is weakened, the other senses can become all the stronger. For instance, loss of sight often results in improved hearing. It's common for people to have heightened sensory experiences, and discover novel erogenous areas, when they are challenged to new ways of perceiving their body after treatment.

"Our sexuality is a strength and a source of good health" the Norwegian Minister of Health states in the strategy plan "Snakk om det!" (2017). There are many reasons that a healthy sexual life can enhance both physical and psychological wellness. Among other things sexual feelings and experiences can increase oxygen, endorphins, dopamine and oxytocine, all of which give the brain and the rest of the body more energy, wellbeing and thereby increase the quality of life.



## Thoughts on diagnosis

Words can affect us in different ways. Immediately after receiving a cancer diagnosis some people will find solace in intimacy and physical affection, while others reject all forms of physical contact while they process their diagnosis.



Many cancer survivors relive their initial emotional stress when they visit their doctor for follow-ups.



"When I was diagnosed, I found solace in making love to my partner. While I was waiting for the operation, we often told each other that this was going to be allright."

"When my doctor told me that I had cancer, my body felt numb and I could not bear to be touched. If someone had given me a hug, I would have been overcome with sadness. My partner respected the fact that I needed some time and space."





"I take things as they come.
Getting the diagnosis wasn't that bad, but it was difficult seeing my partner taking it so hard.
I try to live by King Harald's words in his speech:
"Hope is a way of life"."

"I handled my diagnosis by joining a patient group for people with the same diagnosis on Social Media.
Talking to others with a similar experience was very helpful.
I learned new things about sexuality, and above all it was a place where I could ask any and every question."



#### Hair

Some chemo- and radiotherapies can cause partial or total hair loss. Those who experience these side-effects are entitled to financial support to cover expenses for wigs, hair pieces, extensions or head gear such as caps or hats.



The hair usually grows back after the treatment is ended. Losing hair or body hair can affect your body image regardless of gender.



"I felt unattractive and odd without my hair, but when I told my partner, I was reassured in a very nice way that I was sexy. This helped grow my confidence and desires."

"What depressed me the most was losing my beard. It was a big part of me. Luckily, my hair and beard grew back after a few months. In the meantime I discovered a love for hats and built a collection of them."





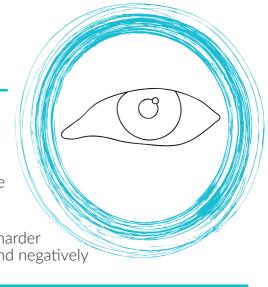
"When I lost my hair I was afraid I was going to lose my image. What saved me was a prescription for a wig of my own choosing. You are entitled to this regardless of gender. I felt more confident and even went out for a date."

"My need to wear make-up and dress nicely increased after losing my hair. Feeling feminine is important to me. I bought false eyelashes and hair extensions, and felt confident enough to invite my partner to a romantic evening."



#### Eyes

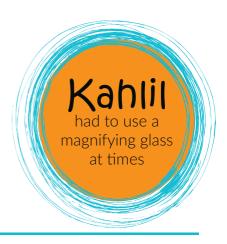
The eyes can be affected in different ways after cancer treatment. Radiatiotherapy of the head can affect the optic nerve. Chemotherapy can cause dryness and changes in fluid pressure inside the eye. Impaired eye sight can make it harder to accomplish everyday tasks and negatively influence one's self image.





"I was unaware that I was blinking a lot. Some misunderstood and thought I was flirting. I needed eyedrops the first year after treatment. It helped my eyes and I avoided misunderstandings."

"My eye sight was severley reduced because my eyes were so dry. I found it hard to read messages on dating apps, but with a magnifying glass I was able to read and reply to messages."



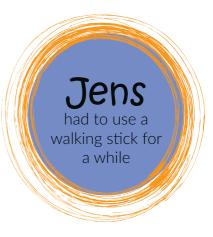


#### Ear

The ears can be affected by chemotherapy, e.g. the microscopic hairs in the ear can fall out just like the hair on the rest of the body. This can cause tinntus in one or both ears as well as changes to ear wax production.

The inner ear can also be affected, thereby reducing balance.

"I was sensitive to sounds and felt dizzy for several months. I felt much sturdier with a walking stick, but it also made me feel old. My partner called my walking stick a magic wand! A sense of humour helped us deal with all the different phases."





"My partner felt rejected. She thought I didn't love her anymore because I was unattentive and forgetful. But when we talked about it we realised it was the medication. It's common for concentration, memory and hearing to be impaired temprarily during treatment."

#### Mouth

Surgery and radiatiotherapy of the head can cause soreness and lesions in the mouth cavity. Chemotherapy is also known to cause dryness, fungal infections and weaken the enamel. te these her sexual

There are several ways to alieviate these problems to allow kissing and other sexual activites involving the mouth.



"Mouth dryness can lead to caries, and it can make oral sex more difficult. I keep lozenges in my night stand. They can be bought in a variety of flavours at the pharmacy."

"It felt like an extra burden to lose the ability to give oral sex due to treatment against my oral cancer. I replaced my oral activites with my hands, and other objects that my partner enjoyed."





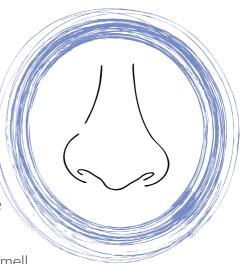
"Even though my chemotherapy was directed against my ovarian cancer, I suffered from dryness of the mouth. Mouth-spray from the pharmacy worked for me. To me kissing is essential in order to get aroused."

"The taste of vomit in my mouth was a big problem for my partner and me. I bought phsyiological salt water at the pharmacy and rinsed my mouth with it several times a day. Now I make my own using a tablespoon og salt per liter of boiled water."



#### Nose

Chemotherapy can cause loss of nostril hair, and thinning of the mucous membrane. The nose can feel blcoked because the "filter" is lost. This can cause difficulties breathing and impair the quality of sleep.



Medication can alter the sense of smell.

Treatment of the airways and upper digestive tract can also give rise to new or altered smells.



"During treatment I almost couldn't kiss anymore. I felt like I was choking because I couldn't breath properly through my nose. With nasal spray form the pharmacy I was able to kiss again."

"With oil-based nose drops, I was finally able to sleep and have the energy to restart my sexlife. My libido got the energy and drive hack."





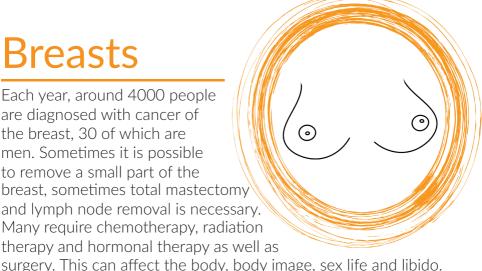
"Smells have always been important for my arousal, so now I use sensual aromas as much as possible. I don't want to smell of illnes!"

"The smell from my airways and oesophagus is so bad that we don't kiss much on the mouth, but we kiss everywhere else on each other's bodies. We enjoy this a lot"



#### **Breasts**

Each year, around 4000 people are diagnosed with cancer of the breast. 30 of which are men. Sometimes it is possible to remove a small part of the breast, sometimes total mastectomy and lymph node removal is necessary. Many require chemotherapy, radiation therapy and hormonal therapy as well as



lisha's sex-life improved after breast reconstruction

"I like being seen and admired for my feminine shapes. I really wanted breast reconstruction. It was a long process, but I enjoy my new breasts a lot."

"I felt as though I had lost both my breasts and my sex life. The first step was to be seen naked and get used to that. We found new ways to give and receive confirmation and love."





"Caressing my breasts was too painful, so we had to find new erogenous areas. I was sad to lose my favourite erogenous are. Now, my throat and neck have become my new favourite places."

"I changed my body image by swapping the word breast with thorax. I needed a vocabulary to address those who asked about the scars."



#### Muscles

Muscles can also be affected by operations, chemotherapy, medication, weight loss and long periods of rest. Some medications affect the heart muscle as well. Muscles can also be altered by changes in hormonal balance.



Research has shown that exercise is of utter importance to an individual's health - including sexual health.



"My problems with balance and unsteady gait gave the impression that I was drunk. The physiotherapist advised me to participate in group training as well as exercises at home. With improved balance, I was able to feel more social and go on several dates."

"My pelvic muscles were weak after treatment and many months without hiking or exercise. After doing pelvic strengthening exercises, I got some strength back. This also helped me achieve orgasm."





"I have to admit I was afraid I was going to lose my wife after all the surgeries. Eventually, I discovered I was not the only one struggling with my sex life. Sharing my experience with other cancer survivors was both helpful and important to me."

"I had reduced strength in my legs, fatigue and was not motivated to be out an about. I finally joined an exercise group for cancer patients. At "Pusterommet" I met a man that motivated me to work out more. We actually got together and are now a couple."



#### **Bones**

Chemotherapy, radiation therapy and medication can affect bone density. Joints can feel stiff and certain movements and positions can be painful.

Physiotherapists and other trained health care workers can help cancer survivors with individual exercising plans and suggestions for adapting movements and exercises.



"She had neck pain after radiation treatment. We went to a physiotherapist together to get advice on pain-free positions. All it took were some small changes of angles and positions to relieve neck pressure and improve pleasure."

"My sex-life was turned upside-down.
From being the "alpha male" and doing most of the physical work in bed, I could now only use intense words and language. I have an understanding partner who found it exciting that I was taking charge with the way I talked."





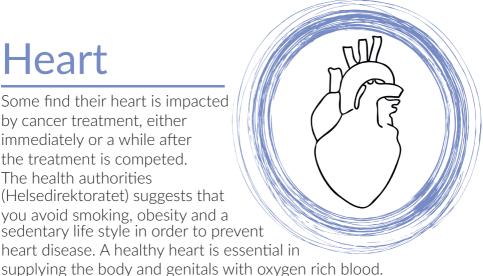
"The cancer treatment caused joint pains for Ina. We bought a bath tub. Being immersed in water reduces the pressure of gravity on the joints. She also tells me achieving orgasm is a great pain-reliever."

"My osteoporosis meant my ribs sprained if I got hugged too hard. I like rough sex, and used rough or heavy music to get in the mood instead. That's just how arousal works for me."



#### Heart

Some find their heart is impacted by cancer treatment, either immediately or a while after the treatment is competed. The health authorities (Helsedirektoratet) suggests that you avoid smoking, obesity and a sedentary life style in order to prevent heart disease. A healthy heart is essential in

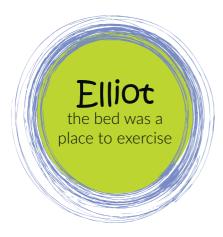




"I was very frustrated that he only focused on intercourse and what wouldn't work like before. He was pulling away. My sexual initiatives were about intimacy and not intercourse. When he realised my initiatives did not mean I expected sex his stress levels reduced."

"We thought our sex life was over, but the doctor changed Varg's medication. He also prescribed sexual aid products (seksualtekniske hjelpemidler). We have found desire again, and the erections last long enough for us"





"Exercise can help prevent cancer relapse, but it is hard exercising with radiation damage to the heart and lungs. So I "exercise" in bed. Sexual activity makes me perspirate as if I had been running!"

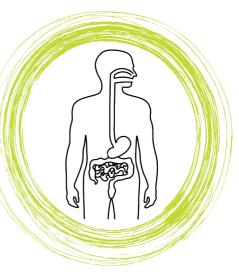
"We didn't know vibration to the underside of the glans could cause orgasms Arne got a vibrator prescribed by his doctor. You don't need and erection to achieve pleasure and orgasms."



# Digestive system

The digestive system can be affected in numerous ways both directly and indirectly by cancer and cancer treatment. This can also affect your sex life.

Both constipation and diarrhoea are common amongst cancer survirors.



Emotional stress and worrying can also negatively affect digestions and thereby quality of life and sexual health.



"I need to be told that I am attractive even though I have scars, wrinkles and bumps on my stomach. "Speak nicely to my body"
I whisper to my partner."

"After radiotherapy to my thorax I had a lot of reflux and bad odours. Medication for acid reflux made it easier for my partner and I to enhoy our intimate moments."



"I often felt my anxiety in my stomach and digestive system, and it overpowered my libido. When my lover takes time to caress my stomach I calm down and when I relax my desire returns."



#### Skin

Cancer can arise in the skin, but treatments against other types of cancer can cause changes in the skin's elasticity, moisture levels and sensitivity. Scars can affect body-image and

Scars can affect body-image and how you perceive yourself. The skin is our largest sensory organ and can be the key to sexual rehabilitation and

discovering new erogenous zones in sex rehabilitation.





"I was worried that massage oil would irritate my skin and work against the anti-oestrogen tablets, but was reassured by the cancer nurse that almond oil was neutral and safe to use."

"My love lay on her death-bed and I was with her at the end. The nurses let us have time to be close and alone together. Ellen could feel hand and foot massages, and she received kisses on the forehead and mouth to the very end."





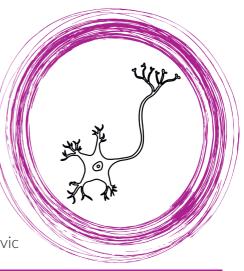
"I was sick and tired of sweating and hot flashes! We bought a latex bedsheet, rubbed ourselves with oil and rubbed erotically against each other. Being shiny and slippery together was arousing."

"The pain in some areas was a turn-off, so I had abandoned my sex life. The doctor advised me to try an anaesthetic cream on the painful areas, and I was finally able to recover pleasure."



#### Nerves

Cancer survivors can be affected by nerve damage in many different ways, and for various reasons. Surgery, radiotherapy and chemotherapy can all damage nerves and alter their functioning. This is a common side-effect when cancers in the pelvic region are surgically removed.





"My prostate cancer was removed, but I suffered from erectile dysfunction. My doctor prescribed a penis pump for free through NAV\* With the pump and a cock ring I was finally able to have intercourse again!"

"Some nerves were cut in the course of the life-saving operation. While in rehab, I was advised to try a vibrator. I use it on several erogenous zones, and experience pleasure and orgasm. My doctor provided a vibrator through NAV\*."





"The tumour was large, but was luckily operable. The procedure resulted in complete loss of erection. We mourned this, but in cooperation with the physiotherapist, we made a choice: we held nothing back in enjoying the rest of the body. Pleasure can be found in more places than between the legs."

"I used to be "the ruler" in bed. With chemotherapy, I lost focus and energy. We exchanged roles. It was hard at first not to be the boss, but we wanted this to work."



### Hands and feet

A common side effect of chemotherapy is damage to the peripheral nerves (polyneuropathy).

This can lead to burning or prickling sensations and numbness in hands and feet, and even a light touch can be painful. Some types of chemotherapy can also affect the nails.



"My wife stopped forbidding socks in bed once I had survived cancer and needed warm socks for my cold feet. Partners can become less demanding when life becomes challenging. At least, that is our experience."

"I told my partner how I felt less attractive now that my nails were damaged. My love gave me long slik gloves. I felt beautiful again, and could feel the skin through the silk."





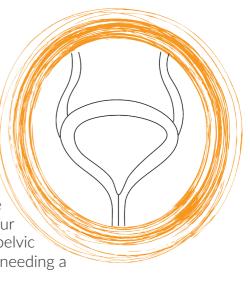
"My restless legs gave me poor quality of sleep. My doctor discovered I had iron deficiency. With iron supplements my sleep improved, and I discovered I need to sleep properly to have enough energy for sex."

"My fingers were painful and my motor skills were so weak that I bought a sex toy in order to satisfy mysef and my partner. I later learned that patients are entitled to sexual aids for free through NAV\* if treatment has had a negative effect on sexual health."



### **Urinary tract**

Cancer survivors may experience frequent urination, incontinence or a burning sensation while urinating. Some problems in the urinary tract are caused by thin, irritated membranes of the urinary tract. Incontinence can occur due to surgery or radiation of the pelvic region. Some patients also end up needing a urostomy.





"My sex life was impaired because I kept worrying about incontinence during sexual activity. I now empty the bladder before sexual activities and use a water proof sheet. I can relax more and my sex life has improved.

"I had a urostomi after surgery.
The urotherapist suggested using
a belt to cover the stoma. I am
less bothered by the bag on my
abdomen when I perform
sexual activities-"





"I felt inhibited by incontinence during sexual activities. With physiotherapy, electrostimulation and homework on pelvic floor exercises my control increased and I also experienced more pleasurable sex."

"I lost my erection completely after all the cancer surgery, and grieved for several years. I was then offered a penile implant. I can now have an erection by pumping a balloon via the scrotum. It was a little strange at first, but I'm used to it now."



## Pelvic area

The pelvic area plays a pivotal role during sexual activity.
Anyone who receives treatment for cancer is at risk of experiencing problems in this area, like stiffness of the hips og muscle aches.



Radiation of the pelvic area can also result in a loss of production of sex hormones, which can also affect libido negatively.



"I could hardly move my body during sex because the paint and joint stiffness were so bad. Thermal therapy helped a lot, because it increased the blood flow to the muscles and joints."

"I was thrown into menopause by the cancer medication and had to find new ways of feeling desire. I was advised to try out exercises to find desire and to learn my own arousal cues."





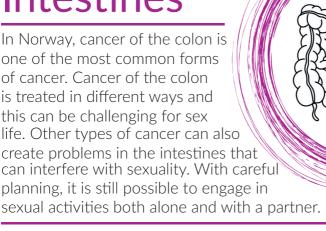
"For many years following cancer treatment, I experienced pain during intercourse. I wish I had known sooner that combining numbing cream and taking more time to get aroused, I think we would have avoided a lot of frustration."

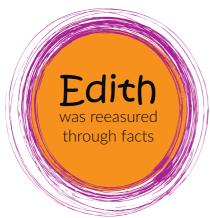
"I exercised my pelvic muscles every day as advised by the doctor and the physiotherapist. This increased blood flow. A few months later, I had my first orgasms."



#### Intestines

In Norway, cancer of the colon is one of the most common forms of cancer. Cancer of the colon is treated in different wavs and this can be challenging for sex life. Other types of cancer can also create problems in the intestines that





"I was cured of cancer and had a colostomy. My libido disappeared because I didn't know how much the colostomy could take. Knowing that a colostomy tolerates pressure and movement helped me relax."

"I found that being open about my situation meant that I found peace and less shame. My partner was determined that my incontinence would not be the end of our sex life. I was refered to a physiotherapist for electrostimulation and biofeedback, and I use an anal plug during sexual activity."





"I was to go on a date and didn't know how to talk about the colostomy. It turned out that my date had heard of it and was understanding. We became a couple and learned to laugh when there is rumbling in the colostomy."

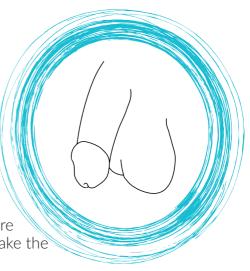
"I had haemorrhoids due to constipation. My doctor prescribed rectal cream. After a couple of weeks, my partner and I could continue anal stimulation. This form of pleasure means a lot to us."



### **Penis**

The penis consists of a series of nerves, spongy tissue and small blood vessels. Blood circulation in the penis can be affected by surgery, chemotherapy and other treatments.

Erection is a complex process where spongy tissue fills with blood to make the penis stiff.



If the erection is impaired or absent, other sexual activities which uses for instance the hands or sexual aids can be used.



"I thought I would never recover my erections, but a vacuum pump helped. These make the spongy tissue in the penis healthy and stiff. NAV paid for this wonderful aid!"

"I can feel lustful without an erection now. I enjoy seeing, hearing and touching even more. We know that an erect penis isn't a measure of lust or how much one loves the other. We've talked it through and found a deep sense of trust in each other."





"I could not get an erection even thoughI tried different things. Talking to my doctor helped! Now, I inject my penis a few minutes before I wish to be hard. This is easier to do than I thought"

"I lost my erections, but my partner used such erotic language that I had an orgasm even though my penis was not stiff. This is really possible, and it's amazing how words can affect our feelings."





"I had cancer of the penis and waited a long time before going to a doctor. My penis had to be amputated in order to save my life. I was devastated. Today, I use a penis prosthetic in order to satisfy my partner. This is important for my self confidence."

# Vagina

The vagina can undergo changes after cancer treatment in the pelvis, or other parts of the body. The vagina can become shorter and less elastic with dry and thin walls. The vaginal entrance can become painful or damaged by friction because of a lack of lubrication and elasticity. When the vagina feels painful to stimulatate, it is possible to do other things on the outside, with the hands or using sexual technical aids.



"After treatment for cervical cancer, I had scarring and was at risk for getting adhesions in my vagina. The doctor got me a dilator set through NAV. I started with the smallest. After a few week, I was able to insert the largest dilator."

"My wife had an operation in the pelvic region. When she was ready to resume sexual activity, deep penetration was painful. The nurse advised us to use a special buffer ring, or to hold my hand around the root of the penis to make the penetration less deep."





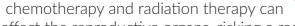
"I was surprised to have a dry vagina after treatment for lung cancer. A nurse advised me to use lubricant and stimulate my clitoris. Penetration was much less painful."

"I had reduced senstation in the pelvis and my doctor was adamant that people who are single also have a right to a sex life and aids. He provided me with vaginal weights which came in a discreet package in the post, through NAV. Exercising increased my sensitivity and please from sexual activites."



Reproductive system

The way fertility is affected by cancer treatment depends on several factors, among others age, type of cancer, type of treatment and how long ago the treatment took place. Surgery,



affect the reproductive organs, risking a reducing fertility and hormone production. For those who want, help can be given through reproductive technology such as freezing of eggs or sperm.



"We were young and newly wed when I had cancer treatment and was advised to use contraception because the treatment could harm the foetus. After treatment, it took us 5 years without contraception to have our "love child"."

"Some people find love later in life, as I did. I was childless and had finished treatment for hereditary cancer when I was 43. Not everyone needs children in order to be happy. I enjoy life with my partner."





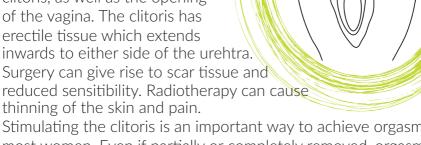
"When I was diagnosed, I thought a lot about whether this would stop me from becoming a father in the future. I wasn't in a relationship at the time. Freezing sperm was a hurdle for an 18 year- old, but I have been grateful for this possibility. We are now a family of three."

"I couldn't have children myself after the treatments, but I met a woman who had two children. Last year we adopted little Tobias. I'm very proud of my perfect family!"



## Vulva

The vulva includes the outer female genitals: the labia and clitoris, as well as the opening of the vagina. The clitoris has erectile tissue which extends inwards to either side of the urehtra. Surgery can give rise to scar tissue and reduced sensitibility. Radiotherapy can cause



Stimulating the clitoris is an important way to achieve orgasm for most women. Even if partially or completely removed, orgasm can still be achieved through learning new techniques or sexual aids.



"My partner and I wanted advice on how to tackle our sex life before and after the operation. The nurse explained that the whole body is erogenous and advised us to talk about what feels good."

"Parts of my vulva and clitoris were removed. This was challenging at first, but the clitoris is much larger than I knew. A strong vibrator made stimulation of the nerves of the clitoris possible. We were both very happy!"





"I was relieved that the operation was successful, but my vulva looked different and I became unsure. When I eventually accepted his many words on how nice my vulva was, I relaxed and pleasure returned!"

"I had pelvic pain for years after cancer treatment. In the end I found a therapist who specialises in the pelvic floor who gave me counseling. I could at last have intercourse without pain again."



## **Authors**

#### **Solveig Fridheim Torp**

Solveig Fridheim Torp is the project manager and author of the pamphlet. She is a cancer nurse and has further education in sexology (UiA) and a masters degree in health science with emphasis on sexual health and rehabilitation in cancer patients. In Kreftomsorg Rogaland, she is a leader, adviser and teacher. She has previously worked in different cancer wards in Oslo and Stavanger.

#### Stine Kühle-Hansen

Stine Kühle-Hansen is an author with a particular focus on the user perspective in this pamphlet. She has had cancer herself and is a member of several groups. Stine is a teacher at OsloMet University with further education in sexology from UiA and UiO. This pamphlet will also be used in teaching at OsloMet in the sexual health parts of the master programme. Stine uses her vast experience to advise, teach, write and make films.

#### **Aron Willems**

Aron Willems is a medical doctor and artist, and has been responsible for the graphic design in this pamphlet. The circles in the pamphlets are a stylized version of a photograph of rotating light which symbolises hope, knowledge and enlightenment. He has also contributed with medical and linguistic insights. He has worked with aids for sex life for several years and has previously worked in the cancer ward at Haukeland Sykehus.

## **Postscript**

Thanks to all patients and their partners who have contributed with their stories.

We would also like to thank patients, their partners and medical staff who have read and given feed-back during the writing of this pamphlet.

The project "Sexual health- when you or someone close to you is affected by cancer" consists of this pamphlet as well as a leaflet directed at medical workers about how they can talk about sexuality.

Thank you for the funds provided by the Ministry of health (Helsedirektoratet) to increase competency about sexual health. These stories would not have been spread without these funds.

#### Seek help:

**kreftomsorg.no**/tjenester/sexologisk-radgivning **helse-stavanger.no**/avdelinger/kvinne-og-barneklinikken/ kvinneklinikken/sexologisk-poliklinikk

finnensexolog.no

#### Read more:

helsenorge.no/sex-og-samliv/kreft-og-seksualitet kreftforeningen.no/rad-og-rettigheter/kreft-og-seksualitet nav.no/soknader/nb/person/hjelpemidler-og-tilrettelegging/ seksualtekniske-hjelpemidler quintet.no/vaare-fagomraader/hjelpemidler-for-seksuallivet GET IN TOUCH 51 56 79 90 post@kreftomsorg.no

STAVANGER Niels Juels gate 10, 4008 Stavanger

BRYNE Hetlandsgata 9, 4340 Bryne

HAUGALANDET Austbøveien 16, 5542 Karmsund

### kreftomsorg.no

"This is a new way to shed light on these important challenges. This pamphlet provides easily accessible information to patients and partners."

Morten Andersen, urologist
 Moelv spesialistsenter





This pamphlet was made by Kreftomsorg Rogaland with financial support from Helsedirektoratet, Quintet and OsloMet University.