NORWEGIAN NATIONAL CENTRE FOR GENDER INCONGRUENCE

Information for patients about assessment and treatment services at NCGI

F-M



Information concerning assessment and treatment services at the Norwegian National Centre for Gender Incongruence (NCGI)

"What is a national centre?"

The health authorities have decided that small groups of patients in need of highly specialised and interdisciplinary services should be offered centralised treatment services.

"Why is there a national centre?"

To ensure equal access to and good quality assessment and treatment services. It can be difficult to offer good services if there are few patients at each treatment site. Cost-effectiveness, it is less expensive for the health care system to have the service in one place.

The main task of the Norwegian National Centre for Gender Incongruence is to:

Assess the psychiatric, endocrinological and surgical treatment potential of persons with Z-76.80, gender incongruence of adolescence and adulthood (ICD-10)

"What is expected of me as a patient?"

You must be prepared to make numerous trips to Oslo over the course of the assessment and treatment. You also have to go to your appointments at NCGI as agreed – and give notice well in advance if you need to change the appointment. You will be charged a double user fee if you do not give notice the day before.

"Will my travel be reimbursed?"

You must contact "Pasientreiser" (Patient Travel) yourself to agree on the type of transport and accommodation to which you are entitled. Your trips – and any overnight stays – are covered by current rules. You must request confirmation of attendance that can be delivered to your school or employer.

"How much does the treatment cost?"

The assessment and treatment are free, but you pay a user fee for outpatient appointments and day treatment. Once you have reached the user fee limit, you will not pay a user fee for the rest of the current year. Operations that require you to be admitted to a ward are free.

"Who will I meet with?"

We work in a multidisciplinary way at the Department of Gender Identity Assessment (adults), that is, the various health professionals have different professional backgrounds and have different work tasks. We have collaborative meetings and discuss patient cases together. A diagnosis is made and treatment is recommended after the team has reached a consensus. It is therefore important that you meet several health professionals during the entire assessment and treatment process.

Administrative assistant: Linn M Karlsen (master's degree in culture and gender studies)

Patient co-ordinator: Trude Rømuld (nurse)

Head of department: Kjersti Gulbrandsen (clinical specialist in nursing)

Chief physician: Abdullah Mohammud (specialist in neurology)

Assessment group:

Anja Pahnke, chief physician (specialist in neurology and neuropsychiatry)

Are Dahl Michaelsen, specialist psychologist (children and adolescents)

Alexander Cannistraci, specialist psychologist (adult)

Cathrine Tennebø Jakobsen, specialist psychologist (adult)

The treatment team:

Endocrinologists: Johan Arild Evang, Thomas Schreiner, Ansgar Heck

Plastic surgeons: Kjell Vidar Husnes w/ team

Nurses: Lene Bjørnson w/ team (PLA ward), Birgit Luksch w/ team (PLA, outpatient

clinic)

Gynaecologists: Karin Langeland w/ team (Ullevål)

Speech therapists: Jorid Løvbakk and Britt Bøyesen w/ team + speech therapists in Bergen and Trondheim

"What are the criteria for the diagnosis Z -76.80 (ICD-10): gender incongruence of adolescence and adulthood?

".. characterised by a marked and persistent incongruence between an individual's experienced gender and the assigned sex, which often leads to a desire to 'transition', in order to live and be accepted as a person of the experienced gender, through hormonal treatment, surgery or other health care services to make the individual's body align, as much as desired and to the extent possible, with the experienced gender.

Diagnostic guidelines:

The diagnosis cannot be made before puberty.

The diagnosis cannot be made on the basis of behaviour or preferences outside the norm of the assigned sex alone"."

"How is the assessment carried out?"

The assessment consists of structured psychiatric interviews and diagnostic consultations with the health professionals on the team. You need to be prepared that challenging questions may be asked and that you sometimes have to repeat things you have said before.

We spend about a year on the assessment, but everyone who comes to us is assessed individually so the length of the assessment will vary from person to person. During the assessment period, it is necessary that you live in your psychological gender in all areas of life, a so-called real-life experience (RLE). This is done to get an experience of how this works for you before embarking on partially <u>irreversible hormone therapy – followed later by an irreversible surgical procedure.</u>

You will have to complete numerous forms ©. The forms are used in the diagnostic work, but also in connection with research. You will be asked to participate in research both during the assessment – and after you have completed treatment. Research must be voluntary and reservation against participation is of course permitted.

"Can I be rejected during the assessment?"

If we assess that you do not meet the diagnostic criteria for gender incongruence, or for various reasons (such as mental or physical illness or obesity) are assessed as not a candidate for hormonal and/or surgical treatment, you will receive feedback on this as early as possible in the assessment process. We strive to have an open dialogue with

everyone who comes to us and with their local health professionals and families. In some cases, the assessment must be terminated for various reasons (for example: psychosocial instability, low level of functioning, drug use, problems getting started with RLE), either before the start of or during the assessment. When this is the case, we will work with your local therapist/GP to find a suitable local follow-up service.

Some choose to end the assessment for various reasons, which is of course perfectly fine. For example, some may find that they are nevertheless satisfied with living in their birth sex without treatment. If your patient relationship is discontinued by us or you yourself want to quit, you can be re-referred to us once you have recovered, achieved better daily functioning, lost or gained weight and/or feel ready to continue the assessment.

"Why is it important to be psychosocially stable?"

Hormonal and surgical gender-affirming treatment is a demanding process, both mentally and physically. You are therefore expected to be psychosocially stable at the start of the assessment at NCGI. Mood stability and frustration tolerance are very important. Experience has shown us that patients experience undesirable psychological and emotional reactions during the start-up of hormones (depression, mood instability). Post-operative reactions (depression, anxiety) also occur in some patients, which may have consequences for the final surgical outcome and long-term prognosis.

While hormones and surgery will help you with gender/body dysphoria, symptoms of depression, anxiety, etc. need to be treated with psychotherapy – and sometimes with medication.

To get through a gender reassignment process with a beneficial outcome, it is important to have a good social environment (family, friends, and daily organised activities).

It is also important to have other interests so that not everything in your life revolves around the assessment and treatment process – there will come a day when your treatment is finished. In order to avoid an experience of emptiness following a prolonged gender reassignment process, it is important to have specific goals for the near future.

"What is real-life experience (RLE) and how do I go about starting it?"

RLE is a psychosocial process that involves living in your experienced or psychological gender role. We require that you, when you are ready, live in your desired social role in all life contexts.

There is no universal "recipe" for how to proceed. You will have to see what works for you. Some ask family and friends for advice. Others consult stylists, look at magazines, go online and observe others concerning clothing style and gestures.

You have to figure out what kind of expression is right for you, but one of the goals of RLE is that others see you the way you want them to see you.

"Why do I have to do that?"

It is necessary to live in one's psychological gender in all areas of life to see if this works for the individual, before embarking on partially irreversible hormonal treatment – followed later by an irreversible surgical procedure.

The process does not end when you complete your treatment at NCGI, but continues in many ways for the rest of your life. The transition after gender reassignment is such a comprehensive process that it has to be considered whether it is something you will cope with in the long term. RLE will help you explore how you can adapt to a new social gender role – to see if you experience it as natural and right for you.

"When and how do I change my name and legal gender?"

It is up to you when you want to do this but it can be helpful while you adjust to living in a changed social gender role. You can go to "Altinn" and apply to change your name and legal gender. You can find a description of how to proceed on their website.

Your new name and national identity number will be changed automatically in all public records. It is up to you to change your driving licence, passport and the like.

"Am I entitled to aids?" If you meet the criteria for gender incongruence, you have rights to treatment aids.

- 1. Speech therapist (following assessment by physician)
- 2. Compression vest (indication; Z-76.89, unspecified gender incongruence)
- 3. Penis prosthesis ("packer")
- 4. Penis prosthesis (sex aid)

NCGI's doctors will help you, in cooperation with your GP, to apply for the treatment aids you need.

"What can I expect from hormone therapy?"

There is a waiting period for the initial consultation with an endocrinologist ("hormone doctor"). You must apply to Helfo, which has a processing time of 2 months, to be granted a "blue prescription". You must have blood tests done and must therefore be able to tolerate them as well as any injections.

<u>Effect:</u> Rougher skin, redistribution of fat, increased muscle mass, increased body hair, darker voice, growth of clitoris, cessation of menstruation.

<u>Side effects</u>: Erythrocytosis (too many red blood cells), cystic acne (pimples), retention/oedema, liver disease, mental reactions, permanently impaired fertility (?).

"Why do I need to be on hormones for at least a year before I can be referred for surgery?"

Hormonbehandlingen påvirker både kroppen og følelseslivet, noen beskriver det som« å gå gjennom puberteten på nytt». Det kan for noen personer ta noen måneder å stabiliseres under hormonbehandlingen. Psykososial stabilitet under den hormonelle behandlingen øker sjansene for at du vil komme deg gjennom den krevende kirurgiske behandlingen på en god måte, uten å bli psykisk ustabil. Kroppslige endringer under hormonbehandlingen kan påvirke muligheter og valg av kirurgisk metode (fjerning av bryst, genitalkonstruksjon)

«Jeg ønsker barn med mine gener- hva er mulighetene?» Behandling med hormoner kan påvirke din mulighet til å bli gravid. Dersom det å være gravid og føde barn er en mulighet for deg, anbefales du å gjøre dette før oppstart på testosteron. Dersom du ønsker å fryse egg anbefales det at du gjør dette før oppstart på testosteron. Lov om bruk av nedfrosne, humane egg forutsetter at du selv må gå gravid og føde.

"Surgical treatment - what does the offer consist of?"

Breast removal: Different methods, some cause more scar tissue than others. The choice of technique depends on the size of the breasts, the amount of skin and tissue. You will stay in the ward for 24 hours due to the risk of post-operative bleeding.

Removal of ovaries and uterus: If you experience dysphoria around your inner genital organs it is possible to have them removed surgically. You will need a gynaecological examination prior to such a procedure. This is to check that everything is in order and ready for carrying out a laparoscopy procedure.

This is irreversible surgery that will deprive you of the possibility of becoming pregnant and giving birth to children.

The operation is done on a day surgery basis at Ullevål Hospital. Those who do not live in Oslo spend the night in a hospital hotel before and the night after the operation. Laparoscopic surgery is used, that is, the surgeon operates via instruments inserted into

the abdomen. The ovaries and uterus are removed vaginally. You will be on sick leave after the operation; the length of the sick leave period is individually arranged.

<u>Complications:</u> Post-operative bleeding, infection or urination problems may occur.

"Can I have a penis constructed?"

Yes, two different methods are offered.

Phalloplasty: Skin and tissue from thighs or groin, no function or sexual feeling. Several procedures must be expected over an extended period of time. There is a risk of complications such as bleeding, infection, and tissue death due to reduced blood circulation.

Metoidioplasty: also called "micropenis". The surgeon straightens the clitoris and constructs a urethra (of vaginal mucosa). Testicular prostheses are inserted into the labia majora (external genitalia). You will have sexual feelings and it will be possible to stand and pee. The operation is largely done in one procedure.

<u>Complications</u>: problems with peeing, fistulas or bleeding/infection. The procedure is not for everyone and individual assessments are made in relation to suitability.

"Is there a wait for the surgical treatment?"

Yes, but the length of the <u>wait for surgery will vary</u> because the scheduling of planned (elective) operations is affected by priorities in the emergency treatment of patients (cancer, accidents, etc.) and general management of operations.

Department of Plastic and Reconstructive Surgery (PLA-RH)

It takes about 6 months to get an initial consultation with a plastic surgeon. The waiting period for breast removal is approx. 12 months after the initial consultation with the surgeon and approx. three years for genital construction (12 December 2019).

If you have the opportunity to meet at short notice, you may have a somewhat shorter waiting time. This assumes that someone cancels their scheduled operation.

Department of Gynaecology (GYN, Ullevål)

Offer of operation about 6-8 months after referral

<u>Contact information – Department of Gender Identity Assessment</u> (adults):

Administrative assistant:

Linn Karlsen

Phone: +47 23074160 Monday-Friday 09:00-11:00 and 13:00-14:00

Patient coordinator:

Trude Rømuld

Phone: +47 23 07 49 33 Tuesday+ Thursday 09:00-11:00

Sources:

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Specialist advisors:

Kjersti Gulbrandsen (assessment)

Kim A Tønseth (surgery)

Thomas Schreiner (endocrinology)

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