

## Hormone Therapy Information for Trans\* & Non-Binary People

### **Guidance for Informed Consent**



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### Introduction & aims of the brochure

#### With this brochure we would like to:

- Provide trans\* and non-binary people with a first opportunity to learn about hormone therapy
- Give orientation about what this form of hormone therapy can do on physical and social levels
- Provide assistance for various decision-making processes related to hormone therapy
- Inform which individual circumstances, e.g. medication use or planned parenthood, should be considered before starting hormone therapy
- Inform about challenges which may arise with hormone therapy, e.g., side effects
- Point out that the decision for or against hormone therapy, as well as the form & length of it, should be based on individual needs
- Provide suggestions and questions that trans\* and non-binary individuals can use to prepare for medical consultations.

This brochure is written from a trans\* and non-binary perspective. It is intended primarily for adults who are considering hormone therapy and who are looking for information about their own healthcare. This brochure is not intended to, and cannot, replace an informed medical consultation, but it may be useful in preparing for or supplementing such a consultation. Likewise, this brochure does not replace in-depth information on individual medical and personal issues, but rather aims to provide an overview of questions that may arise.

In preparing this brochure, we have referred to international patient consent statements (Informed Consent), as well as to other sources of information from the medical and the trans\* and non-binary communities. In addition, many experiences from our trans\* and non-binary counseling work have been incorporated into the brochure. We aim to provide an answer to the questions that are often brought to our counseling center and at the same time give a



good overall view of what should be considered before starting hormone therapy.

You should be aware that the long-term effects of hormone replacement therapy are not well studied or fully known. Current study results are based on preparations and dosages, some of which are no longer used today. There may be important health risks or benefits that are not listed in this brochure and that we do not yet know.

We would like to take this opportunity to thank all those who supported the preparation of this brochure: Mari Günther, Dr. Schuler, Prof. Dr. med Sven Diederich and Dorna Lange, as well as the teams of the Personal Trans\* Inter\* Counseling and the Inter\* Project of TrIQ e.V.<sup>1</sup>

We welcome further suggestions, additions and comments to the brochure.<sup>2</sup> Feel free to write to: **beratung@transinterqueer.org** 

Samuel Baltus & Luan on behalf of TrIQ e.V.

Latest version as of: 20.09.2021

<sup>2</sup> Note on language: For further info sources, the language is usually German, unless otherwise stated. We are also happy to receive further info sources in different languages and will gladly include them in our database.



<sup>1</sup> TransInterQueer, registered association

### **1.** Personal questions to clarify your needs

Before you discuss with your doctors whether and how you will undergo hormone therapy, there are some questions you can consider and discuss with yourself and/or with your friends. They can help you be more specific about how hormone therapy can be designed to support your (transition) goals as much as possible. The questions can also be a preparation for your discussion with the doctor.

- Why do I want hormone therapy?
- Is the desire constant, i.e. (almost) always present? If the desire changes, what causes the change (e.g. fluid gender identity, external pressure, insecurities)?
- What do I need to feel (more) confident with my decision to have or not to have hormone therapy?
- If I tried hormone therapy, how would I know it was right for me? How would I know I didn't want the changes (anymore)?
- How would I handle it if I wanted or needed to stop hormone therapy? Could I then find a good way to deal with the fact that some changes in hormone therapy cannot be (completely) reversed?
- Do I (already) have a realistic assessment of how hormones work? What do I need to be able to (better) assess the effect of hormones on me?
- How long (in perspective) do I want to carry out the hormone treatment? In which dosage (e.g. lower dosage, so called "MicroDosing"), is this expectation feasible and realistic?
- What social and physical effects do I expect?
- Do I have any fears or uncertainties about hormone treatment? Which ones?
- Are there options other than hormone therapy for me e.g., social without medical transition?
- Who will support me socially through the changes? (e.g. circle of friends, groups).



- Are there circumstances e.g. pre-existing conditions that require special support in clarifying my needs?
- In which private and professional contexts do I see myself in a few or many years? What effect could the current decision have on this?
- What reaction do I expect from my social and/or professional environment to taking hormones and how is that for me?
- Am I aware that I will permanently need health insurance and the corresponding coverage of costs due to the treatments or that I may otherwise incur high costs?



#### Our tip for the decision-making process

For many trans<sup>\*</sup> and non-binary people, it is helpful to exchange ideas with others who have gone through a similar decisionmaking process. If you are particularly concerned about personal circumstances (e.g. parenthood, illnesses) in the decision-making process, it makes sense to exchange ideas with others. A search engine entry (e.g. "trans Bochum") can usually help you find local groups or counseling centers. If you don't find an exchange possibility in your area, ask at the next possible place in your region if they know about non-publicly advertised possibilities. Many counseling centers also offer email and phone or video counseling regardless of where you live.

There are also opportunities on the internet to share information about hormone replacement therapy regardless of where you live, e.g., here:

FtM-Portal : German website for trans\* men and other people who have been assigned female but do not (only) feel that way: forum. ftm-portal.net/

Exchange opportunities for young people:

RainbowchatoftheQueerLexicon:queer-lexikon.net/regenbogenchat/ IN- & OUT-counseling (up to 27 years): comingout.de/

Social platforms, e.g. Facebook or Reddit, can also provide opportunities for exchange.



### 2. Basic information about hormone treatment

#### a. Mode of action of hormones

#### What are hormones?

"Hormones are messenger substances in the body, which are produced by the body. They are necessary for the functional processes in the body, which they regulate, control, activate or deactivate. (...) In total, there are about 25 hormones in the human body. Each of the hormones does not work by itself, but it is a complex hormone system: If you change one, all [more precisely: some] others will change with it. As a result, when testosterone is administered, close attention must also be paid to the other body values." (TransMann e.V. website, Jan. 20, 2020, translation by the authors of this brochure)

There are different varieties of hormones. Testosterone and estrogen are sex hormones.

# Further information on the basic mode of action of hormones

Basic information on hormones, as well as testosterone in particular, on the website of TransMann e.V.:

https://www.transmann.de/trans-informationen/medizinisches/ hormone/

On estrogen:

https://www.netdoktor.de/Diagnostik+Behandlungen/Laborwerte/ Oestrogene-Oestradiol-Oestron+-1191.html



### b. Hormone treatment for trans\* & non-binary people

The general conditions for hormone treatment of trans\* people are summarized in the following text by the MDS<sup>3</sup>, which prepares the guidelines for the health insurance companies. Note: The presentation of the MDS takes only very binary<sup>4</sup> and linear identities and transition courses into consideration, this does not correspond to the broad spectrum of identities and needs that are present in trans\* and non-binary people in reality.

"The start of hormone treatment is usually the decisive switch towards somatic<sup>5</sup> interventions. (...) The goals of hormone therapy are a suppression of the unwanted secondary sex characteristics<sup>6</sup> of the biological sex as far as possible and a formation of the sex characteristics of the desired sex.

Under professional supervision, hormone therapy has an acceptable risk profile. Therefore, before initiating therapy, (...) extensive screening for any risk factors is recommended. (...) The therapy and the determination of the frequency of controls should be performed by a physician experienced in endocrinology." (translated from: MDS Guidelines, p.26)

<sup>6</sup> The characteristics that are added by puberty



<sup>3</sup> Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen (Medical Service of the National Association of Health Insurance Funds)

<sup>4</sup> Binary means: Divided into two. In terms of gender: bisexual. This means the idea that there are only two genders, "male" and "female".

<sup>5</sup> Means: physical

#### More information about hormone therapy for trans\* and non-binary people

S3 Guideline<sup>7</sup> "Geschlechtsinkongruenz, Geschlechtsdysphorie und Trans\*-Gesundheit"<sup>8</sup> from Deutsche Gesellschaft für Sexualforschung<sup>9</sup> (DGfS), AWMF-Register-Nr. 138|001:

https://www.awmf.org/uploads/tx\_szleitlinien/138-001I\_S3\_ Geschlechtsdysphorie-Diagnostik-Beratung-Behandlung\_2019-02. pdf

Patient Guide of the Bundesverband Trans<sup>\*10</sup> to the S3 guideline: https://www.awmf.org/uploads/tx\_szleitlinien/138-001p\_ S3\_Geschlechtsdysphorie-Diagnostik-Beratung-Behandlung\_ 2019-11\_1.pdf

- 8 Translation: Gender incongruence, gender dysphoria, and trans\* health.
- 9 Translation: German Society for Sexual Research
- 10 Translation: German Trans\* Umbrella Association



<sup>7</sup> S3 guidelines are guidelines for physicians and other people in the medical field. There are also S1 and S2 guidelines, the "S" stands for "systematic". This means that S3 guidelines are the most scientifically validated. There must be a large consensus of medical experts and detailed proof of the statements through research, so that a guideline can be called an S3 guideline.

#### c. Individuality of hormone action

In hormone therapy, as in any medical intervention, individual differences must be taken into account. This is evident on three levels:

#### Individual effect

The effect of hormones depends in each case on many characteristics of a body. For example, the intensity of the hormone effect and the speed with which hormones are broken down vary. Influencing factors are, for example, whether, how many and which hormones the body (still) produces, how the body processes these hormones in each case and how old someone is. There are many variations in hormone processing, e.g. depending on how the respective metabolism functions. Intersex people and people with metabolic disorders often need particularly good medical advice here. Also, the continued use of medications can alter the metabolism of hormones (see 6.d.).

#### Individual needs

People feel comfortable with different amounts of hormones; and hormone levels are also somewhat different for everyone in general. For example, young adults often have higher hormone levels than older people. Consistency with standard values, which should be checked regularly by a blood test, provides good guidance here. However, individual well-being should also be taken into account. It may be that a person feels more comfortable with a slightly higher or lower hormone value than with the standard value. It is therefore important to tell your doctor what your needs are.



#### Individual goals

People want to achieve different effects with hormone therapy or have different needs regarding the speed of change. It is not possible to accelerate the hormone effect beyond the speed spectrum of puberty. Because of the damage that may result, overdosing is also strongly discouraged. However, it is possible to slow down the hormone effect by taking lower dosages. This is a common request, for example, from people who want a slow change so that they can observe exactly what happens to their body and what changes they feel comfortable with. Some people also want to achieve a more "androgynous" look and therefore only want to take smaller amounts of hormones. Other people choose to take low doses because of health problems. This low dosage, also called "micro-dosing", should in any case be accompanied by doctors who have experience with it, or have exchanged ideas with an experienced colleague. However, it is not possible to influence when exactly which effect occurs (sequence of effects, time period), because this also depends on the individual body. It should also be noted that the level of hormone dosage can affect libido, i.e. have an impact on sexual life. Hormone requirements are also related to age, so requirements change over the course of a person's life.

## More information on the individuality of hormone therapy

Information on the website of TransMann e.V.:

https://www.transmann.de/trans-informationen/medizinisches/ hormone/



### 3. On the way to hormone therapy

#### a. Forms of administering hormones

For both testosterone and estrogen/progesterone, there are different forms of administration in each case.

Common forms of administering testosterone are injections, which cover a 3-week or a 3-month interval, or testosterone gel, which is applied daily, usually in the morning.

Common delivery forms of estrogen are pills, which are either swallowed or taken sublingually, meaning they dissolve in the mouth. Other forms of administration include gel or spray for daily use, and estrogen patches. Estrogen interval injections are not used in Germany.

There are also different forms of administration for other medications related to your hormone therapy. Estrogen treatment, in particular, is often supported by other agents that reduce/block the body's previous, natural hormone production, e.g. progesterone, which is usually taken in gel form and supports the development of secondary characteristics. Other supportive medications include GnRH, AndroCur, or spironolactone:

- GnRH (gonadotropin-releasing hormone) is a hormone medication that causes other hormones, gonatropins LH and FSH, to be increased in the body, inhibiting the body's previous hormone production. The drug, for example the preparation Leuprorelin, is usually injected. It is also available as a nasal spray.
- Androcur injections have an anti-androgen effect. Testicular function is inhibited, which leads to a decrease in the concentration of masculinizing sex hormones (including testosterone) in the body. It also lowers sex drive.
- Spironolactone, on the other hand (often abbreviated as "spiro"), decreases aldosterone action and has a suppressive effect on testos-terone formation. The drug is usually taken in pill form.



Testosterone therapy can also be supported with hormone-blocking GnRH drugs. This is mainly done when patients suffer from menstrual bleeding, which then stops (more quickly). However, progesterone drugs are also used for this purpose, e.g. medroxyprogesterone acetate (MPA) as injections or pills. This is a drug that is otherwise used as a contraceptive for cis women and causes menstrual bleeding to stop.

Since there are different combinations of medications that can be considered for hormone therapy, it is important to be aware of the medications that can be used and to consider different options with your doctor. It should be noted that specific side effects can occur depending on the medication or preparation and that the combination of different medications can also cause side effects.

# Additional resources on medication administration and dosing:

Info for transfem people: https://www.transfemscience.org/articles/

Info for transmasc people:

https://www.reddit.com/r/TestosteroneKickoff

We will gladly add further sources of information here. Please write to: **beratung@transinterqueer.org** 

The delivery methods each have different advantages and disadvantages related to individual needs. In the following, we have compiled some considerations that may play a role in the choice of delivery form. It is important to note that different delivery combinations are also possible under certain circumstances. For example, some individuals use hormone gel to bridge between injection intervals or combine gel and pills for estrogen therapy.



#### (Ir)regularity of the course

When taken daily (by gel or pill), the course of hormone levels is usually quite regular, whereas fluctuations can occur when interval medication (injections) is taken. This means that there may be a (very) high value at the beginning of the interval and a (very) low value at the end of the interval. If necessary, the administration frequency must then be increased, i.e. the drug must be administered again after a shorter period of time.

#### Personal dislikes and health reasons

Individual limitations may also be decisive for the choice of medication, e.g. fear of injections, tendency to severe bruising when injected, aversion to cream application, skin irritation and skin problems when cream is applied, stomach problems when taking pills. Estrogen pills lead to increased liver stress and increase in risk of thrombosis, so overall health should be included here. Alcohol-based gels can be a problem for people who cannot or do not want to consume alcohol, or people with neurodermatitis.

#### Mental reasons & everyday life

Possible advantages with injections are that there is no need to deal with hormone therapy for a longer period of time and that the intake does not have to be integrated into the daily routine, as well as being done on one's own responsibility. However, daily medication use can reinforce daily structure or be framed as a daily time of self-care.

The goal in choosing the form(s) of administration should be to find the way that suits you best, e.g. your daily routine or your individual tolerance.

The prescription of hormone preparations for the treatment of trans\* and non-binary people is an off-label use , i.e. a use of the drug for a use other than that for which it was (originally) approved. The MDS comments on this as follows: "In Germany, there are no drugs with a special approval for use in transsexualism on the market so far, so that hormone replacement therapy for persons with transsexualism is basically an "off-label use". However, existing approvals can be interpreted broadly." (translated from: MDS Guidelines, p.26) Hopefully, in the future, specific medications will be developed for trans\* and



non-binary individuals, or the medications, their approval, and package inserts will be adapted for use for hormone therapy in trans\* and non-binary individuals.

To note: If you have allergies, it is best to discuss this with the doctor treating you, also with regards to the form of administration. Certain hormone preparations use peanut oil as a carrier, for example.

# Further information on forms of administering hormones when traveling

When traveling, it should be borne in mind that transporting hormones in suitcases or hand luggage may raise questions at controls. It may be worth considering whether it makes more sense to inject the medication in advance so that it does not have to be transported, to take syringes with you so that you have to take fewer packages of medication, or to take creams or pills with you so that you can take them on your own-i.e. independently of medical professionals at your destination. In addition, you should consider carrying a letter from the attending physician and be aware of the regulations regarding the transport of medication. The doctor's letter should refer to these regulations of the transport of medication and also state that the medication is for personal use. It should preferably be written in the language of the respective country of travel and in English.

K.Winkler-Crepaz, A.Müller, B.Böttcher, L.Wildt: "Hormon-behandlung bei Transgenderpatienten", In: "Gynäkologische Endokrinologie", 2017, Open Source Link: https://www.link.springer.com/content/ pdf/10.1007/s10304-016-0116-9.pdf



#### b. Prerequisites for hormone therapy

Whether trans<sup>\*</sup> and non-binary people can start a hormone therapy is at the discretion of the respective therapists performing the hormone therapy, who in turn refer to medical guidelines. In our experience, the costs for hormones, as long as they have been prescribed by a doctor, are covered by German or EU health insurances even if no prior application has been made to the insurance company. From the point of view of those affected, this can also avoid lengthy bureaucratic processes with the health insurance companies.

Any doctor licensed by the health insurer can issue a prescription for hormones and carry out the treatment. If another practice has already started the treatment - after a competent assessment - many family doctors, for example, will continue the treatment. This means that once hormone therapy has been started, it is usually possible to continue it in another practice without any problems.

For the start of hormone therapy or the prescription of hormone preparations, the treating physician usually requires a letter of indication with a diagnosis and recommendation of the desired treatment. This indication letter is usually issued by a therapeutic practice, either a psychologist or psychiatrist, who specializes in trans\* and non-binary people. However, some doctors in Germany also prescribe hormones through carefully conducted Informed Consent procedures, which may also include certificates issued after detailed information by trans\*/ non-binary counseling centers.<sup>11</sup>

<sup>11</sup> The S3 guideline explicitly mentions the possibility of an informed consent procedure (p.12/13, cf. also the International Guidelines according to S3 guideline, p.43).



# More information about the prerequisites of hormone therapy

Current guideline of the MDS, as of Aug. 31, 2020:

https://www.mds-ev.de/fileadmin/dokumente/Publikationen/GKV/ Begutachtungsgrundlagen\_GKV/BGA\_Transsexualismus\_201113.pdf

S3 Guideline "Geschlechtsinkongruenz, Geschlechtsdysphorie und Trans\*-Gesundheit" of the Deutsche Gesellschaft für Sexualforschung (DGfS), AWMF-Register-Nr. 138|001:

https://www.awmf.org/uploads/tx\_szleitlinien/138-001I\_S3\_ Geschlechtsdysphorie-Diagnostik-Beratung-Behandlung\_2019-02. pdf

",Leitfaden Trans\* Gesundheit" (patient guide to the S3 guideline) of the Bundesverband Trans\*:

https://www.awmf.org/uploads/tx\_szleitlinien/138-001p\_S3\_ Geschlechtsdysphorie-Diagnostik-Beratung-Behandlung\_ 2019-11\_1.pdf



#### c. Indication letter

An indication letter for hormone therapy should include the following:

- Therapeutic framework (number of sessions, topic of therapy, etc.). Suggested wording: "Patient A. has been undergoing accompanying psychotherapeutic treatment with me since (date). The topic of the therapy is (among others) A.'s need for transition in the sense of a medical gender reassignment. So far (...) sessions have taken place, current sessions are scheduled in a (...) weekly interval. The duration of therapy so far is .... months.<sup>12</sup> Psychotherapeutic adjunctive treat-ment is provided according to current standards and official guidelines on "Gender incongruence, gender dysphoria, and trans\* health: diagnosis, counseling, treatment"<sup>13</sup> (AWMF, 2019)."
- 12 According to the MDS guideline (translated from p.19), the following benchmarks should be met: "In order to be able to adequately assess whether the disease-related suffering could be sufficiently alleviated by psychiatric and psychotherapeutic means, a sufficiently long treatment period is required from a socio-medical perspective. According to the PT-RL, the shortest structured treatment measure comprises a short-term therapy of 12 sessions of 50 minutes each (if necessary, also 24 sessions of 25 minutes each). (...) The treatment of the pathological suffering with psychiatric and psychotherapeutic means, including diagnostics, should therefore not fall short of a period of six months." According to the S3 guideline, however, "If possible, an attempt should be made to keep the diagnostic process as short as possible, so as not to unnecessarily prolong the psychological strain and not to unnecessarily delay the diagnosis, since negative health consequences for those seeking treatment are evident in a diagnosis of uncertain duration. Securing the diagnosis in the context of a longer-term diagnostic-therapeutic process as a task of psychotherapy (...) or through a course observation or a psychotherapeutically accompanied everyday testing (...) is thus obsolete." Here, the S3 guideline and the MDS guideline of the health insurance fund clearly diverge, although the MDS guideline should follow the S3 guideline. Ultimately, the assessment of the therapist is decisive. The S3 guideline also mentions the possibility of an informed consent procedure (p.12/13, cf. also the international guidelines according to the S3 guideline, p.43).
- 13 Translation: Gender incongruence, gender dysphoria, and trans\* health: diagnosis, counseling, treatment



- Diagnosis, i.e. F64.0 (transsexualism) according to the currently valid international diagnosis catalog ICD-10, or alternatively the diagnosis "Gender Incongruence" (gender-specific deviation) according to the new ICD-11, which will be in effect from January 1, 2022.
- Justification of the diagnosis by the identity and needs of the patient. Suggested wording: "In Patient A., based on A's reports and self-description regarding gender identity, a clearly non-(insert: assigned gender) identity development can be determined. Due to trans-sexuality, there is a profound and enduring (insert: gender identity) identification and a persistent discomfort regarding the gender assignment made by the social environment. It is highly likely that A.'s gender perception will continue to be constant within the described identity framework."
- Statement related to mental health or other diagnoses. Suggested wording: "Patient A.'s wishes to be seen and addressed as (gender identity) and to have gender reassignment treatment (here: hormone therapy) is not due to any mental or psychiatric illnesses that could cause a perceptual disorder or identity insecurity."
- With an existing diagnosis of borderline, schizophrenia, psychosis, DIS (dissociative identity structure), etc., the indication may be formulated as follows, for example:
- "Patient A.'s gender identity is stable even in the context of the illnesses and is not a symptom of the illness. However, A.'s stressful experiences due to gender identity have complicated the course of the disease or delayed treatment. Supporting A. with regard to living the desired gender identity makes sense from a therapeutic point of view in order to promote mental health and increases access to treatment with regard to A.'s illnesses."



 Listing of the patient's therapeutically supported treatment wishes. Suggested wording: "Patient A. has a constant wish to undergo the gender reassignment procedure (here: hormone therapy). It can be prognostically assumed that this gender reassignment measure will have a significant relieving effect on A. with regard to everyday life and psychological stress and will correspond to A.'s gender identity, which has been lived for three years in all areas as far as possible. Therefore, from a psychotherapeutic point of view, the start of the measure is advised."

#### Information about the indication letter

According to the S3 guideline, "the letter recommending bodymodifying treatment (...) should be brief. A reference to the S3 guideline is recommended. It should include.

- 1. the underlying diagnosis of the treatment,
- 2. a statement on the accompanying mental disorders, if any,
- 3. the recommended treatment,
- 4. how well informed the person seeking treatment is about the diagnosis; and
- 5. (the treatment-seeker's informedness about alternative treatment option(s). (Translated from p.49)

Criticism of the poor implementation of the S3 guidelines by the MDS guidelines of the health insurance companies, including the exclusion of non-binary people and longer therapy time before diagnosis:



# Statement of the Scientific Societies (request for immediate revision):

https://www.qz-ts-muc.de/zum-download/presseerkl% C3%A4rung/?fbclid=IwAR3a6Zz\_ogbCWmOUR9fX3op3ZK20fr9qSVOhsdgPx9EZtoWaLyb70LZsrQ

Statement of the Federal Chamber of Therapists (demand for the withdrawal of the MDS guidelines): https://www.bptk.de/keinezwangs-psychotherapie-bei-transsexuellen/?fbclid=IwAR3F2YKpjpm w3xPcFKx6rnSosMm4QWbYxcj8LajoesNPuZLIClypMiB\_7MI

Statement Netzwerk Geschlechtliche Vielfalt Trans NRW: https://ngvt. nrw/stellungnahme-ngvt-nrw-begutachtungsanleitung-des-mds/

Statement of VDGE e.V.: https://www.vdge.org/2020/11/30/dieneufassung-der-begutachtungsanleitung-richtlinie-des-gkvspitzenverbandes-nach-%C2%A7282-sgb-v-geschlechtsangleichendemassnahmen-bei-transsexualismus-icd-10-f64-0/



#### d. Searching for a therapist

To find therapists who are experienced in treating trans<sup>\*</sup> and non-binary people, contact your local queer counseling center or ask your local support group. Upon request, many counseling centers will provide lists of therapists who have received positive feedback from patients. It may also be worth driving to the nearest larger city for therapy or hormone treatment if no one experienced can be found nearby. It is often difficult to find a therapist who is experienced in treating trans<sup>\*</sup> and non-binary people. Sometimes it is necessary to go through the "Kostenerstattungsverfahren"<sup>14</sup>. The counseling centers can usually also advise on the reimbursement procedure.

If you plan to undergo therapy to receive an indication letter for hormone therapy, it is best to inform the therapist directly. It is important to note that every patient with statutory health insurance is entitled to 5 probationary sessions ("test" sessions) with a therapist before the therapy must be applied for with the insurance company. According to the S3 guideline, "if possible (...) an attempt should be made to keep the diagnostic process as short as possible, so as not to prolong the suffering unnecessarily and not to delay the diagnosis unnecessarily, since negative health consequences for those seeking treatment are evident in a diagnosis of uncertain duration." Thus, "securing the diagnosis in the context of a longer-term diagnostic-therapeutic process as a task of psychotherapy (...) or through a course observation or a psychotherapeutically accompanied everyday testing (...) is invalid." (translated from p.23) Therefore, in principle, it is not impossible that the diagnosis (and thus the indication) can already be made within the probationary period. This is at the discretion of the respective therapist.<sup>15</sup>

<sup>15</sup> According to the MDS guideline (see 3.c.), the duration of treatment should be no less than 6 months - this is where the S3 guideline and the MDS guideline of the health insurance fund diverge, although the MDS guideline should generally be based on the S3 guideline (see 3.c.). The S3 guideline also mentions the possibility of an informed consent procedure (p.12/13, cf. also the international guidelines according to the S3 guideline, p.43).



<sup>14</sup> Translation: cost reimbursement procedure

A common experience value in Berlin is about 4-6 therapy months until indication. Depending on how complex the situation is, the diagnosis may take longer. In this case, the therapist should explain in a comprehensible way why it takes longer and how much time is likely needed. In order to be able to estimate which time periods to make a diagnosis or to issue an indication are common in the practice, it is also useful to ask directly.

If you want to have gender reassignment surgery, you will need a longer therapy period, if the costs are to be covered by the health insurance. In Germany, the MDS, the "Medical Service of the National Association of Health Insurance Funds" sets the medical guidelines/treatment conditions for trans\* people. The respective regional office, the MDKs ("medical service of the health insurance") make decisions about cost approvals for requested services, such as sex-reconciling operations, based on these guidelines.

Regarding the treatment requirements for the approval of costs of gender reassignment procedures, the MDS guidelines state on page 35:

"In the case of genital reassignment surgery, living in the desired gender for at least 12 months on a day-to-day basis is generally required (...) in order to enable a fully informed social and medical transition and to minimize the risk for regrets and retransitions. Any deviations from this must be clearly justified by those providing treatment. Individual measures, e.g. epilation treatment, hormone treatment or mastectomy, may also be necessary at an earlier stage to enable everyday experiences. This, too, must be justified by those providing treatment."

This means that for gender reassignment surgery, 12 months of proof of therapy is required according to the current MDS guidelines. During these 12 months, at least 12 sessions of 50 minutes each (or 24 sessions of 25 minutes each, if necessary) should be conducted:

"In order to be able to adequately assess whether the disease-related psychological strain could be sufficiently alleviated by psychiatric and psychotherapeutic means, a sufficiently long treatment period is required from a socio-medical point of view. According to the PT-RL, the shortest structured treatment measure comprises a short-term therapy of 12 sessions of 50 minutes each (if necessary, also 24 sessions of 25 minutes each). With regards to the length of time assigned to psychiatric and psychotherapeutic means



for the treatment of the pathological suffering pressure, at least the duration of a short-term therapy is considered to be necessary to clarify whether the pathological suffering pressure could not be sufficiently alleviated by psychiatric and psychotherapeutic means. Therefore, the treatment of the disease-value suffering pressure with psychiatric and psychotherapeutic means should not fall short of six months, including diagnosis." (translated from MDS Guideline, 08.2020, p.19)

Note: The MDS guideline currently refers only to binary trans\* people. There is no separate guideline for non-binary people, who are explicitly excluded here in reference to the guideline. Thus, there is a gap in care through which the need of non-binary people for gender reassignment or dysphoria-reducing measures cannot be met or made visible. However, the need and requirement of non-binary people for medical care is explicitly stated in the S3 guideline of the Society for Sexual Research and in the corresponding patient guide of the Bundesverband Trans\* (National Trans\* Association in Germany).

It is therefore good to discuss with the therapist whether you want to do a short therapy for the indication for hormones, or a longer one, where - if that is desired - a surgery indication is also possible.

Contrary to misinformation that can be read over and over again, a 3-year everyday test is not necessary to start hormone therapy. The therapy, however, also looks at what your needs are in relation to your environment, especially in the transition. Thus, even though it is a hurdle on the way to hormones, etc., therapy can also be very helpful in dealing with the difficulties of coming out. It's about finding a good way for you to live in a way that makes you feel comfortable.



#### Information about the search for a therapist

Mari Günther, Kirsten Teren, Gisela Wolf: Psychotherapeutische Arbeit mit trans\* Personen: Handbuch für die Gesundheitsversorgung, München, 2019, in particular the chapter "Gestaltung der therapeutischen Beziehung" (p. 192 – 199)



#### e. Searching for hormone treatment providers

To find hormone treatment providers who are experienced in treating trans<sup>\*</sup> and non-binary people, contact your local queer counseling center or ask your local support group. Many counseling centers will provide lists of doctors who have received positive feedback from patients upon request. It may also be worthwhile to travel to the nearest larger city for hormone treatment if you can't find anyone experienced nearby.

You can make an appointment with a doctor's office that performs hormone treatments even before receiving an indication letter. Hormone therapy is often performed by endocrinologists, but there are also doctors from the fields of gynecology, urology, andrology or general medicine who perform these treatments. The waiting times to get an initial appointment are often quite long, so it is worth making an appointment there as early as possible (the same applies to therapists). At the first appointment, preliminary examinations are usually made, so you usually do not need an indication for this. Blood is drawn in order to record the initial values - so that the changes can be traced later. In addition, especially for people who want to take estrogen tablets, a liver ultrasound examination should be performed to avoid or reduce the possibility of liver dysfunction.

#### Information about the hormone therapist search



# 4. Physical and psychological effects of hormone therapy

For the changes, we refer to physician consent forms from the USA, including Lyon Martin Hospital in San Francisco. We caution that this is not a complete list or may not be at the latest state of research. In addition to the effects listed here, we have also received individual testimonials in our counseling work about rarer (side) effects of hormone treatment, e.g., changes in the sense of smell. However, many of these rare/individual effects have not yet been studied. If you notice unexpected changes, talk to your doctor about them.

#### Weitere Informationen zu Sozialen Effekten der Hormontherapie Effekte in Bezug auf die Sexualität

Jonas Hamm hat in "Trans\* und Sex" (2020, Psychosozial-Verlag) spannende theoretische Überlegungen und qualitative Ergebnisse zusammengetragen, wie sexuelle Lern- und Entwicklungsprozesse bei trans\* Personen ablaufen können

Kapitel "Sexualität" (S. 147-157), dabei im Besonderen "Einfluss von Hormontherapien auf die Sexualität", In:

Mari Günther, Kirsten Teren, Gisela Wolf: Psychotherapeutische Arbeit mit trans\* Personen: Handbuch für die Gesundheitsversorgung, München, 2019

Wir fügen hier gerne weitere Informations-Quellen ein. Schreib dazu an: beratung@transinterqueer.org



#### a. Changes due to estrogen

Estrogen can cause the following **permanent** changes:

- Breast growth and change in the shape of the nipples, with significant, individual (size) differences
- Decrease in testicle size

Estrogen can cause the following **reversible** changes, meaning they may regress when you stop taking the hormones:

- Less acne
- Slowing of hair loss, especially at the temples and crown of the head
- Softer skin, possible change in sensitivity
- Finer body hair, although it does not disappear
- Less noticeable body odor and a change in the quality of underarm perspiration
- Decreased fat in the abdominal area
- Increased fat on the buttocks and thighs
- Decrease or loss of morning and spontaneous erections
- Inability to get an erection hard enough for penetration
- Decreased sex drive and libido
- Decreased sperm production, infertility



Hormone therapy with estrogen **cannot**:

- eliminate hair follicles
- change the bone shape
- change the voice pitch
- change body size
- protect against sexually transmitted diseases
- guarantee infertility

It can take several months for the feminizing effects to become noticeable and up to five or 10 years to reach their maximum. The speed of these changes is different for each person.

There is no way to definitively predict how or how quickly your body will change and respond to hormone therapy. The right dosage for you may not be the same as someone else's.

More information about changes due to estrogen



#### b. Changes due to testosterone

Testosterone can cause the following **permanent** changes:

- Increased hair growth on the face, arms, legs, chest, back, and abdomen
- Hair loss, especially at the temples and crown of the head, up to complete baldness
- deepened voice
- Enlargement of the clitoris, altered sensitivity
- Cartilage growth, e.g. nose or feet

Testosterone may cause the following **reversible** changes, meaning they may change back when you stop taking testosterone:

- Increased libido and changes in sexual behavior, similar to those seen during puberty
- Increased muscle mass
- Decreased fat in the face, breasts, buttocks & thighs
- Increased fat in the abdominal area
- Increased sweating and changes in body odor
- Increased appetite, weight gain and water retention
- Prominence of veins and coarser skin, possible change in sensitivity
- Acne on the face, back, and chest, especially in the early years of treatment, which, if severe, can lead to permanent scarring
- Vaginal atrophy, which is dryness and itching that can occasionally cause pain with vaginal penetration
- Changes in mood
- Absence of menstruation
- Infertility



Testosterone cannot:

- change body size
- change bone structure
- protect against pregnancy
- protect against sexually transmitted diseases
- guarantee infertility

It can take several months for the masculinizing effects of testosterone to become noticeable and up to five or more years to reach their maximum. The speed of these changes is different for each person.

There is no way to definitively predict if, how, or how quickly your body will change and respond to hormone therapy. The right dosage for you may not be the same as someone else's.

More info about the changes due to testosterone

Info on testosterone therapy on the website of the TransMann e.V.:

https://wwwtransmann.de/trans-informationen/medizinisches/ hormone/

An easy(er)-to-read overview of testosterone therapy is offered in the book by Martin Licht: TM-Brevier, das Handbuch für Transmänner (translation: TM-Brevier, the handbook for transmen.), Chapter 4, p.52 - 62, Hamburg 2012



#### c. Speed of change

There are many individual factors that influence the speed of the changes, e.g. they often occur more slowly at a higher age. Also, not all changes occur in every person. The following tables show average reference values for orientation.

Effect	Expected onset <sup>17</sup>	Expected maximum effect <sup>17</sup>
Skin oiliness/acne	1-6 months	1-2 years
Facial/body hair growth	3-6 months	3-5 years
Scalp hair loss	> 12 months <sup>18</sup>	Variable
Increased muscle mass/ strength	6-12 months	2-5 years <sup>19</sup>
Body fat redistribution	3-6 months	2-5 years
Cessation of menses	2-6 months	n/a
Clitoral enlargement	3-6 months	1-2 years
Vaginal atrophy	3-6 months	1-2 years
Deepened voice	3-12 months	1-2 years

Table 1: Effects and expected time course of masculinizing hormones<sup>16</sup>

Source: World Professional Association for Transgender Health (WPATH), 2012: Standards of Careforthe Health of Transsexual, Transgender, and Gender-Nonconforming People, p.37

19 Significantly dependent on amount of exercise.



<sup>16</sup> Adapted with permission from Hembree et al.(2009). Copyright 2009, The Endocrine Society.

<sup>17</sup> Estimates represent published and unpublished clinical observations.

<sup>18</sup> Highly dependent on age and inheritance; may be minimal.

Table 2: Effects and expected time course of feminizing hormones<sup>20</sup>

Effect	Expected onset <sup>21</sup>	Expected maximum effect <sup>21</sup>
Body fat redistribution	3-6 months	2-5 years
Decreased muscle mass/strength	3-6 months	1-2 years <sup>22</sup>
Softening of skin/decreased oiliness	3-6 months	Unknown
Decreased libido	1-3 months	1-2 years
Decreased spontaneous erections	1-3 months	3-6 months
Male sexual dysfunction	Variable	Variable
Breast growth	3-6 months	2-3 years
Decreased testicular volume	3-6 months	2-3 years
Decreased sperm production	Variable	Variable
Thinning and slowed growth of body and facial hair	6-12 months	>3 years <sup>23</sup>
Male pattern baldness	No regrowth, loss stops 1-3 months	1-2 years

Source: World Professional Association for Transgender Health (WPATH), 2012: Standards of Careforthe Health of Transsexual, Transgender, and Gender-Nonconforming People, p.38

<sup>23</sup> Complete removal of male facial and body hair requires electrolysis, laser treatment, or both.



<sup>20</sup> Adapted with permission from Hembree et al.(2009). Copyright 2009, The Endocrine Society.

<sup>21</sup> Estimates represent published and unpublished clinical observations.

<sup>22</sup> Significantly dependent on amount of exercise.

#### More information on the speed of change

Source of tables 1 and 2: Current MDS guidelines, p.26/27, https://www.mds-ev.de/fileadmin/dokumente/Publikationen/GKV/Begutachtungsgrundlagen\_GKV/BGA\_Trans\*sexualismus\_201113.pdf

Original source on the MDS guidelines table:

Hembree, W. C., Cohen-Kettenis, P. T., Gooren, L., Hannema, S. E., Meyer, W. J., Murad, M. H.,... & T'Sjoen, G. G. (2017). Endocrine treatment of gender-dysphoric/gender-incongruent persons: an Endocrine Society clinical practice guideline. The Journal of Clinical Endocrinology & Metabolism, 102(11), 3869-3903



# 5. (In)fertility & health precautions in hormone therapies

Hormone treatment for trans\* and non-binary people can have significant effects on fertility: It may be more difficult or even impossible to have genetically related offspring in the future, i.e. to father or bear a child yourself.

It is important to deal with this fact before starting hormone treatment and to weigh up how it will affect your own family planning. To do this, it may be useful to look at different family models, e.g. co-parenting, adoption, foster parenting, shared responsibility for children within a shared home.

Similarly, the possibility of preserving sperm or eggs prior to hormone treatment should be considered. This option is offered by various family planning centers in Germany. Sperm banks and counseling centers can help you find out whether your health insurance will cover the costs.

For many trans\* and non-binary people, the possibility to reproduce, i.e. to have children, and to live with and accompany (their own) children, was and is restricted by laws and by their access to money, housing, work and other resources. Examples include legislation that requires sterilization in order for people to change their gender registration, as was the case in Germany until 2011. Or the exclusion of adoption options. Or the removal of children from their parents because it is assumed that they cannot take good care of them due to their identity. Lack of access to health care, e.g. trans\* and non-binary sensitive prenatal classes, specialists and hospitals is also such a limitation. These limitations or impediments affect other queer people as well as people affected by racism or disability, chronic illness, poverty, and social exclusion. The more factors a person is affected by, the more difficult it can be to access self-determination of one's own reproductivity. Moreover, this can also mean limiting access to abortion or protection from unwanted pregnancy. Under the rubric of "reproductive justice," these exclusions are also made visible in various publications and discourses, and access is fought for.



Trans\* and non-binary people find different strategies for dealing with these limitations. Such coping can be, for example, making visible grief and anger about these circumstances. Or trying to change laws and resource access. Or building alternative family models within the existing constraints.

Likewise, it is important to come to terms with the fact that even with hormone treatment, gynecological or urological preventive examinations may still be necessary or even increasingly important.

Check out the PDF version of this brochure for more information on trans\* parenting and healthcare.

# Information on (in)fertility and health precautions for hormone treatment

Info on trans\* and non-binary parenting:

Sascha Rewald: Elternschaften von trans\* Personen (Translation: Parenthoods of trans\* people), In: Appenroth/ Castro Verela (Hrsg.): Trans & Care – Trans Personen zwischen Selbstsorge, Fürsorge und Versorgung

(Translation: Trans persons between self-care, caring and treatment), p. 187-200, Bielefeld, 2019

Article on trans\* parenting with more links:

https://www.regenbogenportal.de/informationen/transelternschaft

Working group on parenthood at the Bundesverband Trans\*: https:// www.bundesverband-trans.de/unsere-arbeit/agen/

Queerulant\_in magazine, issue 8: Trans\* und Elternschaft (Translation: Trans\* and parenthood), https://www.queerulantin. de/?page\_id=796, english translation: https://www.queerulantin. de/?p=840



Queer Midwifery Collective Cocoon:

https://www.cocoon-hebammenkollektiv.de/unser-team/

Health Care:

English website, services in different languages offered by the project "Casa Kua" in Berlin, a TIN community center and health center organized by BIPoC TIN people: https://casa-kua.com/



### a. (In)fertility & health precautions during estrogen therapy

Hormone therapy is not a contraceptive method. If you have sex with a person where pregnancy is possible and pregnancy is undesirable, you should use contraception, for example, condoms.

Hormone therapy does not protect against testicular cancer. You will still need screening if you have not had an orchiectomy, i.e. removal of the testicles.

Likewise, it does not protect against prostate cancer; again, you will still need screening exams. Even if you have an orchiectomy and/or vaginoplasty<sup>24</sup>, the prostate is not removed during these procedures.

You may need more screenings than others your age. You should have these checkups to make sure your body is healthy during hormone therapy.

Discuss the dosage of your hormones with your healthcare provider so that you do not underdose or overdose. Overdose leads to an increased risk of side effects, especially thrombosis.

## Information on (in)fertility and preventive health care with estrogen use

Section "Das selbstbestimmte vorzeitige Beenden der eigenen Fertilität" (Translation: The self-determined premature termination of one's own fertility), p. 174-175, In: Mari Günther, Kirsten Teren, Gisela Wolf: Psychotherapeutische Arbeit mit trans\* Personen: Handbuch für die Gesundheitsversorgung, München, 2019

<sup>24</sup> Surgical construction of a (neo)vagina

### b. (In)fertility & health precaution with testosterone therapy

Testosterone is not a contraceptive method: even if menstruation is absent, an egg can still be ovulated. Pregnancy is less likely while taking testosterone, but possible. If you have vaginal sex with someone who can produce sperm and pregnancy is not desired, you should use contraception such as condoms.

Testosterone can cause severe pregnancy complications if you become pregnant while taking it. If you want to get pregnant, it is best to talk to a doctor who knows about the possibilities. It is sometimes possible to get pregnant even after you have started hormone therapy. However, the hormone therapy must be interrupted for this. You should keep in mind that the hormone changes during pregnancy will cause changes in your body again.

Hormone therapy does not protect against uterine, ovarian, or cervical cancer, so regular pelvic exams and PAP<sup>25</sup> smears are still needed unless a colpectomy<sup>26</sup> has been performed. Even after a hysterectomy<sup>27</sup> and oophorectomy<sup>28</sup>, you may still need regular gynecologic exams and screenings.

Hormone therapy does not prevent breast cancer, so you will still need regular breast exams and/or mammograms<sup>29</sup>. Even a mastectomy<sup>30</sup> does not safely protect against this.

Hormone therapy may require you to have more screenings than others your age. You should take them seriously to make sure your body is healthy during hormone therapy.

If the dose is too high, too much testosterone can be converted by the body into estrogen. This can slow or stop the hormone from having the desired effect. Testosterone levels should be monitored periodically by the doctor through blood tests performed at the lowest level to ensure that a healthy level exists.

- 27 Removal of the uterus
- 28 Removal of the ovaries

<sup>30</sup> Reduction of breast tissue (possibly with removal of glandular tissue) to shape a flat/flatter upper body



<sup>25</sup> Gynecological screening, which is recommended from the age of 20 for the early detection of cervical cancer and should take place annually

<sup>26 (</sup>Partial) removal of the vaginal wall, possibly with closure of the vaginal canal.

<sup>29</sup> Examination by X-rays for the early detection of breast cancer

## Information on (in)fertility and preventive health care with testosterone use

We will gladly add further sources of information here. Please write to: **beratung@transinterqueer.org** 

### 6. Risk of side effects from hormone treatments

Hormone therapy can cause side effects, either from the medication itself, your physical and psychological reaction to the changes it causes, or reactions with other medications you are taking. Talk to your doctor if you take any other medications, have any known medical conditions or allergies, etc. Also ask about possible side effects and read the package insert of your hormone medications (and/or blockers). It can also be helpful to ask other people taking hormones about their experiences with side effects.

If you experience increased depression, anxiety, or suicidal thoughts, you should definitely contact your doctor. There may be hormonal connections that should be clarified and may require a dose adjustment. But the physical changes and altered external perceptions can also be very stressful psychologically. Get help, e.g. find a counseling center or psychotherapist, if your condition does not change through dose adjustment. All in all: Pay attention to possible side effects and consult a specialist accordingly.

In the following list of possible side effects, we refer to medical consent forms from the USA, including Lyon Martin Hospital in San Francisco. In addition, the list has been cross-checked by German physicians who have experience with hormone therapy.

Note: There may be other side effects that are known but not listed here or have not been reported so far. This list does not claim to be complete, but is intended to provide an initial overview. It always depends on the respective hormone



preparation in combination with the individual body and psyche, as well as other medication you may take. In addition to the side effects of testosterone or estrogen therapy described here, there are also side effects that can be caused by other drugs used in hormone therapy (e.g. those mentioned under 3.a.).

More information about hormone therapy side effect

Collection of physician Informed Consent forms from the USA (English & Spanish):

https://wwwtransline.zendesk.com/hc/en-us/articles/229373308-Example-Informed-Consent-Forms-for-Hormone-Therapy



#### a. Possible side effects of estrogen therapy

The following potentially harmful or dangerous medical side effects of estrogen are known:

- Increased risk of blood clots, also called thrombosis, which can lead to significant medical problems (e.g., pulmonary embolism, stroke, brain damage, and/or death). This risk increases if you overdose. In addition, the risk is increased if you smoke tobacco and are over 35 years of age. It is recommended that you do not smoke tobacco. Your doctor can inform you about smoking cessation options if you wish.
- Increase good cholesterol (HDL) and lower bad cholesterol (LDL). This can lower your risk of heart attack and/or stroke in the future. Your doctor should check this before you start hormone therapy and monitor you during hormone therapy with regular blood tests.
- Elevated blood pressure. Blood pressure should be monitored by regular physical exams before starting hormone therapy and during hormone therapy. Certain diets, lifestyle changes, or medications may be needed to keep blood pressure well controlled.
- Elevated liver enzymes, indicating liver inflammation or a back-up of liver products in the bile ducts. This can lead to upper abdominal pain and impaired liver function. Your doctor should check you for liver problems before you start hormone therapy and monitor you during hormone therapy with regular blood tests.
- Possible formation of stones in the gallbladder that may cause discomfort. As long as no symptoms occur, no treatment is usually necessary. If you experience discomfort, such as cramping upper abdominal pain, see your doctor.
- Increasing migraine headaches. If these are severe or prolonged, you should bring them to your doctor's attention.
- Rarely, increasing nausea and vomiting have been reported, similar to morning sickness during pregnancy. If severe or prolonged, you



should talk to your doctor about it.

- Estrogens protect against osteoporosis. Continued underuse or discontinuation of hormones after orchiectomy increases the risk of developing osteoporosis. Your doctor may prescribe supplements, certain foods, and/or exercise to counteract this risk. After a certain age or if you experience an increase in fractures, your doctor may refer you for bone densitometry and/or prescribe medications to increase bone density.
- You may have an increased risk of developing breast cancer. Your doctor may recommend regular breast exams and/or mammograms.<sup>31</sup>
- Possible increase in prolactin levels and/or formation of a pituitary tumor. Your doctor should monitor your prolactin level by regular blood tests before starting and during hormone therapy. If it is elevated, your doctor may recommend decreasing or stopping the hormone dose and/or refer you for brain MRI for monitoring.
- Increased appetite and weight gain are possible.
- It is also possible that mood swings may occur. This is especially true during the period of hormonal transition when taking new hormone medications, but also during the entire period of use.
- When taking estrogen gel: In the case of skin contact, the gel can be transferred to other people and (domestic) animals, provided it has not yet been completely absorbed. Particularly in the case of contact with children, care should therefore be taken to ensure sufficient exposure time (see package insert), or the relevant areas of skin should be covered with clothing to prevent transmission.

<sup>31</sup> At the age of approx. 50-69 years, the costs of these examinations are usually covered by the health insurance companies.



More information about side effect with estrogen intake

We will gladly add further sources of information here. Please write to: **beratung@transinterqueer.org** 

### b. Possible side effects of testosterone therapy

The following potentially harmful or dangerous medical side effects of testosterone are known:

- Possible increased risk of certain gynecological problems, such as vaginal dryness and pain during sexual intercourse. Also, since changes and cancer cannot be ruled out, regular screening is recommended.
- Decrease in good cholesterol (HDL) and increase in bad cholesterol (LDL). This
  may increase the risk of heart attack and/or stroke in the future. Cholesterol
  levels should be monitored by regular blood tests before starting and during
  hormone therapy.
- Elevated blood pressure. Blood pressure should be monitored by regular physical examinations before starting and during hormone therapy. Certain diets, lifestyle changes, or medications may be needed to keep blood pressure well controlled.
- Increased risk of developing or worsening certain diseases (e.g., type 2 diabetes, sleep apnea, and epilepsy). These must then be treated separately from hormone therapy.
- Increased risk of developing polycythemia, an increase in red blood cells that rarely, if severe and untreated, can increase the risk of stroke, heart disease, and blood clots. If you develop polycythemia, your doctor may reduce your dose or recommend a therapeutic phlebotomy (blood donation) and recheck your lab values in 2-3 months.



- Increased risk of skin blemishes and inflammation such as acne. If problems persist or are severe, a dermatologist can help.
- Elevated liver enzymes, indicating liver inflammation or back-up of liver products in the bile ducts. This can lead to upper abdominal pain and/or disturbed liver function. Your doctor should check you for liver problems before you start taking this medicine and monitor you during hormone therapy with regular blood tests.
- Increased risk of developing osteoporosis (thinning of the bones), which may get worse if you underdose after oophorectomy or if you stop taking testosterone. Your doctor may prescribe supplements, certain foods, and/ or exercise to counteract this risk. After a certain age or if you experience an increase in fractures, your doctor may refer you for bone densitometry an/or prescribe medications to increase bone density.
- Likewise, it is possible to experience mood swings. This is especially true during the hormonal transition period when taking new hormone medications, but also during the entire time you are taking them.
- When taking testosterone gel: In the case of skin contact, the gel, insofar as it has not yet been completely absorbed, can be transferred to other persons and (domestic) animals. Particularly when in contact with children, care should therefore be taken to ensure sufficient exposure time (see package insert), or appropriate skin areas should be covered by clothing to avoid transmission.

### More information about side effect when taking testosterone

Website of Transmann e.V.:

https://wwwtransmann.de/trans-informationen/medizinisches/ hormone/



#### c. Possible side effects from hormone blockers

Side effects may also occur with the use of hormone blockers.

In adults, hormone-blocking drugs are sometimes used to support hormone therapy (see also 3.a.).

In the case of testosterone blockers, it is known that some preparations, e.g. Androcur, can cause depression as a side effect. In addition, a decrease with regard to libido and sexual function has been reported. With regard to Androcur, there is also a Red Hand Letter, as the drug can lead to an increased risk of meningiomas, which are benign tumors of the meninges that manifest themselves, for example, as headaches or visual disturbances. Benign and malignant changes in the liver have also been described. All these side effects are dose-dependent, which is why the dosage should be chosen as low as possible (5 - 10 mg daily). Daily doses above 25 mg should be avoided.

It is therefore important to always inform yourself about the side effects of the respective preparation and, if mood changes or side effects occur, to also consider a connection with the hormone blockers.

In addition, hormone blockers can also be used in the treatment of trans\* and non-binary adolescents. In this case, their purpose is to slow down or prevent the development of undesired secondary sexual characteristics. Here, too, it is very important to obtain medical information about possible side effects, also so that they can be recognized as such.



# More information on side effects related to hormone blockers

Red Hand Letter Androcur

Article in the German Pharmacist Newspaper:

https://www.deutsche-apotheker-zeitung.de/news/artikel/2020/ 04/17/anwendungsbeschraenkungen-von-cyproteronacetat-wegenmeningeomen

Download from the Bundesamt für Arzneimittel und Medizinprodukte (Federal Office for Drugs and Medical Devices):

https://www.bfarm.de/SharedDocs/Risikoinformationen/ Pharmakovigilanz/DE/RHB/2020/rhb-cyproteron.html

We will gladly add further sources of information here. Please write to: **beratung@transinterqueer.org** 

### d. Possible side effects with further treatments /existing diseases

In case of existing diseases and treatments, hormone treatment can lead to changes, e.g. a change in effect in case of addiction or depression, or a change in already existing metabolic problems. Since hormone treatment usually has a positive effect on the body perception and thus physical self-care and mental health of trans\* and non-binary patients, these changes can positively influence the course of the disease. Therefore, simultaneous treatment with gender reassignment measures is also recommended by the S3 guideline in the case of a persistent presence of disease:

"In many cases, coming out already leads to, or has already led to, a significant reduction in psychological distress if it occurred before the initial diagnosis. This is especially true for affective disorders and anxiety, but is also not uncommon for symptoms previously assigned to BPD (borderline personality syndrome), which



is not uncommon, for example, in the case of self-injury (...). The initiation of body-modifying treatments also leads in many cases to a decrease not only of the GD (Gender Dysphoria), but also of other possible accompanying psychological symptoms (...). A transition-supportive environment and timely access to body-modifying treatments are considered important protective factors with respect to suicidality (...). In other cases, the mental disorder persists despite adequate treatment of GIK/GD (gender incongruence, gender dysphoria). Here, a longer-term parallel treatment of the intercurrent mental symptomatology should take place according to the guideline for the respective disorder." (translated from S3 Guideline, p.34)

However, there can also be harmful or dangerous medical side effects when combining different medications. If you already have known illnesses or are currently undergoing medical treatment, it is necessary to discuss this with your attending physician and ask about possible mutual effects. Often it is necessary to visit an appropriately specialized medical practice. It can also be helpful to network the respective treating physicians for professional exchange. Specialist literature or studies that deal with corresponding overlaps, or exchange with others who are affected by this, can also help you here.

## Information on possible side effects with existing diseases/treatments

S3 Guideline: https://www.awmf.org/uploads/tx\_szleitlinien/138-001I\_S3\_Geschlechtsdysphorie-Diagnostik-Beratung-Behandlung\_ 2019-02.pdf

On the overlap of addiction therapy & hormone treatment

Magazine "Suchttherapie" (Addiction Therapy), 4th issue 2018, November, pages 161-212, 19th year, theme "Sexuelle Minderheiten und Trans\*" ("Sexu-al Minorities and Trans\*")



### 7. Social effects of hormone therapy

In addition to the physical changes themselves, there are also changes in how others classify and describe your body. People whose bodies have undergone hormonal changes report the following experiences, which may also be or become challenging for you:

#### Change in social perception

Example: many people who substitute estrogen increasingly experience sexism within the hormonal transition, many people who substitute testosterone are more often read as "threatening" by women during and after the hormonal transition.

#### Change in sexuality

Example: some people may feel a change or broadening of sexuality or question the spectrum of one's sexual orientation. If it suits your interests, you may be able to try out new, different spaces and other roles than before to get to know your own sexuality better.

#### Changing the way society assigns roles

Example: People who are outwardly read as (more) female are often socially expected to have caring skills like "listening." People who are outwardly read as (more) male are often socially expected to have technical knowledge.

#### Change in emotional experience

Some report that hormone therapy has changed their emotional thinking and feeling. For example, some individuals experience that it is significantly easier or harder for them to cry or they have a different approach to anger.



### More information on social effects of hormone therapy Effects related to sexuality

In "Trans\* und Sex" (2020, Psychosozial-Verlag), Jonas Hamm has compiled exciting theoretical considerations and qualitative results on how sexual learning and development processes can take place in trans\* people

Chapter "Sexualität" (p. 147-157), in particular "Einfluss von Hormontherapien auf die Sexualität" (Influence of hormone therapies on sexuality) In: Mari Günther, Kirsten Teren, Gisela Wolf: Psychotherapeutische Arbeit mit trans\* Personen: Handbuch für die Gesundheitsversorgung, München, 2019



# 8. Termination or interruption of hormone therapy

Some people realize after some time that they want to de- or re-transition<sup>32</sup>. There can be many reasons for stopping or interrupting hormone therapy:

- You do not feel well emotionally with the changes, it doesn't feel right.
- You suffer from (strong) side effects.
- No changes are occurring.
- Social pressure against transition is high and you don't have the capacity to continue it right now.
- You want to conceive or give birth to a child.
- You realize that the previous changes are enough for you and you don't want any more.
- You learn new things about your gender identity or it changes, e.g. towards your assigned gender, no gender, or a non-binary gender.
- You need a break in order to be able to cope with the changes so far or because you don't want any further upheavals right now.
- ...

32 The terms de- and retransition are quite differently defined and are sometimes used synonymously. What is always meant is reorientation in the social and\_or medical transition, e.g. when a person starts to identify as another gender as in the prozess of transitioning so far and\_or beginns to (re)use other pronouns. Medical processes could include that a person stops taking hormones, or prefers to continue with testosterone after estrogen therapy (or the other way around). Often, the goal of a de- or retransition is to undo (as far as possible) certain medical or social transition steps.



It's okay to stop or realign your hormone treatment at any time. You are free to make your own decisions about your body - the most important thing is that you are comfortable with the changes. No one has the right to tell you whether to transition, for how long, or in what form. You are not accountable to anyone for stopping or redirecting your transition. Whether or not you transition does not determine your gender identity. You can always choose how you gender yourself before, during, and after transition.

It is okay to identify yourself as trans\* or non-binary and not transition medically and/or socially. It is also okay to have had hormone treatment and feel like you belong back to your pre-transition social gender - whether you are physically de-transitioning or not.

Physicians can advise you on whether it may be appropriate for your (transition) goals to adjust the dose of your medications or to interrupt hormone therapy for a specific or indefinite period of time. Depending on whether you have hormone-producing organs (or not) and whether they are active, there are different things to consider when stopping hormone therapy. Community counseling centers can also help you re-transition or de-transition.

De-transitioning people can also be part of the trans<sup>\*</sup> and non-binary community. Sometimes people (continue to) experience trans<sup>\*</sup> and nonbinary hostility after they de-transition because they are not (or no longer) read as cis. Some experiences of re- and de-transitioners are also used for hostile statements aginst trans<sup>\*</sup> and non-binary people. For this very reason, it is important not to be divided and to be in solidarity with each other. There are many shared experiences and common interests regarding a pressure-free, wellinformed and accessible health care and an openness for upheavals in gender positioning.

## More information about stopping or interrupting hormone therapy

Chapter "Re-Transition – Ein neuer Lebensabschnitt" (Re-Transition -A new stage in life), p. 121-127, In: Mari Günther, Kirsten Teren, Gisela Wolf: Psychotherapeutische Arbeit mit trans\* Personen: Handbuch für die Gesundheitsversorgung, München, 2019

Information from Eli Kappo, a non-binary detrans woman:

she sinde transition. word press. com

instagram.com/shesindetransition

English block critiquing transphobic instrumentalization of de-transition (from a de-trans perspective):

https://reclaimingtrans.wordpress.com/home/

We will gladly add further sources of information here. Please write to: **beratung@transinterqueer.org** 

### 9. Imprint

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