**INFORMATION ABOUT TREATMENT WITH TESTOSTERONE**

**(For the Purpose of making a declaration of consent to treatment)**

**What is Testosterone?**

Testosterone is a hormone medication which can help you to masculinise (develop a more male body type) and reduce some more feminine aspects of your body. Before taking the medicine, there are several things you need to know. These are the possible advantages, disadvantages, and risks, as is the case with any medicine that you take. We have listed them here for you. It is important that you understand all of this information before you start taking the medicine so that you can make a decision about whether or not this is the right medicine for you. We are happy to try to answer any questions you may have.

**How is testosterone taken?**

Testosterone can be taken in different ways:

* An injection into a muscle (intramuscular injection)
* A gel applied to the skin (transdermal application)
* Testosterone is **not** available in this service as a tablet or implant

**Managing Change**

The way that you take the testosterone can affect how quickly the changes happen in your body. Some people prefer that they manage the rate of change in their body more slowly. Over time you will have the same amount of body changes whether you choose to use gel or the injection. If you want or need to, we can offer you a dose of testosterone, by either route, which can cause the changes to happen more gradually.

**Who is at higher risk of health problems if they take testosterone?**

**Testosterone MUST NOT be used by anyone who is, or is planning to become, pregnant. If you are thinking of becoming pregnant, please discuss this with us.** You should take a pregnancy test before starting treatment with testosterone if there is **ANY** chance at all that you could be pregnant.

It is important that we understand your full medical history in order to discuss specifically what risks, if any, may be more likely for you.

**Testosterone should be used with caution after a full discussion of risks by anyone who:**

* Has angina or heart disease
* Has breast cancer or other cancers that grow quicker with sex hormones
* Has a family history of breast cancer
* Has had a blood clot (DVT / thrombosis / pulmonary embolism) or is a warfarin user
* Has severe liver disease
* Has a high red blood cell count (also known as polycythaemia or erythrocytosis)
* Has acne
* Uses nicotine, especially in the form of cigarettes
* Has a history of migraine or seizures
* Has a history of depression
* Has pre-diabetes or diabetes
* Has sleep-apnoea

**Blood tests, monitoring, and screening**

Blood tests will be needed to check levels and effects of testosterone. Breast examinations, mammograms and cervical screening in the form of smear tests may **still** be recommended by your doctor in line with the national screening guidelines.

**What testosterone does to your body**

The effects of testosterone vary from person to person, so this is just a rough guide of timescales, which can also be affected by whether you are taking testosterone treatment as an injection or gel.

|  |  |  |
| --- | --- | --- |
| **Effect of Testosterone** | **Expected start of effect** | **Expected end of changes** |
| Increased sex drive | 1-3 months |  |
| Vaginal dryness and thinning of vaginal walls | 1-6 months | 1-2 years |
| Oilier skin and acne | 1-6 months | 1-2 years |
| Increase in amount and thickness of hair on body | 1-3 months | 3-5 years |
| Increase in amount and thickness of facial hair | 6-12 months | 4 years |
| Clitoris growth (on average by roughly 1-3 cm) | 3-6 months | 1-2 years |
| Body fat moves generally from hips and thighs to tummy | 3-6 months | 2-5 years |
| Menstrual period bleeding stops | Up to 6 months |  |
| More red blood cells are made | 3-6 months |  |
| Voice deepens | 3-12 months | 2 years |
| Increase in size and strength of muscles | 6-12 months | 2-5 years |
| Head hair loss | 12 months | variable |

* I know that testosterone may help me appear less feminine and/or **more masculine**
* I understand that it can take **several months** or longer for the effects to become noticeable. I know that no one can predict how fast or how much change will happen.

**How permanent are the effects of testosterone?**

Most of the noticeable changes caused by taking testosterone are **NOT** fully reversible even if you stop taking testosterone.

* Most voice deepening and head hair loss is usually permanent
* Clitoral growth caused by testosterone is permanent although there may be slight reduction in size after stopping
* Body and facial hair changes will decrease but will not usually return to the original appearance
* Menstrual periods will usually return, unless you have reached the menopause.
* Fat, muscle and skin changes will reverse.
* Infertility: The long term effects of testosterone are not fully understood. In the majority of people fertility will be restored within 12 months of stopping. In a small number, the ability for your ovaries to produce eggs may not come back even if you stop taking it. i.e. you may NOT be able to become pregnant if you stop taking testosterone.

If you decide you are unhappy with the effects of testosterone and no longer wish to take it, the NHS is unlikely to provide treatment to reverse changes that have already occurred. But you are entitled to stop taking testosterone at any time.

It is important to recognise that for some people their current gender identity is not permanent. It may be that your gender identity changes in the future and you might not be happy with the permanent changes to your body caused by taking testosterone.

**The effects of prescribed testosterone that are not fully reversible**

* I know that my **facial and body hair** may increase and that if I stop taking testosterone this will not continue to increase but it may not return to the way that it was originally. Treatment to reduce body or facial hair may not be available on the NHS.
* I know that my **voice may deepen** and that it will not return to the original pitch if I stop taking testosterone
* I know that my **clitoris may become enlarged** and that if I stop testosterone it will not return to the original size.
* I know that, if I develop **male pattern head hair loss**, it is very unlikely that any hair that has been lost will grow back.

**The reversible effects of testosterone on the body**

The following changes are usually not permanent and are likely to gradually go away if I stop taking testosterone.

* I know I will probably have more **fat** on my abdomen and less on my buttocks, hips, and thighs. It will be redistributed to a more masculine/less feminine shape.
* I know I may **gain muscle** mass and strength in my upper body
* I know that my skin may become coarser and more oily and that I might develop **acne** or make my existing acne worse.
* I know that my **menstrual periods** may slowly lessen and stop and that if I stop taking testosterone the time that it takes for them to return is uncertain.
* I know that the number of my red blood cells may increase and this may make my blood thicker which increases the risk of developing a **blood clot**.
* I know that my **breasts may shrink** (atrophy).
* I know that testosterone can cause or make headaches or migraines worse.

Some people can experience changes in their mood states with testosterone, the majority noticing an improvement in mood and anxiety. However, some people notice negative changes to their mood such as increased irritability, frustration and anger.

* I know that if my gender dysphoria decreases because of treatment with testosterone, I may have an improvement in my emotional state and sense of general wellbeing.

**The effect of testosterone on fertility**

The long term effects of testosterone on fertility are not fully understood. You might become permanently sterile. In other words, you may not be able to get pregnant even if you stop taking testosterone.

Your body will make less estrogen and progesterone. This may affect your sex life in different ways as well as your fertility.

* Taking testosterone is **NOT a form of** **contraception**. I know that I might get pregnant if I have vaginal intercourse or other intimate sexual contact without contraception.
* I understand that I may have an increased **sex drive** but also experience **vaginal dryness**.
* Getting pregnant whilst taking testosterone can cause the developing baby to be damaged by the testosterone. This is called a **teratogenic** effect.
* The options for **storing of eggs**, to preserve my fertility, have been explained to me.
* Testosterone does not protect me from HIV or sexually transmitted infections and I should use **protective contraception** as usual.

**Menstruation (Periods)**

Testosterone can stop menstruation usually within the first six months of use. If my periods don’t stop then I can discuss a range of other options to stop bleeding with my doctor, if that is important to me.

If your periods persist despite using testosterone therapy, drugs called **gonadotropin releasing-hormone analogues** (GnRHa) can be used to stop them. These drugs are given by injection every few months depending on the preparation used.

**What testosterone can not change**

I know that some parts of my **body** may not change by using this treatment.

* Testosterone is unlikely to change any body image problems that I may have that are not related to gender dysphoria.

I know that some parts of my **life** will not change by using this treatment.

* Although taking testosterone can reduce feelings of gender dysphoria for some people, it will not directly improve mental health problems such as depression if they are unrelated to gender dysphoria.

If you are experiencing difficulties with these areas you may wish to speak to your GP, Clinician or Lead Professional at the Gender Clinic about them.

**Risks of testosterone**

* I know that the side-effects and safety of my treatment are not completely known. **There may be long-term risks that are not yet known.**
* I know that I must not take more testosterone than prescribed, as this will increase health risks and won’t make changes happen any more quickly or profoundly.

**Risk of heart disease**

There is no evidence for an increased risk of heart disease in trans men from testosterone use. However, testosterone has an impact on risk factors which are associated with a higher risk of heart disease.

* I know that testosterone may cause changes that might increase my risk of heart disease. I know that these changes include having:
  + **Higher blood pressure**.
  + Increased risk of abdominal (central) **obesity**.
* I know that my risk of heart disease is higher if people in my **family** have had heart disease, if I am overweight, or if I smoke
* I know that I should have checks of my weight and blood pressure, typically every year, for as long as I take testosterone.
* I know that I should have my cholesterol level checked before treatment and monitored until my dose is stable, then thereafter as advised by my GP.
* I know that testosterone can cause weight gain.

**Risk of blood clots**

* I know testosterone can increase my red blood cell production and this can increase my risk of having a **blood clot, stroke or heart attack**. I know I need to have blood tests with my GP for a full blood count to look at the haematocrit (proportion of blood cells to plasma) every few months when I first start treatment until my dose is stabilised and then once a year, for as long as I take testosterone.

**Risk of cancers**

* I know that my risk of **cancer of the breast** is not known with certainty and I may still be at risk of breast cancer after chest surgery. After surgery, I should aim to be “chest aware” (know what my chest looks and feels like) and report any changes to my GP.
* I know that there is currently no evidence for an increased risk of **endometrial or ovarian cancer** (cancer of the uterus or ovaries) with testosterone treatment although a small increased risk cannot be entirely ruled out. You may want to consider having a **hysterectomy and oophorectomy** (removal of your uterus and ovaries) at some point. If you do not have your uterus and ovaries removed you should report to your GP any symptoms which could suggest a problem with these organs, particularly vaginal bleeding, pelvic pain or abdominal bloating.
* I know that it is important for me to have **cervical screening** in line with national screening guidance

**Other risks**

* I know taking testosterone can thin the tissue of my cervix and the walls of my vagina. This can lead to **tears or abrasions** during vaginal sex play. This raises my risk of getting a **sexually transmitted infection** including **HIV**. I know that I should speak honestly and openly with my GP or clinician about my sex life, to learn the best ways to prevent and check for infections.
* I know that the changes to my body may contribute towards me developing **sleep apnoea** a disordered breathing pattern overnight. I should report symptoms such as snoring heavily, waking gasping for breath or daytime sleepiness to my GP.
* I know that testosterone can increase fluid retention which may make my **ankles swell** and also increase my **blood pressure**.
* I know that testosterone may alter how my body processes sugar, so contributing towards me being more likely to develop pre-diabetes or **type 2 diabetes**.
* I know that testosterone may cause changes to my **liver function** and I know that I have to attend for regular blood tests to monitor this. These changes are usually mild and do not mean I have to stop testosterone treatment.
* I know that for some people their current gender identity is not permanent. It may be that my gender identity **changes in the future** and I might not be happy with the permanent changes to my body caused by taking testosterone.

**Prevention of Medical Complications**

* I know that I must use my treatment at the time and at the **dose recommended by my doctor**, and I should tell my clinic doctor or GP if I have any problems, side-effects or am unhappy with the treatment.
* I know that the dose and type of medication that’s prescribed for me may not be the same as someone else’s.
* I know that some preparations of testosterone may contain traces of **nuts**. I have confirmed my allergy status with my clinician.
* I know I need periodic **blood pressure** and **weight** measurements, and **blood tests** to check for unwanted side effects.
* I know testosterone can **interact with other drugs and medicine**, including alcohol, diet supplements, herbal treatments, other hormones and street drugs. This kind of interaction can cause complications that can occasionally be life-threatening. I know that I need to be honest with my clinician about whatever else I take.
* I know that my risk of medical problems can increase if I have **other medical conditions** and take testosterone. I agree to discuss with my clinician if I know of any medical conditions and to tell them or my GP of any new illness.
* I know that using testosterone during **pregnancy** poses a serious risk to the health of an unborn child.
* I know that I should not breast feed while using testosterone.
* I know that using most of these drugs to promote masculinising body changes is an **off-licence use** that is not approved by the UK medicines regulatory authority for this purpose. I know that the medicine and dose that is recommended for me is based on currently available research evidence, clinical guidelines, and the judgment and experience of my clinician.

**Stopping testosterone**

For most people testosterone will be a lifelong treatment.

* I know that I can **choose to stop** taking testosterone at any time. I know that if I decide to do that, I should do it with the help of my clinician. This will help me make sure there are no negative reactions. I also know my clinician may suggest that I reduce the dose or stop taking it altogether, if the side effects are severe or there are health risks that cannot be controlled.
* I know that if I stop testosterone I may be at risk of osteoporosis and cardiovascular disease if I have had removal of my uterus and ovaries.

**More information**

I know that I can obtain clarification or more information about any aspect of my treatment from the gender clinic.

**Statements:**

* **I have read and understood this information and have no other questions about my treatment**
* I need help with losing weight
* I need help with stopping smoking
* I need help with alcohol or substance use
* I need advice about sexual health
* I need more information about \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**I confirm that I have had the treatment fully explained to me and have had the opportunity to ask questions.** My attention has been drawn to the potential **side effects**, and I understand that if I experience any of these side effects I must seek advice.

**I have agreed that I will only take hormone treatment as prescribed by or recommended by the Gender Identity Service, and that I will avoid using any other hormone treatments.**

I know that for some people their gender identity may change over time. It may be that my gender identity changes in the future and I am not satisfied with the **irreversible changes to my body caused by testosterone**. I am willing to consent to taking testosterone under these circumstances.

I understand that I can **withdraw** from this treatment at any time. If I do so I will inform my clinician.

**Name \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

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**For staff to complete**

I am satisfied that \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ understands the nature of the proposed treatment and has a full appreciation of the consequences of both the treatment in terms of benefits and possible side-effects and also the possible consequences of not undergoing this treatment. They have retained the information contained within this form and are able to communicate their decision to me today.

**Signature \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

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*Leeds GID: Written by hormone prescribers 06/2020*