Patient education for transgender feminizing hormone therapy

- Some transsexual, transgender, and gender non-conforming people choose to take hormone therapy to treat gender dysphoria and others do not.
  - This is a choice based on personal preferences and medical need.
- Hormones are not required to make complete legal transition in California. (Some states or countries require specific surgery to change birth certificate information.)
- Well informed patients with realistic expectations have the best results from hormone therapy.
- If you have any questions about hormone therapy we are prepared to answer them or direct you where you can go to get more information.
  - Asking questions will not jeopardize your chance to get hormone therapy.
- Some effects of hormone therapy are permanent and irreversible.
- Feminizing hormone therapy may include medication to block and/or lower testosterone.
  - Spironolactone is the most common testosterone lowering and blocking medication used in the USA
- Feminizing hormone therapy may include estrogen medication.
  - Various forms of estradiol are the safest and most effective estrogen medications used.
- Some people take only testosterone blocking medication or only estrogen but for most people a combination is most effective.
- Other medications in addition to spironolactone and estradiol may be used for specific situations.
- Each medication used for hormone therapy has certain expected desirable effects and certain adverse effects.
- Each person responds differently to each different medication.
  - Some factors that may influence the positive or negative effects of a medication include age when starting, dose, cigarette smoking, other medical problems, other medications, alcohol and drug use, and the genetic background of the patient.
- Each person has individual hopes and desires for the effects of hormone therapy.
  - It is advisable that you discuss the specific effects you are hoping for with your healthcare team and others you are close to.
  - It is very important that patients and their medical provider discuss expectations and limitations of each type of therapy.
- Feminizing hormone therapy has some possible severe and life threatening side effects.
  - It is important that every patient considering hormone therapy understand how to minimize the risk of these side effects and how to identify the early signs of them.
- Some side effects are common, others are less common.
- Some possible side effects are rare or scientifically possible but we have not proven that they occur.
Spironolactone is a medication that lowers testosterone production and blocks the effects of testosterone (the male hormone).

For most patients spironolactone is safe but some people need alternative medications.

There are other medications that may lower or block testosterone but they may be more expensive, not covered by insurance, or have more side effects.

The effects of spironolactone therapy may include:
- Decreased facial and body hair growth
- Decreased progression of male pattern baldness
- Decreased libido, Decreased erections, Decreased testicle size
- Mild breast growth (irreversible)
- Allow estrogens to have more pronounced effects

The effects of spironolactone are limited because:
- For most people spironolactone alone causes minimal breast growth, body fat changes, and skin changes
- Body and bone structure do not change
- Genital anatomy does not change
- Number of hair follicles is not reduced

The side effects of spironolactone may include:
- Common side effects
  - Decreased libido and erections
  - Mild diuretic but it is rare that people experience excess urination
- Less Common but serious side effects
  - High potassium (potentially life threatening)
    - This may be at higher risk to occur when higher than prescribed doses are taken or when people do not get recommended monitoring blood tests
    - This may be a higher risk to occur when combined with blood pressure medications of the ACEI or ARB types
    - This may be a higher risk to occur in people with kidney disease
      - To reduce the risk of high potassium get blood tests as recommended and check with your medical provider before starting new medications

The effects of spironolactone on mood, behavior, and sexual functioning vary widely between different people. Effects are more pronounced when starting or stopping or changing doses.
- Decreased libido & erections are desirable for some people and undesirable for others. It is important that doctors and patients discuss this before starting.
- Some people experience lower sex drive but feel better about themselves sexually and are therefore more satisfied.
- Some people have a remarkably positive mood effect when testosterone is lowered.
- Some people feel fatigued and depressed when testosterone is lowered.
- Mood and energy may drop but be offset by satisfaction with positive effects of transition.
Education about Estrogens

- Estrogens are the hormone responsible for female secondary sexual characteristics
- Estradiol and various other estrogens have been used for feminizing hormone therapy.
- The effects of estrogen include
  - Breast development (irreversible)
  - Redistribution of body fat (partly reversible)
  - Softening of skin
  - Suppression of testosterone production
    - Requires higher doses when used without anti-androgen
  - Improved mood
  - Shrinkage of testes (partly reversible)
- The effects of estrogen are limited because
  - Degree of breast growth, fat redistribution, skin softening, etc are very variable
    - Breast growth rarely greater than B cup and structure of chest remains male
    - Generally most changes in younger people, least in older people
    - Height, basic body structure, facial structure don’t change
    - Genital anatomy does not change
- It can take several months or longer for the effects of estrogen to become noticeable. No one can predict how fast – or how much – change will happen.
- Maximum changes will usually occur 2-3 years after being on average to high doses of estrogen.
  - Changes may take longer on lower doses but reach the same maximum point.
  - After the body’s maximum possible changes have occurred it is possible and usually advisable to decrease the dose of estrogen to a lower dose to maintain changes
- Estrogen is available in several types and forms
  - Estradiol (oral, sub-lingual, shots, patches, etc – many brand names) is considered the safest type
  - Conjugated equine estrogens (aka Premarin, aka horse estrogen) is still used by some people but is considered less safe
    - Many people are concerned about the ethics of using Premarin because it is collected from the urine of immobilized catheterized pregnant horses
  - Ethinyl estradiol (estrogen in birth control pills) – This is no longer used for feminization due to increased risk of blood clots and death

Estrogen – mood, behavioral, and sexual effects

- Mood swings / “moodiness”
  - It is advisable to be in the best possible psychological condition when starting hormone therapy or changing doses
    - Some people find help by getting support from family or friends, seeking support from others in the transgender community, working with a therapist, and avoiding other severe stresses at the same time
- Decreased libido
  - Despite decreased sex drive many people describe feeling more comfortable or desirable sexually
- Emotional changes especially when starting or stopping or changing dose
• It is advisable when possible to slowly increase or decrease dose rather than make sudden changes in dosage.
• Decrease in sexually stimulated erections
• Changes in sexual interest / orientation

**Estrogen – Side Effects**

• Estrogens can have several side effects. The risk of side effects depends upon type of estrogen used, how it is taken (patch, shot, pill under the tongue, swallowed pill, etc), dose, how long it is taken for, and each patient’s individual risk factors
• For most patients estradiol is safe but it is not safe at any dose if someone has an estrogen dependent cancer.
• Some people have extra risks of harmful effects due to their current or past medical history
• Each person will need to have a discussion with their healthcare providers so they can understand the possible risks and benefits.
• Conditions that may create extra risk of severe side effects include:
  o Cigarette smoking
  o Obesity
  o History of blood clots
  o High risk of blood clot
  o Strong family history of breast cancer
  o Heart disease

**Blood Clots**

• Blood clots that can form in veins and travel to the heart and lungs are the most dreaded and serious side effect caused by estrogen
  o Blood clots are not common
  o Blood clots can be life threatening and may have serious long term effects even when they are not life threatening
  o Signs of a blood clot include a swollen or painful leg, chest pain, shortness of breath
    • Seek medical attention for unexplained or sudden onset of any of these signs
  o Other types of thrombotic conditions such as stroke, heart attack, retinal vein and artery blood clots are increased by estrogens but are still rare

**Common Side Effects**

• Increased weight
  o This can be helped by increased exercise and diet
• Adverse changes in lipid levels
  o This is monitored by fasting blood tests
  o Increases in LDL “bad” cholesterol and triglyceride may increase the risk of heart attack or stroke
  o This sometimes requires treatment with medications
• Increased prolactin levels
  o prolactin is a hormone made by the pituitary gland at the base of the brain
  o Increased prolactin alone is not dangerous
• nausea / vomiting
This can be a problem when starting or increasing doses
It can be treated by reducing dosage or changing to a different form of estrogen
Sometimes an anti-nausea medication may be used

migraine / headache
This is a more common problem for people who already have migraine headache
Effective treatment of migraine before starting estrogen is advised

melasma (skin darkening)
This occurs on the face
Avoiding sun exposure and using sunscreens can be helpful
Avoiding progesterone type hormones can be helpful
Skin bleaching creams are sometimes used

skin irritation from estradiol patches
some people are allergic to the adhesive or other components of the estradiol patch
Changing to a different brand of patch can sometimes help

Less Common Side Effects
Increased risk of cardiovascular events in those over age 50 with other cardiovascular risk factors
Especially those taking progesterones in addition to estrogens
Reducing other risk factors such as cigarette smoking and high cholesterol can reduce this risk

Transient liver enzyme abnormalities (temporarily abnormal liver blood tests)
Damage to the liver is rarely caused by estrogen
Liver health can be helped by reducing other causes of liver disease such as alcohol use, obesity, rapid weight gain or weight loss, certain medications, and avoiding infection with hepatitis viruses

Increased risk of gallbladder stones
Signs of gallstones include abdominal pain especially on the right upper side and triggered by fatty meals
Seek medical attention for any severe or prolonged abdominal pain

Increased risk of diabetes mellitus
Effective treatment of diabetes or pre-diabetes before starting estrogen is advised
Estrogen doesn't commonly cause diabetes but may contribute in people with other risks such as family history and obesity
If diabetes develops in patients on estrogen it is treated in the same way as in other people with diabetes

Increase in blood pressure
Effective treatment of hypertension before starting estrogen is advised
Estrogen doesn't commonly cause hypertension but may contribute in people with other risks such as family history and obesity
Spironolactone helps lower blood pressure.
If hypertension develops in patients on estrogen it is treated in the same way as in other people with hypertension

Regret of irreversible changes
Regret is not common in people with gender dysphoria treated with estrogen
Regret can be reduced by good education and preparation before starting estrogens. Discussing concerns and asking questions to your health care providers is the best way to have accurate expectations about the effects of estrogen therapy.

- Asking questions will not jeopardize your chance of getting hormones.

**Rare Side Effects**

- Liver damage
  - Even in patients with liver disease from hepatitis or fatty liver, it is rare for estrogens to cause harm to the liver.
- Prolactinoma
  - Enlargement of the pituitary gland is rare.
  - Taking excessive doses of estrogen above the prescribed dose may increase the risk.
- Permanent sterility
  - See education section about fertility and hormones.
- Increased risk of breast cancer
  - There is a theoretical risk of breast cancer from hormones, but only a few cases of breast cancer in transgender women have ever been reported.
  - The risk may be higher when compared to men.
  - The risk is not as high as in other women.

**Patient education about fertility**

- Feminizing hormone therapy may interfere with sperm production and other aspects of fertility.
- Permanent loss of fertility due to spironolactone or estrogens is theoretically possible.
- Sperm banking is possible for those who wish to maintain their fertility.
  - Sperm banking before starting hormone therapy is most reliable.
  - It is possible to stop hormone therapy for a period of time and then bank sperm.
    - It may take several months for sperm count and activity to come to maximum after stopping hormone therapy.
  - Sperm banking may be expensive and may not be covered by insurance.
- Hormone therapy is not a reliable means of contraception and other birth control methods should be used for patients who have vaginal intercourse with partners with child bearing potential.

All of the information on this form has been reviewed with me and I understand it and have had any questions answered.

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_Patient / client signature_

I have reviewed all of the information on this form with my patient / client and I am confident that my patient / client understands this information.

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_Clinician name and signature_