Male hormones, hypogonadism and fertility

This booklet provides information about male sex hormones and how they can be affected by pituitary conditions. It also looks at the treatment for this, and possible fertility issues it may cause.

The Pituitary Foundation
For hormones • For health • For life

Contents

Language used in this booklet

This booklet will use the words “male”, “man” and “men” throughout. The use of these words all refers to men, transgender, and non-binary people who are registered with the male sex at birth.

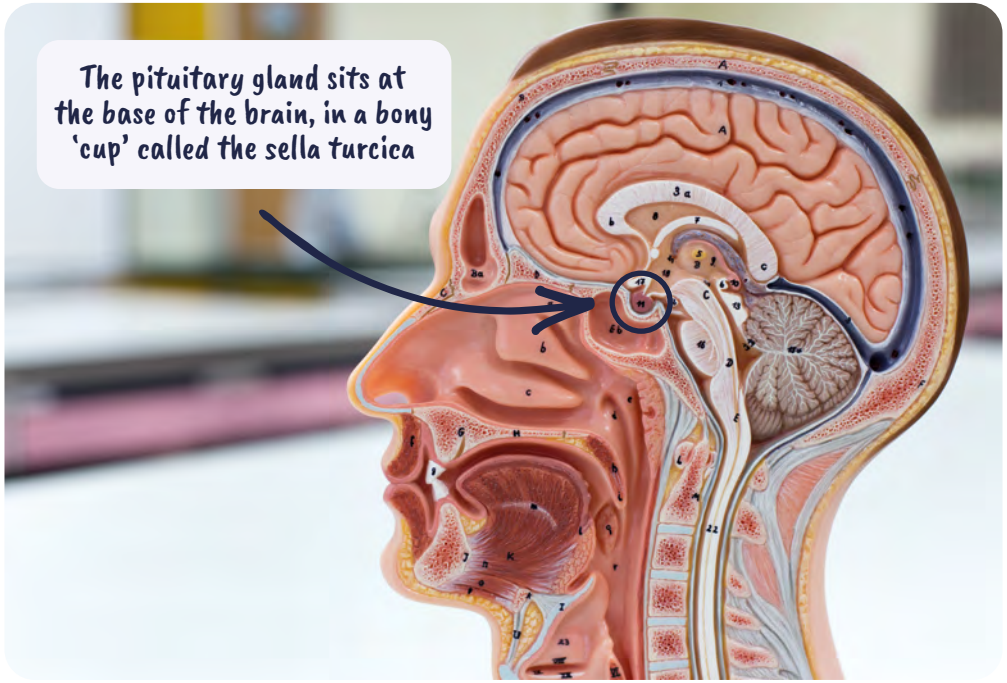
The Pituitary Foundation is always striving to ensure everyone feels more represented in the information we provide for our community. We recognise that the sex you are registered with at birth does not always correspond with your gender identity.

Your pituitary gland and hormones

The pituitary gland

The pituitary gland is a small gland at the base of the brain that makes hormones. Hormones are chemicals that carry messages from one cell to another. These messages can tell your body what it needs to do, and they control a lot of processes in the body, like sleep, hunger and fertility.

The pituitary gland is controlled by another gland that sits above it, called the **hypothalamus**. The hypothalamus sends hormone signals to the pituitary gland, to tell it what to do.



What hormones does the pituitary gland make?

The pituitary gland makes lots of hormones. Some of these hormones are important for male puberty and fertility. These hormones are called **gonadotropins**. The two gonadotropins that the pituitary gland makes are **luteinising hormone** (LH) and **follicle-stimulating hormone** (FSH).

LH and FSH are important for male development and wellbeing. These hormones help your testicles (also known as testes, or balls) work normally.

FSH causes the testicles to make sperm. Sperm is found in semen, which is the fluid ejaculated during sexual activity. Sperm are the cells that join with an egg to cause pregnancy. They contain the genetic information that is passed on to children. If you do not have enough FSH, your sperm levels may be low.

LH causes your testicles to make testosterone. This is another important male sex hormone.

Testosterone

Testosterone is a sex hormone that plays a key role in men's overall health and wellbeing. It is also important for the development of male characteristics during puberty. This development includes:

- increased muscle mass and strength
- increased bone growth, bone mass and bone strength
- deepening of the voice
- growth of the penis and testicles
- growth of facial and body hair
- sex drive (also called libido)
- the ability to get an erection and keep an erection long enough to have sex

What is hypogonadism?

Hypogonadism, also known as testosterone deficiency, is a condition that happens when the body does not make enough testosterone. There are two types of hypogonadism: **primary hypogonadism and secondary hypogonadism**. This booklet looks specifically at secondary hypogonadism. This is referred to as both 'hypogonadism' and 'testosterone deficiency' throughout this booklet.

Primary hypogonadism is when there is damage to your testicles that causes them to not make enough testosterone or sperm. This damage can be caused by many things, including injury, surgery and radiotherapy.

Secondary hypogonadism is caused by a condition affecting the pituitary gland or hypothalamus. This leads to the pituitary gland not making enough of the gonadotropin hormones LH and FSH. Without enough LH and FSH, the testicles cannot make testosterone or sperm properly.

Low testosterone can also affect your sexual health and general wellbeing. This may include sex drive (libido), erectile function, muscle strength, mood and energy levels. The low sperm levels can also affect your fertility.

Testosterone is a sex hormone that plays a key role in men's overall health and wellbeing. It is also important for the development of male characteristics during puberty.

What causes hypogonadism?

A pituitary tumour is the most common reason why the pituitary gland may not make enough LH and FSH. **These tumours are almost always benign**, which means they are not cancerous and do not spread to other parts of the body.

Doctors may use the terms “tumour”, “adenoma” or “pituitary neuroendocine tumour”. These words all refer to a non-cancerous growth in the pituitary gland. As a pituitary tumour grows, it can press on and damage the healthy cells in the pituitary gland. This is what causes the pituitary gland to not make enough hormones, including LH and FSH.

You may have treatment to remove or shrink the size of your pituitary tumour, such as surgery or radiotherapy. Certain tumours (called prolactinomas) can be treated with tablets.

Whilst surgery and radiotherapy do treat the tumour, they can sometimes damage the pituitary gland in the process. This can also affect normal pituitary function.

Hypogonadism is sometimes be caused by cysts in the pituitary gland or serious head injuries.

A pituitary tumour is the most common reason why the pituitary gland may not make enough LH and FSH.

Your healthcare team may refer to your pituitary tumour as a **pituitary neuroendocrine tumour (PitNET)**. This means a tumour that affects hormone-producing cells, such as the cells in the pituitary gland. The term pituitary neuroendocrine tumour is just another name for a pituitary adenoma, which are almost always benign. Some neuroendocrine tumours can be cancerous and occur in other areas of the body, like the lungs and intestines.

It is important to know that whilst a pituitary tumour may be called a neuroendocrine tumour, it is not the same as cancerous neuroendocrine tumours. If you are worried or do not understand your diagnosis, you should speak to your endocrine team.

What are the symptoms?

The most common and noticeable symptoms of testosterone deficiency include changes in sexual function. This may look like a loss of sex drive (libido) and difficulties with erections (erectile dysfunction).

However, you may notice other symptoms, such as:

- loss of body, facial and pubic hair (you may notice yourself shaving less often)
- increased breast tissue (called gynaecomastia)
- reduced muscle strength
- bones becoming thinner and weaker. You may notice your bones break more easily
- physical fatigue and tiredness
- lack of energy
- poor concentration
- changes to mood and overall wellbeing. This may look like feeling more irritable, feeling less confident or a general lack of enjoyment in life

Some of the most common symptoms of testosterone deficiency include low sex drive and sexual problems.

Hypogonadism and fertility issues

Hypogonadism can cause low testosterone levels and low sperm levels. This can impact your fertility and chances of having a baby naturally.

Pregnancy happens when a sperm cell from a male joins with an egg cell from a female. For this to take place, semen must have enough healthy, active sperm cells. If you have a low sperm count, there is a lower chance of a sperm cell joining with an egg cell to create a pregnancy.

If there is a lower chance of you getting someone pregnant naturally, this is called **subfertility**. If you are unable to get someone pregnant after 12 months or more of regular, unprotected sex, this is called **infertility**.

This booklet will talk about both subfertility and infertility.

Diagnosis of hypogonadism and fertility issues

The tests used to diagnose hypogonadism and subfertility are often quite straightforward.

Blood tests

You will have blood tests to measure the levels of important hormones in your blood, which include testosterone, LH, and FSH. Other hormones, like sex hormone-binding globulin (SHBG) and prolactin, are also measured. This is because these hormones can affect testosterone levels.

You should have your blood test early in the morning (before 10 am). This is because testosterone levels are highest in the morning and get lower as the day goes on. You will also be required to fast (no food or drink for at least eight hours before the blood test) as food naturally lowers testosterone levels in the blood.

Your doctor will usually require you to have two early morning blood tests. This is to make sure your blood test results are accurate before you start any treatment.

You will have blood tests to measure the levels of important hormones in your blood.

Sperm count

One of the most important tests to assess your fertility is your sperm count (also known as sperm or semen analysis).

You will be asked to give a sample of your semen. This sample is obtained by masturbation. The sample is then looked at in a laboratory under a microscope to check the number, movement, and overall health of the sperm.

Scans

In most cases, you will need to have a scan of your head to see if there are any problems with the pituitary gland. This could include an enlargement of the pituitary gland or a pituitary tumour.

The scan is usually an MRI (magnetic resonance imaging) scan. An MRI scan shows a detailed image of the inside of your body.

During the MRI scan, you will be asked to lie on a bed that moves into the MRI machine, which has a short tunnel. You will be asked to lie still on the bed as you go through the tunnel for around 30 minutes.

The MRI scan is painless and does not hurt. It can be very noisy, and it may involve being inside the scanner for around half an hour. If you think this will make you claustrophobic or nervous, tell your doctor. They can often give you something to help you relax.

There are also some mindfulness and relaxation exercises you can do to help with MRI anxiety. You can read more about these in our ***Living well with a pituitary condition*** booklet.

If you are unable to have an MRI scan, a CT (computed tomography) scan is an alternative. CT scans are also painless.

Sometimes you may also have a special scan of your hips and spine. This is called a dual-energy X-ray absorptiometry (or DEXA/DXA) scan. This is to check for any sign of bone thinning, known as osteoporosis.

If you are feeling anxious about MRI scans, it can help to talk to your nurse or the person doing the scan to understand why it is important. Knowing why this is important for your health can help motivate you to do the scan. Of course, it's also important to not push yourself if it feels too difficult.

Phil, Helpline Volunteer living with hypogonadism.

Treatment for testosterone deficiency

In men with hypogonadism, the aim of treatment is to replace the missing hormone, testosterone, to restore normal levels. This can help bring back normal sexual function and wellbeing, but does not restore fertility.

The type of treatment that you receive will therefore depend on whether you want to start a family, as this can be affected by some treatments. There are specific treatment options available that can help improve your fertility. These are covered later on.

Testosterone replacement therapy (TRT)

As hypogonadism is a deficiency of testosterone, it is usually treated with testosterone replacement therapy (TRT). TRT can help with many of the symptoms of hypogonadism.

This can include:

- restoring or improving sex drive (libido)
- improving erectile function
- developing male physical characteristics
- improving wellbeing and energy levels
- improving muscle and bone strength

It is important to remember that everyone responds differently to TRT. How much TRT will help your symptoms varies from person to person.

It is necessary to give TRT enough time to work. Some improvements, like a better sex drive and erectile function, can take several weeks. Other improvements, like increased energy levels or muscle strength, can take many months.

It is also important to know that testosterone therapy does not improve sperm count.

This means that TRT does not help improve your fertility. In fact, it can temporarily lower sperm count and reduce testicular size.

If you want to improve your fertility, you should discuss this with your doctor before you start TRT.

I was deficient in testosterone for a long time before I started treatment. Being without for so long, it was quite a shock when I did start treatment. The changes felt more intense at the start. It can take a while for things to settle down, but they did in the end.

Phil, Helpline Volunteer living with hypogonadism.

How to take TRT

There are many different ways you can take TRT. Your doctor will talk with you about the different options. The best method for you will depend on different things, including your medical needs, lifestyle, preferences, and what forms of treatment are available.

Remember that whatever option you choose does not have to be permanent. If you have problems with one type of treatment, or if you would like to try a different option, you can discuss this with your doctor. This section explores the different methods of taking TRT.

Gels

In the UK, there are currently three testosterone gel formulations available. These are:

- Testogel®
- Testavan®
- Tostran®

These gels all contain a bioidentical form of testosterone. This means the drug is chemically identical to the testosterone that is naturally made in the human body.

Your testosterone dose can be easily adjusted or stopped if needed. Each of the gel preparations listed on the previous page has a different concentration of testosterone. This means that the dose you are prescribed to achieve normal testosterone levels will be slightly different with each of these gels.

How to apply testosterone gel

1. Apply the prescribed dose (number of squirts prescribed) once daily to clean, dry, non-hairy skin
2. Where you apply testosterone gel depends on the brand you are using. This may include the upper arms, shoulders, abdomen or inner thighs
3. If you plan to shower or bathe, do so before applying the gel. Apply the gel only after you have finished and your skin is completely dry. Allow the gel to dry completely for a minimum of three to five minutes before dressing or the gel will be absorbed into your clothes
4. Avoid washing, swimming, or showering for four to six hours after application
5. Wash your hands thoroughly after applying the gel

The testosterone is absorbed steadily through the skin throughout the day. This helps to maintain stable, normal blood levels.

Testosterone gel can be harmful if transferred to others, especially children and those who are pregnant or breastfeeding. Avoid letting anyone touch the area where you applied the gel. **If close skin-to-skin contact is likely, keep the application site covered with clothing at all times.** This is also why it is important to wash your hands after applying the gel.

Injections

Testosterone injections are given deep into the muscle (intramuscular). The most common and convenient option used in the UK is a long-acting form called Nebido®. Long-acting medications are medicines that are designed to work slowly and steadily over a long time, instead of all at once. Short-acting injections are also available.

Nebido® injections

The Nebido® injection can only be given by a healthcare professional. It is given approximately once every three months, deep into your buttock (bottom) muscle.

Testosterone levels begin to rise within 24 hours of being given the Nebido® injection. The injection can provide stable testosterone levels for up to 14 weeks.

When starting treatment, the first injection is followed by a second injection shortly after. In most cases, this takes place six weeks later. After this, it is most common for people to have the Nebido® injection every 12 weeks (three months).

Once testosterone levels are stable, some people find that they can go slightly longer than 12 weeks in between injections. How often you have injections will depend on your testosterone levels and how your body responds to the medication.

Short-acting injections

Short-acting injections work very quickly. As the effects only work for a short period of time, you will need to take them more regularly than long-acting injections.

Short-acting forms include:

- testosterone enanthate
- testosterone cypionate
- combinations of testosterone forms (e.g. Sustanon®)

These are typically given every two to four weeks.

Short-acting injections are sometimes hard to get in UK pharmacies because of supply issues. They also lead to greater variation in testosterone levels and side effects, compared to longer-lasting injections. For these reasons, long-acting Nebido® injections have become the main choice for people who want injections.

In men with hypogonadism, the aim of treatment is to replace the missing hormone, testosterone.

What are the main side effects of TRT?

You may have some side effects from using TRT but side effects are usually uncommon. The side effects you have may also depend on what type of TRT you use. Side effects can include:

- headaches
- spots (acne), usually on the back or chest. This is often temporary and usually a sign that your dose is too high
- weight gain and swelling (oedema). Swelling is usually temporary
- painful and long-lasting erections
- male breast tissue growth and tenderness (gynaecomastia). If this does happen, it is usually temporary
- male pattern baldness
- for testosterone gel, you may get some skin irritation where you apply the gel
- reduction in size (shrinkage) of testicles

Many people with hypogonadism also have deficiencies of other pituitary hormones. These deficiencies can cause symptoms similar to the side effects above, such as headaches or weight gain. For this reason, it may be hard to know what changes are from your medication and what are from other conditions.

You should talk to your GP or endocrine team about any side effects you experience.

You will have regular blood tests to see how well you are responding and to check for serious side effects.

How your treatment will be monitored

Blood tests

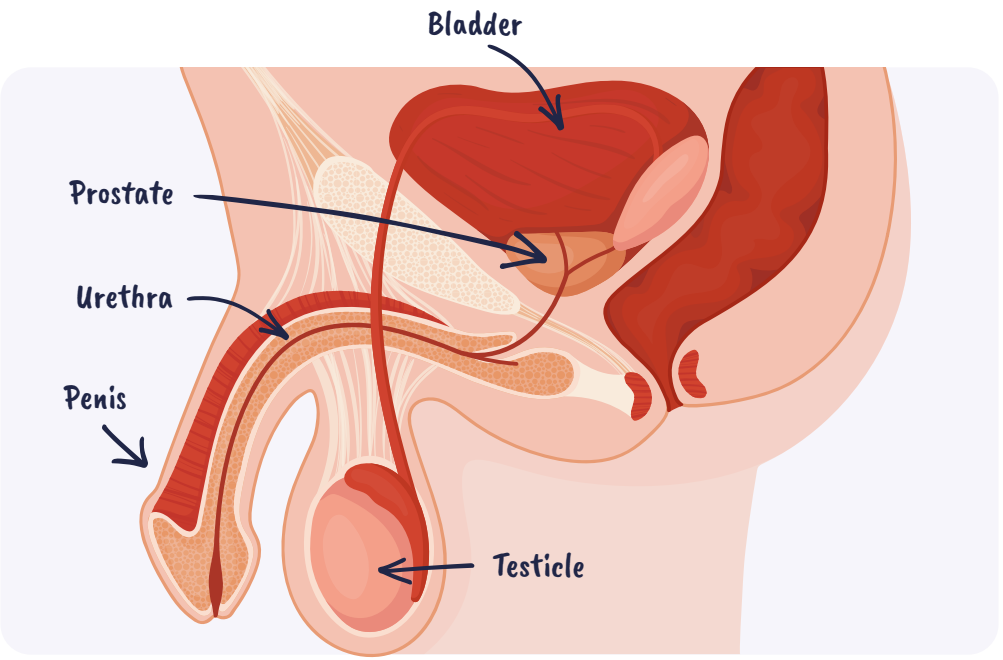
You will have a number of blood tests before starting TRT. These will check your full blood count, liver function, testosterone and other things.

For the first year starting TRT, you will have regular blood tests every three months. This is to check how you are responding to the treatment and to help find the best dose for you. The tests you have will depend on which treatment you are on.

After this, you will move to having check-ups every year.

Prostate checks and PSA tests

The prostate is a small gland below the bladder. It makes semen and controls the flow of pee from your bladder to your penis. The prostate makes a hormone called **prostate-specific antigen** (PSA). When taking TRT, you will have blood tests to measure your PSA levels.



A PSA test is used to check for prostate conditions, like prostate cancer and an enlarged prostate. High levels of PSA may be a sign of these conditions.

You will likely have a PSA test before starting TRT. You will then have further PSA tests after three months, and then again, between six and 12 months. After this, if your PSA levels are stable, you will have these tests every year.

These tests are important as TRT can cause a small increase in PSA levels. In some men, this increase may be larger and mean that more tests are needed to check this.

If your PSA levels are higher than expected, or there are other concerns about your prostate, you may need a prostate exam. You may also need to be reviewed by a urologist, who specialises in the prostate gland.

A prostate exam is a physical exam that a doctor or healthcare professional may do to feel your prostate and check its size and shape. This is also sometimes called a digital rectal exam (DRE).

You may feel anxious about having prostate tests or blood tests, which is normal and understandable. Your healthcare team will talk you through the tests and make sure you feel comfortable. They can answer any questions you have and can help you feel less anxious.

Who cannot take TRT?

Some conditions can make it more difficult for you to take TRT safely. You may still be able to take TRT, but you will need to have a specialist assessment before this can happen. These conditions include:

- breast cancer (in men)
- prostate cancer

If you have had any of these in the past, or think you may have them, you should speak to your endocrine team.

Treatment for fertility issues

As mentioned at the start of this booklet, hypogonadism can cause fertility issues. If your pituitary gland does not make enough LH, FSH, or both, this can affect your sperm levels and fertility. Therefore, you may need fertility treatment to help your body make more sperm. This treatment uses injections that replace the missing hormones, LH and FSH.

The type of medicines used for this are called **gonadotropin injections**. Gonadotropin injections cause the testicles to make both testosterone and sperm. These injections are given just under the skin and you, or your partner, would need to inject them.

The two gonadotropin injections used for this are:

- human chorionic gonadotropin (hCG)
- human menopausal gonadotropin (hMG) or recombinant FSH (rFSH)

You will usually need to be referred to a specialist fertility clinic for this type of treatment.

If you are taking TRT, this will usually be stopped before starting gonadotropin injections.

How long will I need to take gonadotropin injections?

You will usually have gonadotropin injections two or three times a week. The aim is to increase your sperm levels enough to get someone pregnant, or to have enough sperm for assisted fertility techniques, like IVF. It may take up to two years of regular injections to get your sperm levels high enough. However, most men see an increase within the first six months to a year.

You will continue treatment until a natural pregnancy happens. If this has not happened in two years, your treatment will likely be stopped. However, other options for assisted fertility techniques (like IVF) will be explored beforehand. Your healthcare team can talk about this more with you.

Fertility issues can be very difficult to deal with, and you may have feelings of worry, sadness, anger or grief during this time. There is a lot of support available for you and your loved ones to help you with this. You can also contact our helplines or go to our website for more information and support.

You can find more information about fertility support towards the end of this booklet.

What are the main side effects of gonadotropin injections?

Side effects may include:

- pain, redness, and swelling of the skin at the injection site
- stomach ache or nausea
- headaches
- male breast tissue growth (gynaecomastia)

Side effects like gynaecomastia are not very common.

How your treatment will be monitored

You will be checked often to see how well you are responding to treatment, and to check for side effects. Your doctor will also check to see if your dose is correct and can adjust this if necessary. A semen test will also be needed when appropriate.

Common questions about treatment

If I want to improve my fertility, can I have gonadotropin therapy?

If you have secondary hypogonadism and want to improve your fertility, gonadotropin injections (LH and FSH hormones) could help you. These medicines help stimulate the testicles so they can start making sperm again.

How long will I need to take replacement testosterone?

If your pituitary gland is missing or irreversibly damaged, you will need to take replacement testosterone for the rest of your life. As you age, your testosterone levels would naturally decrease anyway, so you may be given less.

Will TRT affect my fertility and chances of having children?

TRT increases your testosterone levels but it will not increase your sperm count. In fact, it can reduce sperm count. However, it does not cause permanent infertility. If your priority is fertility, you should talk to your healthcare team to see what treatment options are best for you.

How do I store my medicines?

All TRT medication can be stored at normal room temperature (up to 25°C). Gonadotropin injections must be stored in the fridge as per the manufacturer's recommendations. If you are taking gonadotropin injections, your endocrine team will talk to you about how to store these.

Can you drink alcohol whilst taking testosterone replacement?

It is fine to drink alcohol while taking these drugs. You should follow the government's advice on limiting alcohol intake to no more than 14 units a week.

Long-term care

If you have hypogonadism, you will likely need long-term treatment and monitoring. This monitoring will be carried out by your endocrinologist and/or your GP. As pituitary conditions are rare, you might be the only person with pituitary-related hypogonadism at your GP.

You may find it helpful to signpost your GP to The Pituitary Foundation. This may help them better understand and support your needs.

Prescriptions

In England, you can get free prescriptions for testosterone if you are an adult male who has a confirmed diagnosis of male hypogonadism caused by a pituitary condition.

Depending on where you live, you may also receive gonadotropin therapy for free if you have a clinical diagnosis of male hypogonadism caused by a pituitary condition.

To get free prescriptions, you will need to get a **medical exemption certificate**. There are forms that you need to fill out to get this certificate. You should speak to your GP, pharmacist or hospital about medical exemption certificates.

You can also find more information about prescriptions and medical exemptions on our website.

Coping with fertility issues

Hypogonadism can affect your fertility and make it difficult to have children naturally. Whilst there are many options available to help with this, it may be the case that treatment does not work.

If you are dealing with fertility issues, this can be very difficult. It is normal to feel a range of emotions when you find out that you are infertile. You may be initially shocked to find out that you can't get a partner pregnant. It is also common to deal with feelings of anger, guilt, or shame towards yourself or your body. It is important to remember that it is not your fault and there is nothing you could have done to prevent having fertility issues.

You may also have feelings of sadness or grief for the future life plans that you had before finding out that you were infertile. This can be very difficult to deal with. Some men feel the need to hide these feelings to appear "strong" for their partner, or their friends and family. It is important to remember that it is completely normal to experience these feelings. Hiding your feelings can make you feel isolated or alone. It is therefore important to talk to your friends or family about how you feel.

Our ***Relationships and Communication*** **booklet** has lots of useful information and tips to help you talk to friends, family, partners and others about your condition and the impacts of this.

If you would like to find out more about treatment options for infertility, and what support is available, you can visit our website or call our **Nurse Endocrine Helpline** or **General Information Helpline**.

There are a number of charities in the UK who support people affected by fertility issues. On the next page, you can find details of who to contact for more support.

If you need urgent emotional support, please contact:

Samaritans - Call 116 123

NHS - Call 111

Emergency services if you are in immediate danger

Useful resources

The Fertility Alliance
www.thefertilityalliance.org.uk
Email: thefertilityalliance@outlook.com
The Fertility Alliance is a national fertility charity offering support and evidence based information to anyone affected by fertility issues.

You and Your Hormones
www.yourhormones.info/endocrine-conditions/male-hypogonadism
Information from the Society for Endocrinology on endocrine conditions

Relate
www.relate.org.uk
Phone: 0333 320 2206
A charity that can offer counselling, relationship advice and sex therapy for individuals and couples experiencing fertility issues

More information

We have a full range of booklets to support people with their pituitary conditions, as well as information across our website. You can find this at **www.pituitary.org.uk**.

If you would like more support then we have a range of services that may be suitable:

Scan to see our website

Endocrine Nurse Helpline

Our specialist endocrine nurses can provide medical guidance.

Information and Support Helpline

Our volunteer- and staff-run helpline allows you to speak to others with pituitary conditions, and ask practical questions about living with a pituitary condition.

Telephone Buddy

This service provides one to one support with someone with a similar pituitary journey as you. For example someone with the same condition, or a parent of someone with a condition.

Support Groups

We have a number of volunteer-led support groups across the UK, which host meetings with endocrinologists and provide peer support for patients.

Events

We host online and in-person events with endocrinologists on specific conditions and topics. These give people the opportunity to hear from professionals and ask questions.

Psychological Support

You can find out more about our psychological support services on our website.

About
The Pituitary Foundation

We're a dedicated team offering practical, emotional and peer support to everyone living with or impacted by a pituitary condition, to feel empowered and live with a greater sense of wellbeing.

For over 30 years, we've been amplifying voices and striving towards positive developments for the pituitary community. We work alongside healthcare professionals, clinical research teams and specialist organisations to raise the profile of pituitary conditions, finding better solutions for everyone affected by these life changing illnesses now and in the future.

Become a member and support our work

Becoming a member is an excellent way to show your support for our work at The Pituitary Foundation.

As a member, you'll enjoy a range of benefits including free copies of Pituitary Life magazine – full of great articles from endocrinologists and inspiring stories from people living with pituitary conditions. You'll also be able to have a say on how the charity is run, and get early access to our fantastic events.

A yearly donation of £25 allows us to continue our work now and in the future.

You can become a member at: **www.pituitary.org.uk/membership**

All information in this guide is general. If you have any concern about your treatment or any side effects please read the Patient Information Leaflet enclosed with your medication, or consult your GP or endocrinologist.

Our publications are supported financially by several pharmaceutical companies, in line with ABPI guidelines, including Ipsen, Merck, Sandoz and Sparrow Pharmaceuticals.

This booklet was produced in collaboration with medical experts and patients with lived experience of pituitary conditions. All information has been verified as accurate by clinicians from our Medical Committee. This booklet holds the PIF TICK quality mark for health information.

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