

A GUIDE TO HYPOPITUITARISM



WHAT IS HYPOPITUITARISM?

Hypopituitarism occurs when your pituitary gland doesn't make enough of one or more pituitary hormones.

Your pituitary gland is the size of a pea and sits at the bottom of the brain. This gland releases hormones that control or play a role in many of your body's functions. It also stimulates other glands to release hormones. If your body doesn't make enough pituitary hormones, other glands that rely on these hormones are also affected.

WHAT CAUSES HYPOPITUITARISM?

There are many causes, such as²:

- **Tumours** – a tumour in or near the pituitary gland can cause pressure on normal tissue and affect hormone levels
- **Surgery** – removing a pituitary tumour can cause temporary or permanent hypopituitarism
- **Radiotherapy** – sometimes, radiotherapy treatment for a brain tumour can damage the pituitary gland.
- **Congenital** - a condition or malformation of the pituitary gland present from birth

Less common causes include:

- Head or brain injury
- Severe bleeding in the brain
- Severe blood loss during childbirth (Sheehan's Syndrome)
- Rare diseases or infections (meningitis, tuberculosis)
- Certain conditions present at birth (congenital)
- Inflammation processes involving the pituitary gland.
- Certain medications e.g long term use of opioids

HOW COMMON IS IT?

Approximately 11,600 Australians currently live with hypopituitarism. Around 1,070 people are diagnosed every year.

WHAT ARE THE SIGNS AND SYMPTOMS?

Signs and symptoms develop gradually and worsen over time. They can be subtle and overlooked for months or years. In some people, signs develop quickly.

Signs and symptoms vary depending on the hormones affected. Having multiple hormones affected can mask the signs of the first deficiency.

COMMON SYMPTOMS (AND TARGET ORGAN AFFECTED)

Growth hormone deficiency (whole body)

- Lack of growth and sexual development (in children)
- Excessive tiredness
- Muscle weakness
- Decreased bone density
- Increased body fat
- Poor quality of life

Adreno-corticotrophic hormone deficiency (adrenal glands)

- Pale appearance
- Low blood pressure
- Dizziness
- Tiredness
- Weight loss
- Stomach pain
- Depression
- Low stress tolerance
- Poor quality of life
- Hypoglaecemia at birth

Thyroid-stimulating hormone deficiency (thyroid)

- Weight gain
- Decrease energy
- Sensitivity to cold
- Constipation
- Dry skin
- Hair loss
- Concentration difficulties
- Prolonged jaundice in babies

Follicle-stimulating hormone / Luteinising hormone deficiency in females (ovaries)

- Oestrogen and progesterone
- Irregular or loss of periods
- Low libido (sex drive)
- Hot flushes
- Loss of body hair
- Vaginal dryness (pain during sex)
- Sleep disturbance

Follicle-stimulating hormone / Luteinising hormone deficiency in males (testes)

- Erectile dysfunction
- Low libido (sex drive)
- Low sperm count
- Infertility
- Loss of facial and body hair

Prolactin deficiency (breast)

- Inability to produce breast milk

Antidiuretic hormone deficiency (kidneys)

- Extreme thirst
- Frequent urination and a large volume of urine (polyuria)
- Signs of Arginine Vasopressin Deficiency (formerly known as diabetes insipidus)

DIAGNOSIS

Tests to confirm a diagnosis include one or a combination of the following tests:

- **Blood tests** – to measure hormone levels
- **Stimulation tests** – to assess the body's response to certain hormones
- **Scans** – a magnetic resonance imaging (MRI) or computed tomography (CT) scan can examine the pituitary gland
- **Vision testing** – to check for eye problems, as tumours can affect the optic nerve.

You may need further tests, depending on your symptoms and results.

Other tests may check your:

- **Adrenal function** – tests include the insulin tolerance test, glucagon stimulation test, short synacthen test and early morning cortisol
- **Growth hormone levels** – a glucagon stimulation or insulin tolerance tests are commonly used to assess adequacy of growth hormone levels
- **Sex hormones** – a blood test to measure sex hormone levels, menstrual history and semen analysis
- **Thyroid function** – a blood test can check thyroid hormone levels
- **Risk of arginine vasopressin deficiency** – urine volume, urine and blood sodium levels, hypertonic saline stimulation test and water deprivation tests.

TREATMENT

Hormone replacement therapy is often the first treatment step. Your dose will match the amount your body would typically produce. The medications you need depend on the specific hormones that need replacing.

Sometimes, treating the condition that causes low hormone levels can correct hypopituitarism.

MISSING PITUITARY HORMONE	MEDICATION
Growth hormone	Growth hormone injections into the fat under the skin: Replaces growth hormone (you will need tests and an application to prove you need it)
Adrenocorticotrophic hormone	Hydrocortisone, cortisone acetate or prednisolone tablets: Replaces cortisol (steroid therapy)
Follicle-stimulating hormone / Luteinising hormone	Oestrogen (patches, gel or tablets) with progesterone (patches, tablets or IUD) (women): Replaces oestrogen or progesterone. In women without a uterus progesterone replacement is not required. Testosterone muscle injection, patches or gel applied to the skin, or tablets (men): Replaces testosterone Gonadotropin (men and women): Induces ovulation or sperm production if you want to get pregnant
Thyroid-stimulating hormone	Levothyroxine tablets: Replace thyroid hormone levels
Antidiuretic hormone	Desmopressin taken by tablets or melt-wafer: Treats arginine vasopressin deficiency

WHAT YOU NEED TO KNOW ABOUT CORTISOL REPLACEMENT THERAPY

Your doctor will work with you to find the most suitable dose. You will take higher amounts in the morning to match your body's natural cycle. If you are sick or stressed, you may need to change your dose to match the natural increase in cortisol that would normally occur.

Your doctor will closely monitor your medications to maintain the right balance. Pituitary hormones interact between themselves and other hormones. Finding a medication regime that works for you can take up to two years.

You may also need to adjust your medications, depending on your symptoms and situation, such as:

- Illness
- Pregnancy and breastfeeding
- Surgery
- Stress
- Trauma
- Weight changes.

After a serious accident or medical emergency, you may need a hydrocortisone injection. Your endocrinologist can give you more advice on this. If you are vomiting or have diarrhoea, seek urgent medical attention. You will not absorb your medication and may need a cortisone injection.

Wearing a medical alert bracelet or tag and carrying instructions for emergency steroid treatment is essential. Low cortisol levels can be a life-threatening emergency.

ONGOING MANAGEMENT

You will need regular check-ups to monitor your:

- Hormone levels
- Medications
- Physical health and wellbeing
- Mental health
- Heart and bone health
- Tumour growth.

COMMON QUESTIONS

If I take hormone replacement therapy, will I feel the same as before my hypopituitarism developed?

Hormone replacement therapy replaces hormones to levels that would occur if your pituitary gland was working normally. However, it is hard to mimic the natural hormone changes that occur in response to everyday experiences.

Everyone is different, so getting the balance right can take a while.

Medications also cause side effects in some people. Always talk to your doctor before changing any medication doses.

Will I still be able to have a family?

In some cases, treatment can restore your sex hormones to normal levels and fertility. Talk to your doctor about your desire to have a family.

How long will I need to take medication?

If you have a tumour or treatment that has affected the pituitary gland function, and your function does not recover, you may need to take medications for life.

You may need a single medication or a combination of tablets, patches, gels or injections.

What are the long-term implications of having hypopituitarism?

Many people need to take daily medication for life to reduce the risk of health conditions caused by missing hormones, like osteoporosis, heart disease and stroke.

Regular visits to your doctor will help find any changes needed to your medication and support your overall health and wellbeing.

MORE INFORMATION

The Australian Pituitary Foundation provides social support for patients and carers, and has published a range of patient resources on pituitary conditions and treatments.

For more information, please visit our website: www.pituitary.asn.au

Email: support@pituitary.asn.au

Phone: 1300 331 807

REFERENCES

1. Regal M, Paramo C, Sierra SM, Garcia- Mayor RV. Prevalence and incidence of hypopituitarism in an adult Caucasian population in northwestern Spain. Clin Endocrinol (Oxf) 2001;55:735-40.
2. Higham CE, Johannsson G, Shalet SM. Hypopituitarism. Lancet 2016;388:2403

Acknowledgement – We are grateful to the members of the Australian Pituitary Foundation for reviewing this information.

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