Information for Patients with Aggressive Pituitary Tumours (APT) and Pituitary Carcinomas (PC)

This patient leaflet is based on the Revised European Society of Endocrinology (ESE) Clinical Practice Guideline for the management of aggressive pituitary tumours and pituitary carcinomas (2025). It was written by a team of international experts in endocrinology, neurosurgery, (radiation) oncology and pathology. The aim is to support patients living with these rare forms of pituitary tumours.

This leaflet does not replace advice from your medical team.

European Society of Endocrinology

What are aggressive pituitary tumours (APT) and pituitary carcinomas (PC)?

Pituitary tumours arise from the pituitary gland; a small organ located at the base of your brain which makes and controls many hormones (see Figure 1 and 2). Most pituitary tumours are benign and grow slowly. However, a small number do not adequately respond to standard treatments like surgery, medication or radiotherapy and they can grow quickly. These are called aggressive pituitary tumours (APT). In very rare cases, the tumour can spread to other parts of the brain or body, in which case it is called a pituitary carcinoma (PC).Early identification and expert management are crucial.

How are APT and PC diagnosed?

Doctors may suspect an APT if your tumour was initially growing into surrounding structures and:

- Grows quickly (within months)
- Continues to grow despite active treatment
- Comes back multiple times after surgery and radiation therapy

You may need:

- **MRI scans** to track size and growth
- **Blood tests** to check hormone levels
- **Eyesight tests** to assess the consequences of the tumour growth
- **Biopsies:** taking a tissue sample to assess tumour cell type and growing properties

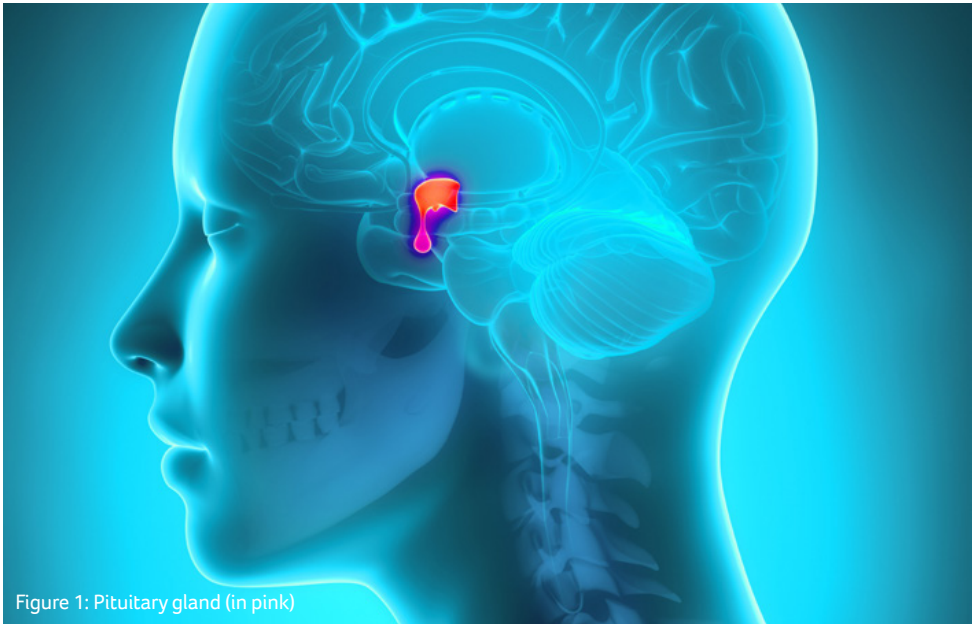

Figure 1: Pituitary gland (in pink)

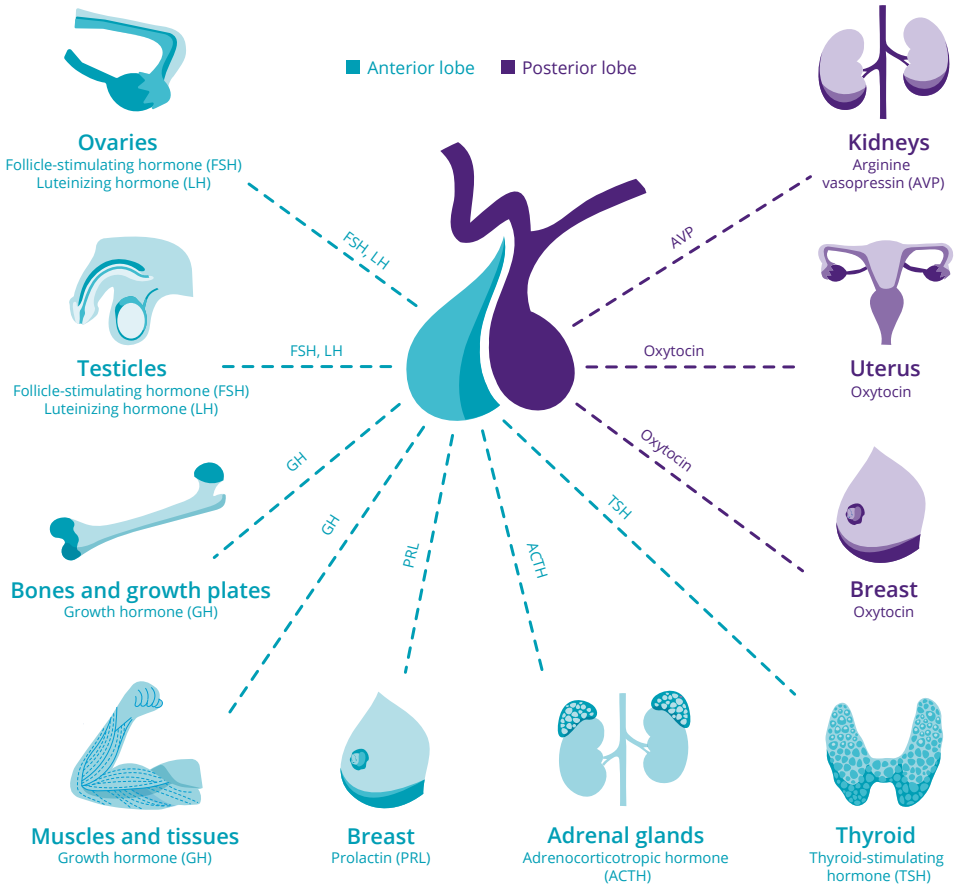

Figure 2: Hormones produced by the pituitary gland

Which tests help predict tumour behaviour?

Certain features in your tumour tissue help doctors predict how it might behave:

- **Pathology characteristics** that measure the pace at which cells are dividing
- **Genetic characteristics:** some tumours may carry changes in genes that impact their behaviour

Tumours with high values of these characteristics, plus signs of growth into surrounding tissues, are more likely to behave aggressively.

What treatments are available?

There are several options to treat an APT. Your doctor will discuss which treatment is most suitable in your case with you.

1. Surgery

- First-line treatment in most cases
- Performed by expert neurosurgeons
- Sometimes repeated if the tumour continues to grow

2. Radiotherapy

- May be used after surgery if tumour remains or regrows
- Could be used as a first-line treatment, alongside medical treatment, in rare instances when surgery is not feasible
- Sometimes repeated if the tumour continues to grow

3. Medication

- If your tumour produces hormones, medication that reduces hormone production may help
- Medication can control both tumour growth and hormone production

4. Chemotherapy

- **Temozolomide** is the most common drug used in treating APT when the tumour does not respond well to the above treatments
- It is taken in cycles and can help shrink or stabilise the tumour

5. Newer treatments (under investigation)

- Clinical trials may be available to evaluate the benefit of new treatments; ask your doctor

Will I need regular follow-up?

Yes. Close monitoring is key in APT/PC:

- **MRI scans** every 2–12 months, depending on tumour growth
- **Blood tests** every 3–12 months to check hormone levels
- **Hormone replacement** therapy may be needed if the tumour, or its treatment, affects the way the pituitary gland works, resulting in a shortage of hormones that the pituitary gland is normally able to produce and that are essential for good health
- **Functional imaging (scans which measure activity in certain tissues)** may be required to assess tumour spread

Q & A

Q1: Is it common for a pituitary tumour to turn into an APT?
A1: No. Although pituitary tumours are common and occur in about 1 in 1,000 people, less than 1% of these tumours become aggressive.

Q2: Is APT the same as cancer?
A2: No. APT is not cancer in most cases. It means the tumour is difficult to control and may behave more aggressively than usual. If it spreads (metastasizes), it becomes cancer and it is called a pituitary carcinoma.

Q3: Can APT be cured?
A3: Some aggressive tumours can be controlled long-term, but cure is rare. The goal is to control growth, preserve vision and hormonal balance and maintain quality of life.

Q4: Can these tumours run in families?
A4: Rarely. Genetic testing may be suggested if you're young or have a family history of similar tumours.

Q5: What can I do?
A5: Stay engaged with your care team, attend regular follow-ups, and ask if you're eligible for any clinical trials. And if you have questions don't hesitate to ask your doctor and/or endocrine nurse.

More information and support
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www.ese-hormones.org/patient-zone

European Society of Endocrinology

T: +44 (0)117 440 6489
E: info@ese-hormones.org

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