

Pituitary Patients Handbook

For those seeking diagnosis,
the newly diagnosed & diagnosed patient



The Pituitary Foundation Information Booklets

The
Pituitary
FOUNDATION

Working to support pituitary patients, their carers & families

The Pituitary Foundation is a charity working in the United Kingdom and Republic of Ireland supporting patients with pituitary conditions, their carers, family and friends.

Our aims are to offer support through the pituitary journey, provide information to the community, and act as the patient voice to raise awareness and improve services.

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Introduction

Perhaps this is the first time you have heard the word ‘pituitary’, or maybe you are already on your journey, and have a certain amount of pituitary knowledge already.

Perhaps you are somewhere in between, being at one stage or another of your own pituitary journey. Whatever stage you have reached, The Pituitary Foundation realises that it can be a bewildering and sometimes isolating experience.

Research and progress can of course slowly change treatments, but we strongly believe that the fundamental issues and questions faced by pituitary patients remain the same. This Handbook has been produced to help you better understand your needs and entitlements, providing information to help you from pre-diagnosis onwards.

To help you find information quickly and relative to your stage of your pituitary journey, there are easy to find, clear sections, from seeking a diagnosis, through to being newly diagnosed, and then for all patients who are diagnosed and on their journey.

Fellow patients have thought long and hard about the many presenting symptoms of pituitary disease and also considered the relevant questions you may like to ask your GP and/or consultant. We’ve considered, and included, the problems that we as pituitary patients have experienced through our own particular journeys and included as much information as possible to best support you and those who care for you - your family and friends.

The Pituitary Foundation offers a range of services and information to support patients and their carers:

Helpline: ☎ **0117 370 1320** -

Monday - Friday, 10:00am - 4:00pm

Endocrine Nurse Helpline:

☎ **0117 370 1317** - scheduled hours only

Website: **www.pituitary.org.uk**

Forum (for subscribed members)

A variety of information booklets & GP Fact File

Pituitary Life magazine (for subscribing members)

National Conferences

Local Support Groups

Trained Telephone Buddies

The Pituitary Foundation Patients Charter

This charter informs you, as a pituitary patient within the United Kingdom and Republic of Ireland, about what The Foundation currently identifies as best medical practice. By understanding what is available, you can be confident that you and your medical management team, are doing the best in your interest. This is a living document. We are striving towards ensuring that all patients have access to the correct and best possible treatment, together with the earliest achievable diagnosis.

For all patients

WE ALL HAVE THE RIGHT TO BE TREATED WITH RESPECT

Although not everyone you meet on your pituitary journey will have heard of or seen the symptoms of pituitary conditions during his/her career, this does not mean the effects are not genuine and deserving of medical care, together with further and appropriate investigations and treatment.

The Pituitary Foundation expects all patients with pituitary conditions to receive equal treatment regardless of age, gender or geographical location within the UK and ROI. This statement should enable its user to gauge his or her satisfaction with their treatment and empower them to ask for a second opinion if they don't believe they are getting the support to which they are entitled.

Once diagnosis is suspected, patients should be referred to a specialist endocrine (tertiary) centre with a full range of expertise available, for further assessment and treatment. An accredited clinical endocrinologist should be responsible for coordinating all treatment, both to ensure proper diagnosis is made and for long-term care. All endocrine referrals should be managed within 18 weeks.

Please note: The exception for patients with (as an example) a small prolactinoma, will be treated appropriately by endocrinologists in secondary care, rather than requiring referral to a tertiary centre.

At the centre it is vital that the following expertise and services are available:

- A Multi-Disciplinary Team (MDT), made up of endocrinologists, pituitary neurosurgeons, (specialist pituitary ENT surgeons where applicable), radiotherapists and other specialists as needed, who meet together and agree management of the patient's condition, whilst in close communication with the patient.
- Pituitary imaging (MRI & CT scanning) should be performed in a centre where pituitary scans are carried out regularly by experienced professionals.
- Vision and visual field testing are readily available.
- Access to bone density (DEXA) scanning should be available.
- Pituitary function testing to be carried out in a fully equipped investigation unit by experienced personnel, including specialist endocrine nurses where available. It is important for both diagnosis and future treatment that the full range of tests are carried out.
- It is essential that surgery is performed by surgeons who specialise in pituitary surgery and so are able to choose the most appropriate method of operation for patients with either 'non-functioning' or 'hormone secreting' tumours (microadenoma and macroadenoma). The endocrinologist should know the outcome of the operation by the surgeon.
- An experienced histopathologist, with a specialised pituitary or endocrine interest, should perform laboratory testing.
- Access to a specialist endocrine nurse who can offer support, educational information, advice and guidance.

For all patients

For your longer-term care it is important that the following should happen:

- Providing education to patients and carers on routine training and regular refresher training in injections of hydrocortisone, as part of annual clinical review or as an annual reminder letter from the GP practice, inviting patients to see a practice nurse for a refresher session.
- Safe management and instruction of their condition and when accessing non- endocrine care or emergency care as appropriate.
- Patients should be provided with a list of symptoms of concern that if they occur should trigger the patient to return to hospital, along with contact details in case of an emergency.
- Smooth transition of young people from adolescent services, supported initially by joint transitional clinics, with support from clinicians from both paediatric and adult services
- All patients should have access to, and receive, detailed explanation of their condition and treatments plus emotional care by professionals conversant with all aspects of their condition - including immediate and long-term outcomes. Patients should be informed of patient support organisations, such as The Pituitary Foundation.
- Literature relative to pituitary conditions, treatments and lifestyle issues should be available in clinics, investigation units and in-patient wards.
- Introductions and referrals should be provided where necessary to other specialists, such as gynaecologists for infertility and hormone

replacement therapy, psychological support and counselling about endocrine disease and treatment, educational psychologists for child patients and dietary support information. Also, Occupational Therapy - for example, returning to work, mobility enablement etc.

- Agreed management of care between the specialist centre, GP and more local clinicians to enable some aspects of long-term care to be provided more locally (a district general hospital) to the patient.
- Patients should be offered access to a second opinion, either through their GP or endocrine specialist, if they are unhappy about any aspect of the management of their condition.
- Patients should receive regular checks where their condition may affect other aspects of their health in the longer term. For instance, osteoporosis or visual problems.
- Advice should be given in respect of the criteria for social benefits, for example, free prescriptions.
- Particular hormone replacement medication should be prescribed as the branded product.
- Repeat prescribing for life-long endocrine medication should be on a minimum of 56-day prescriptions.

The Pituitary Foundation will promote the essence of this Charter within both the medical and patient communities. It is The Foundation's hope that the above services, together with any necessary medication and specialised treatment, are available to ALL patients regardless of the area in which they live.

Part 1 - for those **seeking a diagnosis**

Seeking a diagnosis

You might have been suffering from unexplained symptoms for some time, which you believe might be linked to a pituitary problem. Your GP will probably be the first point of contact, but in some cases your optician, dentist or other clinician may have been consulted and referred you to your GP for further tests.

As pituitary conditions are considered quite rare, your GP may not have come across another patient in their practice and may investigate other more common conditions (for example: diabetes mellitus, migraine, and menopause) before considering pituitary disease. You might have visited your GP already, on a number of occasions, and perhaps have been told that your symptoms are, or could be, due to more common illnesses.

The suggestions given below could be helpful for you when approaching your GP.

General suggestions when seeking a diagnosis

Write down a list of your symptoms as they present, and if possible, dates that they began, and take notes of the outcome of your visit.

If you can **draw a simple graph**, showing months along the bottom and a scale of 1-10 for symptoms, down one side. You could then use different coloured lines for each symptom, to show how symptoms varied on scale 1-10, over time

Take photos of how you were/looked before

you became ill, to show the doctor of physical effects and changes as a comparison.

Take a friend or family member with you to your consultations, so they can give the doctor any information you may not recall. Also, they may remember more of what the doctor says and could take notes.

Make a list of any medicines you take - including alternative therapies and vitamins. List any family illnesses or conditions e.g., TB, heart disease, diabetes, etc.

Have an eye test with your local optician.

Be positive about your visit. The GP is there to help you and good communication is essential. If you are dissatisfied, it may be possible for you to see another GP within your practice.

Suggested questions to ask your GP

As my periods have stopped (and I'm not pregnant / breastfeeding / menopausal) **could you test my prolactin level?** Mention also if you have any loss of sex drive and/or milk production from your nipples.

I'm feeling cold, tired and gaining weight, even though I'm not eating more; **could you test my thyroid levels?**

I have flu-like symptoms, sometimes suffer

Part 1 - for those **seeking a diagnosis**

a 'hangover' type feeling and suffer minor infections regularly; is this related to my cortisol production and **could you test my cortisol?**

My joints are aching, my family have noticed an increase in the size of my hands and feet and I have facial changes; **could I possibly have excess growth hormone?** (It is a good idea to show your GP a series of photographs of yourself over a period of years, if you feel your features have altered considerably.)

The headaches I experience are not of the type I've ever had before. I don't believe they are migraine, as they feel like...(explain where the pain is, how long it lasts, and if it makes you feel, or be, sick).

I am passing urine every (however many) minutes, and cannot quench my thirst that is present 24 hours. My mouth is parched; please look at my tongue / lips. I don't have a water drinking habit. **If you test for Diabetes Mellitus and this is clear, could you consider Diabetes Insipidus?**

My vision is unusual; I'm having difficulty seeing out of the sides of my eyes. I don't wear glasses, nor have optical checks, so **should I see an optician and report back to you?**

I'm putting on weight, have excessive facial hair, have a fatty hump at the top of my back, have stretch marks and suffer awful mood swings; **could this be Cushing's, and could this be checked with a cortisol blood test?**

I realise that I am consulting you on a regular basis and would understand if you felt my symptoms were 'in my mind', as they are varied and could be matched to many common conditions. I'm struggling with daily life as I'm feeling so unwell and **I would appreciate some pituitary hormone testing**, as these tests haven't been carried out to investigate the cause of my problems.

If your GP has a computer in their examination room, you may wish to direct them to The Foundation's website:

www.pituitary.org.uk

Along the top side menu is a section called, **'For Health Professionals'** with a sub-section entitled, **'GPs and Practice Nurses.** In this section is our GP Fact File which is written by endocrinologists for GPs, it is easy-to-read, to-the-point and thorough. It includes presenting symptoms, investigations, possible treatments, management, watch points and questions patients may ask. It also includes links and references to more specialist information. This could be an excellent resource for your GP to use as they are assisting you with diagnosis.

Part 1 - for those **seeking a diagnosis**

Check list of symptoms associated with pituitary conditions

This isn't a guide to self-diagnosis; it is a list of symptoms which other patients have experienced. You may suffer from none of these, a few, or many of them. Once you are diagnosed, it may help you to know about other symptoms which you might experience that are associated with your condition. Please make sure you tell your doctors about all symptoms that you experience. This will help them to treat you.

Acromegaly

- Increased shoe size, gloves, hats, shirt collar, over months or years
- Headaches
- Joint pains
- Facial pain - changes to bite as the jaw moves forward and/or spacing of teeth may change
- Sweating
- Increased weight
- Mood swings
- Tongue grows
- Speech differences - i.e, deeper voice, with possible lisping sound
- Sleep apnoea - snoring with episodes of interrupted catching of breath

Diabetes Insipidus (DI)

- Passing excessive urine much more than usual during the day and frequently through the night
- Urine is very pale, possibly clear and doesn't concentrate
- Extreme thirst, which cannot be quenched
- Preference of icy cold drinks

- Headaches (which may be due to dehydration)
- Exhaustion
- Shivering
- Nausea
- De-hydration symptoms - parched mouth, cracked lips, coated tongue, dry eyes and dry skin
- Most dry, savoury foods may be difficult to eat, with a preference to drink fluids which are very cold
- Weight loss

Cushing's

- Weight gain to trunk of body, plus rounding of face
- Fatty hump at top of spine/back
- Flushed appearance and roundness of face
- Low mood, can feel depressed
- Extreme mood swings
- Weakness, possible muscle wasting
- Darkening of skin pigmentation
- Dark purple striae - similar to stretch marks on abdomen and tops of thighs
- Hirsutism (extreme hairiness)

Hypopituitarism (can include cortisol, growth hormone and thyroid deficiencies)

- Flu type feelings - low or no cortisol in body, could make symptoms of colds, flu and minor infections more severe, or recovery slower
- 'Hung over' type feeling without having drunk alcohol
- No body temperature control - either feeling too hot, or too cold
- Nausea

seeking a diagnosis

- Mood swings - feelings of depression, apathy or low mood
- Joint aches and pains, and/or poor muscle tone
- Exhaustion
- Constipation
- Difficulty finding words
- Poor sleep patterns
- Low blood pressure - feeling light-headed
- Pale complexion

Prolactinoma

- Loss of periods (female)
- Infertility
- Low or lack of libido - prominent symptom, and often not mentioned by patient
- Weight gain - bloated stomach
- Headaches
- Milk/fluid excreting from nipples when not pregnant (males can have this too)

Referral to an Endocrinologist (a consultant who specialises in hormones)

If your GP suspects a pituitary problem, he/she should refer you to an endocrinologist for further investigations. It is very important and we strongly recommend that you be referred to an endocrinologist who specialises in pituitary conditions.

At your first appointment with an endocrinologist, it is usual for the following things to happen:

- A full medical history will be taken - lots of general health questions e.g. when you experienced your symptoms, how they felt, and your family history of general health.

- You will probably be given a physical examination - blood pressure, pulse, chest and heart checked. The doctor will look into the back of your eyes and may check your 'fields of vision' (how far you can see to each side without moving the eye).
- Blood tests are taken to test relevant hormone levels (this is quick and quite painless). The results usually take 1-2 weeks, a copy of these should be given to your GP for his files.
- The endocrinologist may want you to have a scan of the pituitary gland using an MRI or CT scanner - the waiting list can be more than several weeks/months in some hospitals. Having a scan is painless and will not harm you. An MRI offers a much clearer picture and involves being in a more confined space than a CT scanner. If you are concerned about this or suffer from claustrophobia, please let your GP know as he/she can offer a relaxant which does help. MRI scanners are noisy but ear plugs can be provided by the imaging department.
- You can take along your partner, relative or friend with you to this, (and any future) appointments. It is also a good idea to jot down (and take with you) notes of symptoms you wish to discuss in case you forget during the consultation.

Please note:

- Almost all pituitary tumours are benign - they are not cancer - however, many still require treatment.
- It is highly unlikely that any visual problems will deteriorate further, and it is more likely for your sight to improve following treatment.

Part 2 - for those newly diagnosed

Treatment if a pituitary condition is diagnosed

Once you have had your blood test results, and your scan (if needed) and returned to see the endocrinologist, your treatment (if any required) will be started. This may include any of the following:

- **Hormone treatment** - sometimes medication and/or replacement hormones are given, and the endocrinologist will monitor your levels with regular blood tests.
- **Surgery** - the endocrinologist works in conjunction with a neurosurgeon (usually based within the same hospital or nearby). The neurosurgeon will see you to discuss the type of surgery he will perform, how long he/she expects you to be in hospital and recovery period afterwards. You will be able to discuss any problems or fears you have at this time. The majority of pituitary surgery is done through the nostril/sinus to reach the pituitary.
- **Radiotherapy** - this may be given instead of, or following surgery - or later if it is necessary. This is a procedure carried out at a specialist centre (nearest to your home) and can be used to complement surgery. Having radiotherapy does not mean that your pituitary tumour is malignant (or cancerous).

For further and more in-depth information on treatments, please do see our website and booklets.

Emotional issues - for those newly diagnosed

Being diagnosed with a pituitary condition can sometimes take months or even years, causing suffering physically and emotionally. Although rarer, there are some people who might be diagnosed suddenly due to a much more rapid and dramatic onset of symptoms. A sudden diagnosis (and possible emergency treatment) can of course cause shock and trauma.

Often, the word '*tumour*' will be used when you are diagnosed - this term can be a great shock, unless it is explained to you properly. Hearing the words '*brain surgery*' or perhaps '*neurosurgeon*' may be very frightening for you. Add to all of this, learning that you will have a long-term (or life-long) condition, which may mean you having to take medication for the rest of your life, this could all very well have an immense impact emotionally on you and your family.

Clinicians may not always understand, or recognise, the possible trauma experienced by a patient who they have recently diagnosed. They may simply not have the time within the clinic to address your fears, or perhaps because they are familiar with pituitary disease, they don't think of a diagnosis as being something that anyone should be unusually traumatised about. However, feeling shocked, frightened or anxious are common experiences which many others felt when they were newly diagnosed. You even might be feeling so shocked that you just want to get out of the clinic, without attempting to ask any questions.

We recommend that you read our booklet

Part 2 - for those **newly diagnosed**



'Psychological Impact of a Pituitary Condition: Diagnosis and Treatment' which aims to offer strategies to deal with these emotional issues.

For those facing surgery

The mere thought of having to have surgery in their brain can of course be concerning for many patients. From what we hear from other patients, who have had their surgery, is that generally the operation and the experience surrounding, was not anywhere near as awful as they had anticipated.

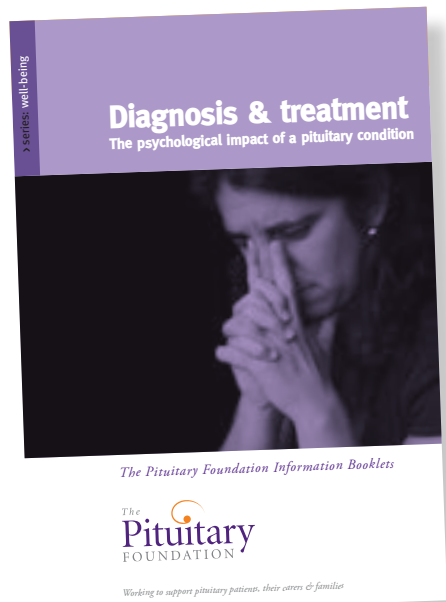
A specialist pituitary surgeon will be operating on you (a surgeon who is used to carrying out pituitary surgery) plus a team of nursing staff, who are expertly trained, to care for you before and after your surgery. If you have any questions about your operation, the surgeon or nurses will answer these. For those who are referred for surgery they can ask for the contact details of the endocrine nurse specialist who has been

allocated to be their key worker.

Please see our booklet called *'Surgery & Radiotherapy'* and our *Post-op fact sheet*.

You can contact The Pituitary Foundation Helpline for help at every stage of your journey. We have a list of trained *'Telephone Buddies'* who are patients (or carers) and so have direct, personal experience of your particular condition. Some patients find it helpful to attend a local support group meeting so they can talk to fellow patients who also have personal experience. The Foundation also has a *'Well-being'* series of booklets.

As mentioned above, for those newly diagnosed, having or, just had surgery or beginning treatment, we recommend our booklet called *'The Psychological Impact of a Pituitary Condition: Diagnosis and Treatment'*.



Part 2 - for those newly diagnosed

Medication names of various treatments

If you have been given medication to take, this section explains the various names of medication; for what pituitary condition they are given and how they are taken, i.e., tablets, injections, patches, gels, etc.

Please Note: A more comprehensive list of treatments is available on our website.



Condition	Name of treatment(s)	Delivery versions
Acromegaly	Parlodel (Bromocriptine), Dostinex (Cabergoline), Sandostatin, Somatuline, Somavert, Pegvisamont	Tablets and injections
Diabetes insipidus	DDAVP Intranasal, DesmoSpray, DDAVPMelts, DesmoTabs	Nasal applications, tablets or Melts (placed under the tongue)
Growth hormone deficiency	Genotropin, Humatrope, Norditropin, Saizen	Daily injections
Raised prolactin	Dostinex (Cabergoline), Norprolac, Parlodel (Bromocriptine)	Tablets
Hypoadrenalism (cortisol deficiency)	Hydrocortisone, Prednisolone, Plenadren	Tablets, injections for emergency purposes
Hypogonadism female (lack of oestrogen)	Various brands of HRT (full list on our website)	Tablets
Hypogonadism male (lack of testosterone)	Nebido, Sustanon, Testim Gel, Testogel, Tostran	Injections, patches or gels
Hypothyroidism (lack of thyroid hormone)	Levothyroxine	Tablets

Part 2 - for those **newly diagnosed**

Questions you may want to ask when you start your treatment - and who to ask

It can be difficult to know what questions to ask, or who you ask, especially as you might not have much information about what is going to happen to you at this point. The questions below will be a guide for you to begin discussion with your endocrinologist and/or GP.

Do I have a choice of surgery, radiotherapy or medication and what do you believe would be the best course of action for my particular condition/tumour? *(to endocrinologist)*

Do I have any choice of hospital, surgeon or radiotherapy department? *(to GP, endocrinologist or Pituitary Foundation)*

Will I remain on replacement hormones for life and how often will I be monitored? *(to endocrinologist)*

What part will my GP play, with regard to carrying out tests, prescribing my medication and caring for me post surgery? *(to endocrinologist)*

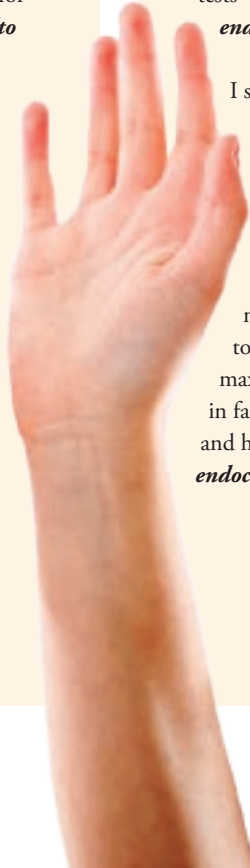
Will my GP receive my results from your clinic and in what time frame? *(to endocrinologist)*

I haven't felt much benefit from my current dose of thyroxin (after 3 months) can I be tested in case the levels aren't correct? *(to GP or endocrinologist)*

If you are a DI patient: Could I have regular sodium (and possibly potassium) tests - 6 or 12 monthly? *(to GP or endocrinologist)*

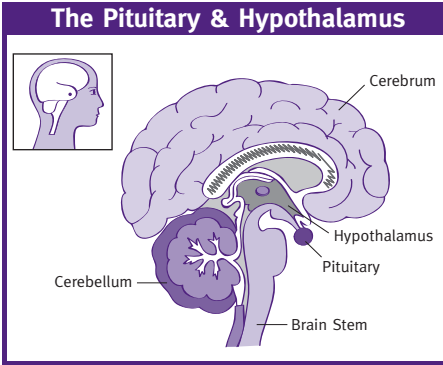
I still experience extreme headaches since my surgery; can you investigate these as I'm taking strong painkillers regularly? *(to surgeon or endocrinologist)*

I'm having problems with my jaw, these may be related to my headaches; could I see a maxillofacial consultant (a specialist in face, jaw mouth & neck problems) and have an x-ray? *(to GP or endocrinologist)*

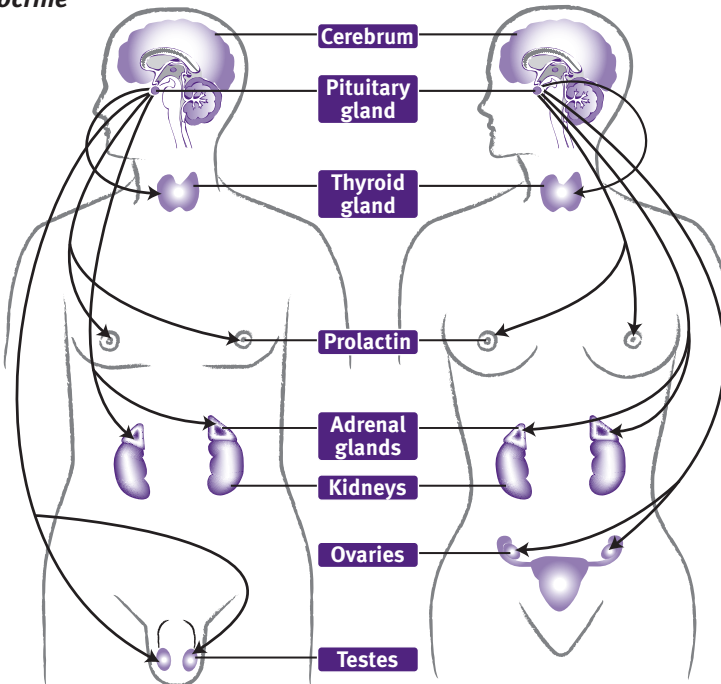


Part 2 - for those newly diagnosed

An explanation of hormones - where they are secreted from and what they do



The endocrine system



Part 2 - for those **newly diagnosed**

Hormone anterior - front part	Target	Function
Adrenocorticotrophic Hormone (ACTH)	Adrenals	Stimulates the adrenal gland to produce a hormone called cortisol. ACTH is also known as corticotrophin. Cortisol promotes normal metabolism, maintains blood sugar levels and blood pressure. It provides resistance to stress and has anti-inflammatory properties. Cortisol also helps to regulate fluid balance in the body.
Thyroid Stimulating Hormone (TSH)	Thyroid	Stimulates the thyroid gland to secrete its own hormone called thyroxine (T4). TSH is also known as thyrotropin. Another hormone produced from the thyroid is called tri-iodothyronine or T3. Thyroxine controls many bodily functions, including heart rate, temperature and metabolism. It also helps metabolise calcium in the body.
Lutenising Hormone (LH) and Follicle-Stimulating Hormone (FSH)	Ovaries (females) Testes (males)	Control reproduction and sexual characteristics. Stimulate the ovaries to produce oestrogen and progesterone and the testes to produce testosterone and sperm. LH and FSH are also known collectively as gonadotrophins. Oestrogen helps with growth of tissue of the sex organs and reproductive parts. It also strengthens bones and has a positive effect on the heart. Testosterone is responsible for the masculine characteristics including hair growth on the face and body and muscle development. It is essential for producing sperm and strengthening the bones.
Prolactin	Breasts	Stimulates the breasts to produce milk and is secreted in large amounts during pregnancy and breastfeeding. It is however present at all times in both males and females.
Growth Hormone (GH)	All cells in the body	GH is important for growth in children, and important in teenagers and young adults to achieve their peak bone and muscle strength. In adults it also has a role in energy levels and well being.
Hormone posterior - back part	Target	Function
Antidiuretic Hormone (ADH)	Kidneys	ADH regulates the salt and water levels in the circulation (or blood stream). This hormone is also known as vasopressin.
Oxytocin	Uterus Breasts	Affects the uterine contractions in childbirth and the subsequent release of milk for breast feeding

Part 3 - for all

Pituitary tests explained

At the start and throughout your journey, your hormone levels will be monitored through various tests. By regular testing, your clinicians are able to understand how your hormones

are working (or not) and ensure you are appropriately treated.

The following sections shows all of the usual tests carried out, but please note that you might not require all of these tests.

Name of test	What it is tested for	Test procedure	What results mean	Any side effects	How often is test needed
ACTH	Useful in diagnosing the cause of Cushing's syndrome and adrenal insufficiency	Blood sample in hospital first thing in the morning	Deficiency of ACTH: adrenal insufficiency. Raised ACTH: excess cortisol.	None	When endocrinologist feels necessary
Dexamethasone Suppression	Excess cortisol	Tablet taken at midnight, then a blood test the following morning	Normal individuals would have suppressed cortisol levels	None	To aid diagnosis
Synacthen	Low levels of cortisol	Intravenous injection in hospital, then a blood test	Poor response shows cortisol deficiency	None	Varies, dependent on individual
Day Curve	For those taking hydrocortisone, to assess adequate levels	Take usual dose of hydrocortisone and blood samples taken several times throughout day	Shows under or over replacement of medication	None	Varies, when endocrinologist feels necessary
24 hour urine collection	Over replacement of cortisol	Containers provided to collect urine at home	Used in conjunction with day curve test to assess over replacement of cortisol	None	Varies
FSH Follicle stimulating hormone	Production of sperm in males and follicle development in ovaries females	Blood sample	Depends on age and timing of menstrual cycle	None	Varies

Part 3 - for all

Name of test	What it is tested for	Test procedure	What results mean	Any side effects	How often is test needed
Glucose Tolerance	To diagnose acromegaly	Glucose drink given in hospital and blood sample taken at 30 minute intervals for two hours	Normal individuals suppress growth hormone levels	Most experience no symptoms	To make diagnosis and review purposes thereafter
IGF-1	To monitor base line and review patients on growth hormone (GH) replacement	Blood sample	Guide to overall circulating levels of GH in the blood stream	None	Varies, but at least annually when established on GH replacement
Insulin Stress	Test to assess accurate levels of cortisol and GH	Insulin injection given in hospital, then blood samples taken every 30 minutes for two hours	Lowering blood sugar causes stress; body should respond to this stress by secreting cortisol and GH	Lowered blood sugar may cause nausea, dizzy and sweaty. These effects are short acting	Post operative, to assess pituitary function. Diagnosis for GH deficiency
LH Luteinising hormone	Acts on testes to stimulate testosterone (males); acts on ovaries to stimulate oestrogen (females)	Blood sample	Depends on age and timing of menstrual cycle	None	Varies
Oestrogen	To assess levels of oestrogen in females	Blood sample	Depends on age and timing of menstrual cycle	None	Varies
Sodium	To assess levels for diabetes insipidus patients	Blood sample	To monitor patient under or over replacing desmopressin	None	Six to 12 monthly
Testosterone	To assess levels of testosterone in males	Blood sample in morning	To diagnose deficiency	None	Varies, but required for review purposes

Part 3 - for all

Name of test	What it is tested for	Test procedure	What results mean	Any side effects	How often is test needed
Thyroid TSH, T4, T3	To assess thyroid function	Blood sample	To diagnose under or over active thyroid	None	Varies, but required for review purposes
Water Deprivation	To diagnose diabetes insipidus (DI)	Patient deprived of fluids in hospital for approximately eight hours. Blood and urine samples taken and weight checked at regular intervals	Specialist interpretation required	If you have DI, this test can be very uncomfortable as no fluids allowed	Diagnostic purposes only

Patients will probably be given a patient information leaflet about the test that has been recommended for them, before the test is carried out.

Recognising practical and emotional Issues

The following issues (in no specific order of importance) may or may not relate to you, but will possibly help you in knowing that other patients experience some of these problems too.

The patient and doctor relationship

This relationship can feel unequal to many people. Being a patient and realising you need medical care can be distressing for an individual. You may also feel powerless and you could have expectations that the doctor becomes the powerful one in the relationship. When the doctor is thought of as powerful, the patient's expectations, both realistic and unrealistic, can develop. Remember that the doctor may know more about medicine than you, but you know more about your symptoms and the difficulties that you are experiencing than the doctor.

If you do have unrealistic expectations, you may think that the doctor should realise your concerns, needs and symptoms without you having to communicate these. If the doctor doesn't meet these unrealistic expectations, you may then feel ignored, misunderstood and alone. However, if you have realistic expectations together with feeling able to assist the doctor in your care, this can achieve benefits for both of you to pave the way for good relations and exchange of information.

It is good to remember that the doctor is a human being too.

Although patient care is improving, there may still be problems for some patients. Issues include

non-continuity of care, i.e. the patient may be seen by a different doctor at each clinic visit. Patients can, however, request to be seen by a particular consultant if they request this in advance of their appointment. This might not be possible or this may mean you will have a longer wait, so be prepared (i.e., bring a book or magazine to fill your time).

For many, the regular check up can be unnerving (memories of being told you have 'a brain tumour', re-visiting the hospital site, etc.). It could be helpful (both to you and the doctor seeing you) if you briefly explain why you are anxious or upset at attending clinic.

Blood test results may be delayed for an unacceptable time and sometimes aren't acted upon as quickly as they should be (if hormone levels suggest change of dosage, for instance). It is helpful if your blood can be taken six weeks prior to your hospital visit so that results will be recent and in front of the consultant or doctor at your visit. Ask the endocrine nurse for a blood test form at least six weeks before your next appointment.

Access to a clinician can be difficult if you need urgent advice. If there is an endocrine nurse at your endocrine clinic you can contact her/him or contact your GP.

Physical appearance

Some patients suffer side effects from their condition or treatment. Your clinician may suggest that weight gain is due to inactivity or overeating, which can be distressing if you are eating a healthy diet. Discuss possible causes (e.g. steroid medication or thyroxin doses) with your consultant. Acromegalics may experience

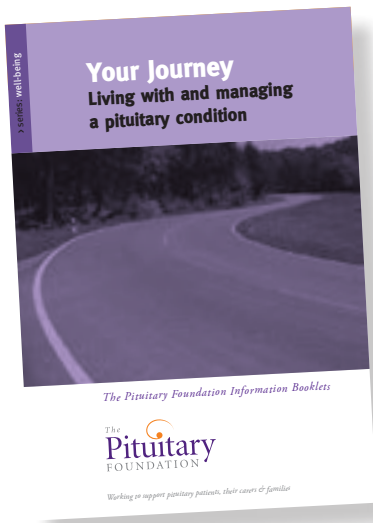
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problems with clothing and/or footwear. There are specialist retailers who can provide extended size ranges (you can contact The Foundation for information on retailers).

GPs and consultants can help you to access counselling that help overcome physical and emotional change. The charity, Changing Faces, advises on physical appearance issues.

The Foundation has a wide range of booklets available, including our Well-being series; the booklets below could be of help to you:

- For those who have been diagnosed for a while - please see our booklet called *'Your Journey: Living with and Managing a Pituitary Condition'*
- We also produce booklets called *'Relationships & Communication: with Yourself and with Others'* and *'Living with Infertility'* that might have information that will be useful to you.



Going in to hospital for tests

Short stay tests

Some tests are carried out over several hours during the day and would usually begin in the morning.

There will be a bed or comfortable arm chair provided for you, and you should be allowed to take someone with you for company. For these tests you won't need to take your nightwear with you, as you'll stay in your clothes throughout. Comfortable clothing is advised, with something to read. Refreshments and drinks are provided if the test allows, and certainly at the end of the test.

If you are having a more intensive test, you might not feel like driving or getting public transport home - ask someone if they can pick you up.

At least the day before you go, it is advised to ask the endocrine unit who will be testing you, if you should take your usual medication at home, for the evening before and on the morning of the test. Also ask if you can eat and drink normally prior to the test; if you aren't allowed to, ask for specific times you should not eat and drink and when you can start eating and drinking again.

For in-patient stays

Patients shared their tips on things to take with them to make the experience as comfortable as possible. These included:

- Three pairs of pyjamas or nightdresses, and/or tracksuit bottoms and loose tops for comfortable day gear
- Lightweight dressing gown

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- Slippers with non-slip soles
- Toothbrush and toothpaste
- Brush or comb
- Face, or baby wipes
- Earplugs (wards can be noisy)
- Eye mask (keeps the bright ward lights out)
- Notebook and pen
- Change for buying newspapers, drinks, etc.
- Small tin of Vaseline or balm (for the lips)
- Lots of drinks (non-alcoholic naturally, Lucozade or squash)
- Sanitary items (for ladies only), if required
- Soft / balm tissues - LOTS - “the hospital will provide but they are a bit rough”
- A cheap pair of flip flops for use in the shower
- Cardigans are better than over the head sweaters - in case it gets a bit chilly
- Nibbles that don't make a mess in your bed
- Sweets / mints
- Books / puzzle books
- Two or three pens
- List of phone numbers
- MP3 or an old CD player and two or three of your favourite CDs plus charger or batteries
- A couple of cuddly teddies (optional)
- Don't take jewellery - including wedding rings.

And some suggestions from other patients:

“Go out and buy a nice light perfume or body spray. Not your usual one, because you will probably always associate it with your stay in hospital, so if you throw it away afterwards, it doesn't matter. It makes you feel so much better having a quick 'spritz'. The other daft things I did were things like taking a face pack in with me for when feeling better post-op. I could convince myself it was a spa not a hospital. Being in my own room helped with that one!”

“Designate one person to ring the ward and have a cascade system for letting people know how you are doing. Organising things like that before hand can give you a sense of control.”

“Plan something for afterwards. After my hysterectomy, a dear friend came to visit. I was two days post-op and feeling awful and she TOLD me I was going on a trip with her school to a Tapas bar in five weeks time. Seems an odd school trip, but they had been taking Spanish lessons!! Seemed impossible, but I was determined. I went, had a great time with all the children and was so glad I had set myself an achievable target.”

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"If someone says 'can I do anything?' say yes!! Helps you and makes others feel very worthy. A friend cleaned out my rabbits - just what I needed!"

"I had one day when I was visited by work mates, friends and family - not a good idea and hubby was annoyed as it completely tired me out - stagger the visitors!!! DEFINITELY needed a couple of pens and someone bought me a beautiful journal to keep notes in which were handy when the numerous consultants bombarded me with info."

"I took a photo in of the family and had it on my bedside trolley which was nice to look at. "

"Don't wear nail varnish to theatre as the nail bed gives a good indication of the circulation, especially immediately post-op as you are waking up. Face make-up is not a good idea either. The anaesthetist needs to see your normal colour. It has been known for patients to come to theatre with the full works, including hair spray!! Someone forgot to tell them it was an operating theatre they were going to!!"



Holiday and travel information

It is important that you are able to enjoy a holiday without having undue concern about your pituitary condition. These are some tips to help you whilst travelling:

- When going on holiday, especially abroad, it is important that you obtain from the hospital, or your GP, a letter of confirmation that you are carrying medication, including hydrocortisone for injecting, needles and syringes for your own personal use in an emergency situation relating to your medical condition. This should be on the hospital or GP's letter headed paper. We have a template travel letter your GP or endocrine nurse can use, if you contact helpline@pituitary.org.uk
- Do not place your hydrocortisone emergency kit, growth hormone, or any of your medications in your hold baggage - **always carry them in your hand luggage**. Make sure

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that you carry your medication in the original pharmacy container it was given to you in by your chemist - with your name on any separate container.

- Tell the check-in staff and also **airport security** personnel before passing through security (after Passport Control) that you are carrying necessary medications. Have your letter of confirmation available to show them and also have it ready upon arrival at your destination. A repeat prescription can also be carried as evidence of your prescribed medication.
- It is important to note that **airport** policy takes priority over **airline** policy, i.e. if the airline check-in counter personnel tells you that you can carry needles, etc. the airport security may have an issue with this. Be certain to make sure you are covered for **both** the airline and airport policies by checking their websites or phoning.
- Take sufficient supplies (7 to 14 days extra amounts) of your hydrocortisone to allow for any increase should you feel unwell, journeys are delayed, or (rarely) if luggage is mislaid. Also take spare supplies (several days) of any other medication you take.
- Be certain to take disposal container for any needles you use.
- Have a written checklist to remind you of the hydrocortisone emergency injection procedure - please see our ***Hydrocortisone Advice Leaflet***.
- If you take growth hormone, you can store this quite safely whilst travelling in a cool bag with frozen blocks inside until you reach your destination. It is advised to ask if there is a refrigerator in your holiday accommodation, or if there isn't, could you store spare freezer blocks in a hotel freezer (for example). If you can use a freezer, it is best to take spare freezer blocks in your luggage, for rotating the blocks in order to keep your medication cool all of the time in your cool bag. Again, it is recommended that you arrange this **before** travel.
- Carry a **Toilet Access Card** with you if you have Diabetes Insipidus (these can be obtained from The Pituitary Foundation).
- Take and wear your medical information talisman at all times during your journey and stay. For further information about medical talisman, and companies providing these, please see our website at www.pituitary.org.uk. The Foundation provides a **Patient Care Card** which will be helpful too. Please contact us at helpline@pituitary.org.uk or **0117 370 1320** for your card.

Please support The Pituitary Foundation

Join the The Pituitary Foundation today and enjoy the benefits of membership!

- ✓ Receive our members' magazine, *Pituitary Life*, three times a year full of the latest information, updates and patient stories, to help you better understand, or manage your pituitary condition.
- ✓ Our monthly e-bulletin, which includes the latest pituitary news, information and ways to get involved.
- ✓ Become an important part of the only charity in the UK providing support to pituitary patients.
- ✓ Receive a welcome pack and a membership card and enjoy discounts to Pituitary Foundation events, such as our conferences.
- ✓ Give us a stronger voice to raise awareness, and understanding, of pituitary disorders.

Individual membership costs **£25.00** for a full year, which is only **£2.08** a month!
(Family, concessionary and life membership rates are also available). To become a member, please complete the form below and return to us with your payment (cheques made payable to *The Pituitary Foundation*) to:

The Pituitary Foundation,
86 Colston Street,
Bristol, BS1 5BB

If you would like to pay for your membership by standing order, please contact **0117 370 1333** or to join online visit www.pituitary.org.uk



I wish to become a Member of **THE PITUITARY FOUNDATION**

Title:		First Name:		Surname:	
Home Address:					
Postcode:					
Telephone No:				Email:	

Please tick (✓) the type of Membership you require:

Individual	<input type="checkbox"/>	£25.00 (annual)	Joint	<input type="checkbox"/>	£35.00 (annual)
Life Membership	<input type="checkbox"/>	£350.00	Concessionary*	<input type="checkbox"/>	£15.00 (annual)
Additional donation (optional) £					

*(Concessionary rate for people on a state pension, in receipt of state benefits, on low income, students, and under 18s only).

Yes! I want to Gift Aid any donations I have made in the past, present and future to The Pituitary Foundation. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. Please notify The Foundation if you want to cancel this declaration, change your name or full address, or no longer pay sufficient tax on your Income or Capital Gains.

Signature:		Date:	
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Notes:

Notes:

Helpline

Monday - Friday 10:00am-4:00pm
0117 370 1320

Endocrine Nurse Helpline

available scheduled hours
0117 370 1317

Website: www.pituitary.org.uk

Email: helpline@pituitary.org.uk

More Information

The Pituitary Foundation publishes a library of booklets on pituitary conditions, treatments and well-being issues.

For more information please visit our website, or call our Helpline.

The Pituitary Foundation

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enclosed with your medication or consult your GP or
endocrinologist



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The
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Working to support pituitary patients, their carers & families