

HelpLine

Monday - Friday 9:00am – 5:00pm
0845 450 0375

Endocrine Nurse HelpLine

available scheduled hours
0845 450 0377



Website: www.pituitary.org.uk

Email: helpline@pituitary.org.uk

More Information

The Pituitary Foundation publishes a library of leaflets 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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DISCLAIMER All information is general. If you or your carer, 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

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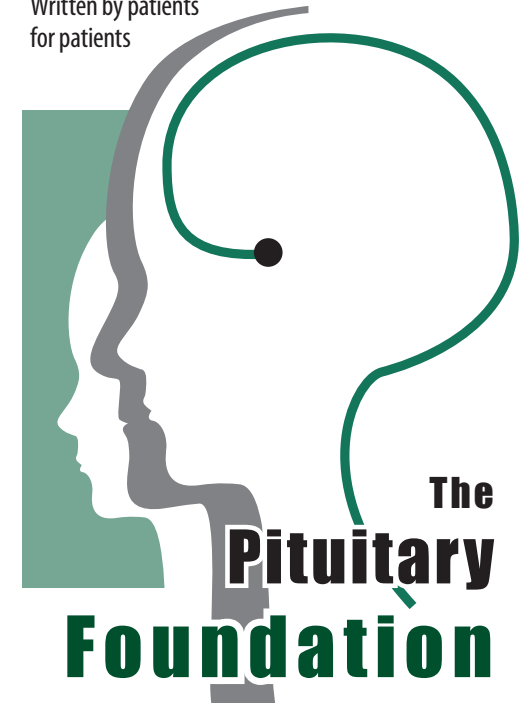
*Working to support pituitary patients,
their carers & families*

THE PITUITARY FOUNDATION INFORMATION LEAFLETS

PITUITARY PATIENTS HANDBOOK

For those seeking diagnosis, the newly diagnosed & diagnosed patient

Written by patients
for patients



*Working to support pituitary patients,
their carers & families*

SERIES : GENERAL

The Pituitary Foundation

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, knowing a certain amount of pituitary knowledge already. Or 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: **0845 450 0375** - Monday - Friday, 9:00 - 5:00
- Endocrine Nurse HelpLine: **0845 450 0377** - Scheduled hours only
- Website: **www.pituitary.org.uk**
- Forum (for subscribed members)
- A variety of information leaflets & GP Fact File
- Pituitary Life newsletter (for subscribing members)
- Regional Conferences
- Local Support Groups
- Trained Telephone Buddies

THE PITUITARY PATIENTS CHARTER

This charter informs you, as a pituitary patient within the UK 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.

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 disease 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 disease to receive equal treatment regardless of age, gender or geographical location within the United Kingdom and Republic of Ireland. 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 centre with a full range of expertise available, for further assessment and treatment. An accredited clinical endocrinologist should be responsible for co-ordinating all treatment, both to ensure proper diagnosis is made and for long-term care.

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

- Endocrinologists, pituitary neurosurgeons, radiotherapists and other specialists as needed 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.
- 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 be 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.
- 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.

THE PITUITARY PATIENTS CHARTER

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

- 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, psychiatric services for counselling and educational psychologists for child patients.
- 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 to 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.



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.

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. 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 dates if possible that they began, and take notes of the outcome of your visit.

If you can draw a simple graph, showing months down one side and symptoms along the bottom, it gives an obvious and speedy indication to your doctor of how often and when the symptoms occur.

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 practise.



SEEKING A DIAGNOSIS

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 libido or crusting 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 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?

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.

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?

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 left side menu is a section called, 'For Medical Professionals' with a sub-section entitled, 'Medical Information'.

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.

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 foods intolerable with a preference to drink fluids
- 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
- Loss of bone density (if left untreated over time) due to excess cortisol
- 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, regular colds and/or infections
- 'Hung over' type feeling without having drunk alcohol
- No body temperature control - either feeling too hot, or too cold
- Nausea
- 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 pallor

CHECK LIST OF SYMPTOMS ASSOCIATED WITH PITUITARY CONDITIONS

PROLACTINOMA

- Loss of periods (female)
- Infertility
- Low or lack of libido - prominent symptom, often not mentioned by patient
- Weight gain - bloated stomach
- Lethargy/exhaustion, falling asleep during day
- 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 2-3 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.
- 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

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 expects you to be in hospital and recuperation period afterwards. You will be able to discuss any problems or fears you have at this time.
- **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 leaflets.

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 leaflet '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 it, 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.

Please see our leaflet called 'Surgery & Radiotherapy' too.

Some patients mentioned that following their surgery, a few things which concerned them were:

- Fear of damage to the head (banging it or dropping something on it).
- Questions such as, can you get water up your nose (in the bath, or shower); can you swim, and how soon; can you fly abroad; can you resume your usual sports?
- Fears that any headache, even a twinge, may be a sign of re-growth of tumour.
- Reaction of others to you (knowing that you've had a 'brain operation') - are you 'all there'; will you look or act differently?
- There may be problems within your relationship, due to one or more issues (e.g., loss of libido, lack of energy, physical changes).

You can contact The Pituitary Foundation 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 leaflets.

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

