

Prolactinoma



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.

About this booklet

The aim of this booklet is to provide information and understanding about **hyperprolactinaemia** (raised levels of the hormone prolactin in the bloodstream) and **prolactinoma** (a prolactin secreting growth on the pituitary gland).

You may not find that all of the information applies to you in particular but we hope it helps you to understand your condition better and offers you a basis for discussion with your GP and endocrinologist.

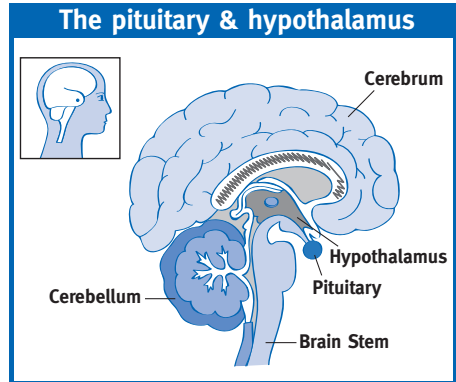
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Prolactinoma an explanation of hormones

Where they are secreted from and what they do

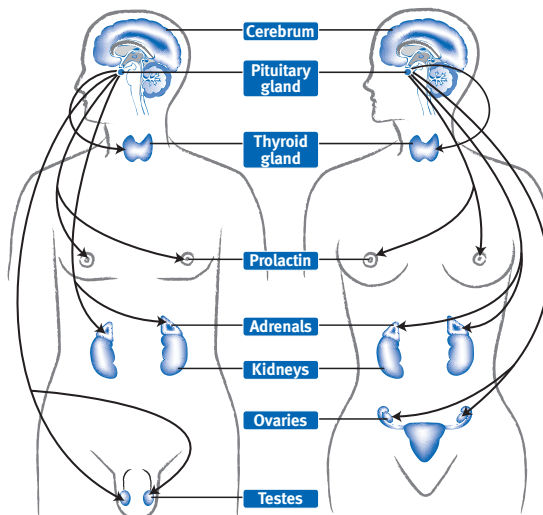
The pituitary gland

The pituitary gland produces a number of hormones, including: prolactin, ACTH, TSH and GH, follicle stimulating hormone (FSH) and luteinizing hormone (LH). Prolactin is sometimes known as the 'milk hormone' because it stimulates milk production after childbirth, but it is also produced in men, although in smaller amounts. FSH and LH control sex and reproduction. In women they cause release of the sex hormone oestrogen and stimulate the ovaries to produce eggs; these hormones are essential for a normal menstrual



cycle. In men, they cause the release of testosterone and stimulate production of sperm from the testicles.

The endocrine system



What causes the **Prolactin** level to be raised?

Common causes of raised prolactin

- Pregnancy
- Nipple stimulation and suckling
- Stress
- Certain medications such as:
 - Anti sickness medications e.g. Metoclopramide, stemetil, Domperidone, also acid reducing medication like Omeprazole can raise your prolactin level.
 - Certain antidepressants and tranquillisers used to treat mental health illness can raise prolactin: examples include Amytriptyline and Fluoxetine (Prozac) and risperidone.
 - Some homeopathic and herbal medications.
- Another possibility of raised prolactin is an underactive thyroid gland, which can be diagnosed by a simple blood test and which requires treatment with thyroid hormone tablets. Once your doctor has excluded these causes, he or she will consider the possibility of a prolactinoma.

Make sure you tell your doctor about all your current prescribed and any non-prescription medication you are taking.

What is a Prolactinoma?

A prolactinoma is a prolactin-producing tumour of the pituitary gland. Please be assured that this is a benign tumour, and not a brain tumour or cancer.

Doctors use the words 'tumour', 'adenoma' or 'growth' which means a swelling on the pituitary gland. These tumours only grow very slowly and many do not seem to grow at all. We do not know exactly what causes prolactinomas, but they are the most common type of hormone-producing pituitary tumour.

The action and stress of performing a blood test can mildly elevate the prolactin level and for this reason more than one level requires to be checked.

An appointment with an endocrinologist is usually sought by the GP, when there have been repeated raised levels of prolactin. Following referral to an endocrine department, the initial appointment will probably entail having your prolactin level re-checked.

Prolactinomas come in various sizes, but the vast majority are less than 10mm (3/8 inch) in diameter. These are called **microprolactinomas**. The rarer, large tumours greater than 10 mm in size are called **macroprolactinomas**. Prolactinomas can occur in men and women. The symptoms produced by a prolactinoma depend on the sex of the patient and the size of the tumour.

Signs and symptoms of a Prolactinoma

Signs and symptoms presenting in women

Most women with prolactinomas are likely to have microprolactinomas. Your first symptoms may relate to loss of periods (amenorrhoea) as excessive prolactin interferes with the pituitary's production of the hormones FSH and LH which control the menstrual cycle. You may have reduced interest in sex (low libido) and experience vaginal dryness and discomfort during intercourse. You may also be infertile because of impaired egg release by the ovaries - as we shall see later, there is usually effective treatment for this problem. You may also develop excess breast milk production (called galactorrhoea), which may leak spontaneously. This is due simply to the biological action of prolactin and is not a sign of breast disease, particularly breast cancer. **Women with prolactinomas do not have any increased risk of breast cancer.**

NB: If galactorrhoea is a symptom: it is important to note that self examination and expressing of milk acts as stimulation and therefore reinforces the raised prolactin level, making galactorrhoea persist! Although it is tempting to look to see if it is still present, you should resist the temptation.

Signs and symptoms presenting in men

Men with prolactinomas usually have tumours larger than 10mm in diameter (macroprolactinomas). However, a larger size tumour does not rule out an excellent response to tablet treatment. As in women, excessive prolactin reduces production of FSH and LH by the pituitary gland. This in turn lowers



testosterone levels and may result in a reduced interest in sex (low libido) and in impotence. Men may also have infertility due to a low sperm count. Milk production by the male breast can occur but is very uncommon even when prolactin levels are very high.

Once diagnosed and treatment with medication has been established and the abnormal level of prolactin starts to decrease, the abnormally low testosterone level should in turn start to recover and rise again. This does not happen in all cases and in that instance the men will go on to have hormone replacement therapy in the form of testosterone.

Large tumours

If you have a large tumour, you may have pressure symptoms such as headache or visual problems. This is because the nerves to your eyes pass over the top of the pituitary gland. In a minority of patients, an increase in pituitary size may cause pressure on these nerves and produce visual disturbance. Again, even these prolactinomas can usually be treated effectively with tablets, rather than surgery.

Diagnosis and what tests are carried out?

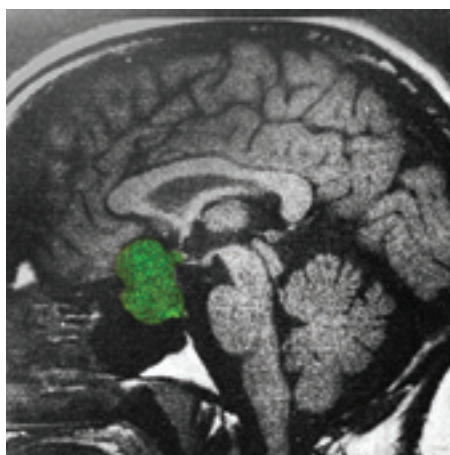
How is a Prolactinoma diagnosed?

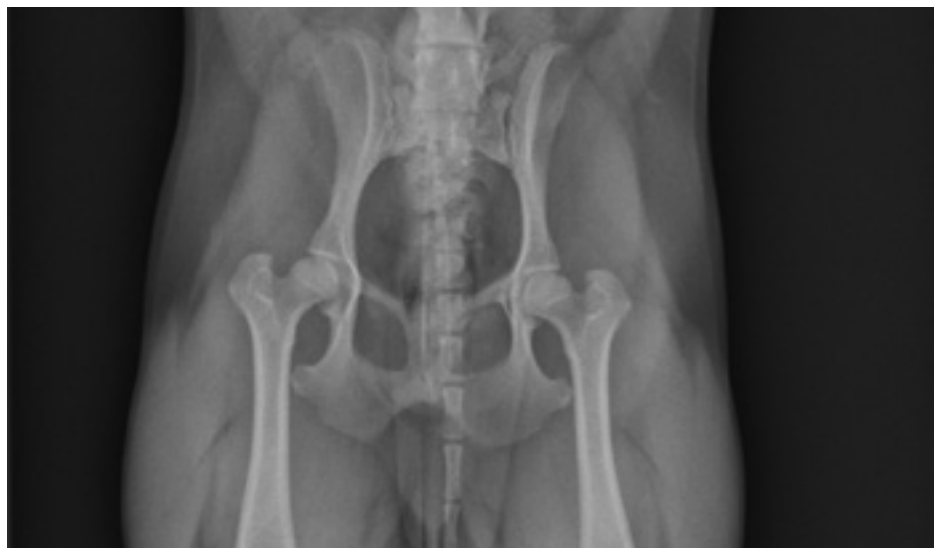
The tests to diagnose a prolactinoma are relatively straightforward and should not cause you too many problems. They consist of blood tests to check hormone levels and a scan of the pituitary gland to show the size of the prolactinoma. As mentioned previously, stress and the insertion of a needle to take a blood sample can slightly raise your prolactin level, so it requires to be repeated more than once to ensure the result is consistently high and a true value. Another cause of raised prolactin can be a benign condition called macroprolactinaemia, which is an artefactual elevation of serum prolactin measurement, as a result of prolactin with certain blood proteins. It is of no clinical significance but must be distinguished from prolactin-producing pituitary tumours.

Your GP may carry out initial tests on your prolactin and thyroid levels. You then would need to attend a specialist endocrine clinic as an outpatient for further tests, including any scans (see below).

As mentioned previously, a further blood sample will be taken to make sure your thyroid gland is functioning normally. The other hormones produced by the pituitary will also need to be checked; this can be done by a single blood sample.

Some specialists may recommend further tests to better assess pituitary gland function. These will be explained to you should you fall into this category. Mostly these investigations involve timed blood sampling and possible administration of a hormone or specific drug to produce stimulation or suppression.





A scan is usually carried out to give detailed pictures of the pituitary gland. There are two types of scan:

- **MRI** (magnetic resonance imaging, using a special magnetic technique)
- **CT** or **CAT** (computerised tomography, using X-ray imaging)

MRI is the scan of choice. Both types of scan involve you lying on a moveable table and passing into a cylindrical piece of equipment. You may find the examination a bit noisy or claustrophobic, but you will probably find that it does not give you too much trouble. If you feel it might cause you concern, ask your GP beforehand if you can have a sedative to take. During the scan, the radiologist may inject a special dye into your arm so that your prolactinoma can be seen more clearly.

A minority of patients are allergic to this injection, so do tell the specialist if you have asthma or any allergies.

If you have any problems with your vision, you will probably be seen by an eye specialist (ophthalmologist) who will check the strength of your eyesight and chart your fields of vision. Sometimes an X-ray scan of your spine and hip bones (bone densitometry) may be recommended to see whether there is any evidence of thinning of the bones (osteoporosis). This is a painless and straightforward test commonly called a **DEXA** scan.

Women who have not had periods for a year, and male patients with prolonged low testosterone levels should be offered bone density tests to ensure that they are not developing osteoporosis.

How is a **Prolactinoma** treated?



Medication treatment

Whatever the size of your prolactinoma, it is likely that your treatment will be with tablets. Drugs known as dopamine agonists are the first line medication in patients presenting with a prolactinoma.

Cabergoline (brand name - Dostinex), **Bromocriptine** (brand name - Parlodel) and a third drug, **Quinagolide** (brand name - Norprolac) are the three available medications. All these drugs act by reducing prolactin secretion by the prolactinoma.

- **Cabergoline** is long acting and requires one or two doses per week. The usual dose of cabergoline is one tablet (0.5mg) once or twice a week, although higher doses are occasionally required. Sometimes the dose can be reduced later during long-term treatment.
- **Bromocriptine** is usually given twice or three times daily (one tablet 2.5mg)
- **Quinagolide** is taken once daily, with the dose increased gradually to 75micrograms.

These drugs are safe and well tolerated by most patients. To minimise any side effects, particularly dizziness on standing up, nausea and headaches they should be taken with food.

Cabergoline should be taken at night when going to bed with a light supper or snack e.g., tea/milk and a biscuit. This should reduce the chance of any unwanted effects.

Your doctor will give you instructions on how to build up the dose slowly, again to minimise any side effects, particularly dizziness on standing up and headaches. Generally these side effects will diminish as your body becomes used to the medication but should they persist or become unbearable please discuss with your consultant or endocrine nurse specialist at your endocrine clinic. Occasionally, the medications may cause slight constipation, but this can usually be cured by increasing the amount of fibre in your diet. Other side effects include tiredness, abdominal pain, breast discomfort and nasal congestion. Psychological disturbance may be a rare complication of either cabergoline or bromocriptine.

Dopamine agonists

Recent findings in patients with Parkinson's disease using dopamine agonists in large doses (often at least 20 times those used for prolactinoma treatment) have shown some heart valve problems, however, there is no evidence that this occurs in patients with prolactinoma on the lower doses of cabergoline which are generally used in this condition. Patients taking Cabergoline or Bromocriptine for pituitary conditions will be advised to have occasional echocardiograms (heart scans) as a precaution. Your endocrinologist or GP will arrange this for you.

How is a **Prolactinoma** treated?



Prolactin levels often fall to normal within a few weeks of starting the treatment. In women, once prolactin has fallen to normal, menstrual cycles usually resume; interest in sex is regained and fertility is restored in most cases. In men, testosterone levels may raise, which often improves sex drive and potency.

Nearly all prolactinomas shrink in size following treatment with the tablets. If your prolactinoma is pressing on the nerves to the eyes, there is a good chance that your vision will improve as the tumour shrinks. If you have a large prolactinoma, you may have several pituitary scans over the months and years so that the shrinkage can be assessed.

Pregnancy

Fertility may return quite quickly, so if you do not wish to become pregnant, you and your

doctor will need to discuss an effective method of contraception, before medication is started. If pregnancy is wished, it is advisable to see your endocrinologist for pre-pregnancy planning and advice. Once pregnancy is established, most patients are recommended to discontinue medication but you should seek advice from your endocrinologist. You will continue to be seen by your endocrinologist throughout your pregnancy, to monitor progress. Checking blood levels of prolactin during pregnancy is unhelpful since they rise during a normal pregnancy. There is good safety data for babies conceived whilst the mother is taking dopamine agonists.

Breast feeding

If you wish to breast feed you should discuss this with your endocrinologist during your pregnancy. Following the birth you will be reassessed by your endocrinologist regarding the need for further treatment for your Prolactinoma.

Surgical treatment

The use of surgery and radiotherapy for prolactinomas has declined in recent years, due to the remarkable effectiveness of tablet treatment. Very few patients with microprolactinomas will require these treatments, although some hospitals may offer surgery as an option - most commonly for patients who are resistant to the drugs (5%) or suffer side-effects (5%). For the minority of patients with macroprolactinoma, which do not shrink following medical treatment (less than 10%), surgery may be required, particularly if

How is a **Prolactinoma** treated?

your vision has not improved. However, what was previously a big operation has now been greatly simplified by a more minor procedure through the air sinuses at the back of the nose. This is known as **trans-sphenoidal surgery**, which uses an operating microscope and there is now **endoscopic trans-sphenoidal surgery**, the same surgery performed using an endoscope, an option which may be available in your area. Please see our *Surgery and Radiotherapy* Booklet.

If a large prolactinoma does shrink effectively following tablet treatment, most specialists simply continue the drug, but perhaps in a reduced dose. General pituitary function may improve after tumour shrinkage has occurred.

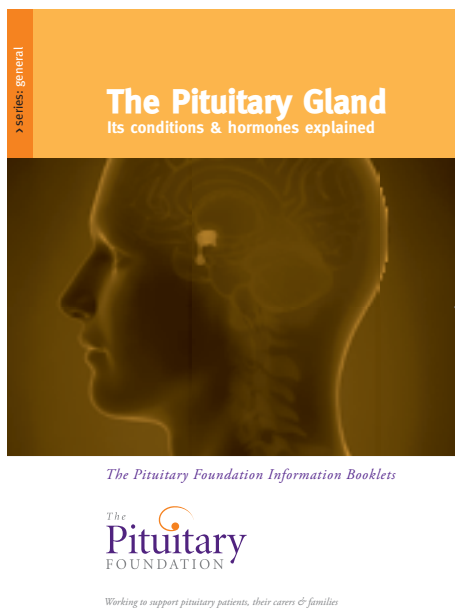
However, if you continue to have pituitary under-activity following treatment of your prolactinoma, then hormone supplements may be required. These may include steroid tablets for adrenal under-activity, thyroid hormone tablets for thyroid under-activity and possibly, oestrogen HRT for women or testosterone supplements for men. Growth hormone replacement therapy may also be required. Please see *The Pituitary Gland; Its Conditions and Hormones Explained* Booklet.

If you notice any clear watery fluid coming from one or both nostrils, report this immediately to your doctor, just in case it might be leakage of CSF (cerebrospinal fluid which surrounds the brain).

Prolactinoma aftercare

You will be reviewed by your endocrinologist. Initially, this may be every 3-6 months but once blood levels and treatment doses are stabilised you will be reviewed once a year. Obviously during this time you will be able to contact your own endocrine department should you have any problems.

Some small prolactinomas can go into remission after dopamine agonist treatment. In some patients, a trial period of withdrawal of treatment may be recommended after 3-5 years.



How will a **Prolactinoma** affect my lifestyle?

Employment

For your stay in hospital if you have had surgery, the ward staff will give you a certificate for your employer and advise you how long you will be expected to remain off work. Your GP can issue further certificates if you require these.

If you are experiencing any difficulties in retaining or returning to your employment, at any stage of your pituitary condition, we suggest that you contact The Foundation's Helpline or your local Citizens Advice for the most up to date information about employment rights and where to get advice about benefits. If you need extra employment support because of a disability, your local Jobcentre Plus can put you in touch with one of their Disability Employment Advisers. You can also see The Foundation's *Employment* Booklet for more information.

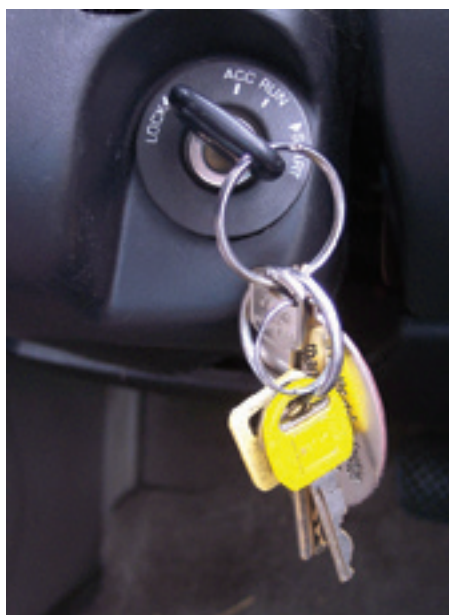
Driving

You have a legal obligation to advise the Driver and Vehicle Licensing Agency (DVLA) if there is any reason why you should not drive. Many patients with pituitary conditions will find there are no restrictions on their driving, but you should check with your GP. The only condition likely to affect patients is having a problem with your eyesight. Transsphenoidal surgery does not in itself limit your entitlement to drive and your doctor or specialist will give you full advice. DVLA say that patients with a pituitary tumour should tick the 'brain tumour' box and put a note at the side of the form, stating 'pituitary tumour'. DVLA will accept any extra brief notes with the form (or at side of form)

regarding the patient's condition, such as stating 'pituitary tumour' etc. and that DVLA should contact their specialist endocrinologist for further information if required.

You may also seek further advice from the DVLA by consulting for England, Scotland and Wales: **The Medical Adviser, Drivers Medical Group, DVLA, Longview Road, Morriston, Swansea SA99 1TU.**

Tel: 01792 782337 (medical professionals only) or **mailto:medadviser@dvla.gsi.gov.uk** (medical professionals only) For Northern Ireland: **Driver and Vehicle Licensing Northern Ireland, Castlerock Road, Coleraine, BT51 3TB. Tel: 028 4703 41369**



How will a **Prolactinoma** affect my lifestyle?

Insurance and pensions

Your current insurance provider will require medical reports and each case will be assessed individually to make any adjustments found to be necessary on your premiums. Company policies do vary widely and you may need to shop around. Don't be disheartened if the first response is disappointing. For travel insurance information, please see our website.

Prescriptions

Dopamine agonists aren't exempt from prescription charges if they are taken on their own but if you suffer from hypopituitarism your medications will be exempt from charges, as below.

If you have to take any of the following: hydrocortisone, thyroxine or desmopressin permanently you will receive free prescriptions for all medicines. Ask at your GP's, pharmacist or endocrine clinic for form FP92 or (EC92A if you live in Scotland). The form (which will need to be signed by your doctor) tells you what to do to apply for exemption and you will receive an exemption certificate. These certificates need to be renewed and you will receive an application when this is due for renewal. Information about free prescriptions and the full list of medical conditions which qualify for exemption from prescription charges can be found in leaflet H11, available from pharmacies and main Post Offices or on www.dh.gov.uk. If you are not sure whether you are entitled to free prescriptions, you must pay for your prescription and ask for a NHS receipt (form FP57 in England, EC57 in Scotland)

when you pay; you can't get one at a later date. This form will explain how to claim your money back and must be within three months of paying.

If you don't qualify for free prescriptions and need more than five prescription items in four months, or more than 14 in a year, ask your pharmacist about a pre-payment certificate, which is more economical for you. If you live in Wales you don't have to pay prescription charges.



Personal medical identification

If you are taking hormone replacement medication, it is a good idea to wear a medical information bracelet or equivalent as the information will help doctors if you have an accident and are unconscious. There are various medical emblems available; our website includes contact details for several organisations.

Alcohol

Generally, there is no interaction when drinking alcohol in moderation (such as the national guidelines - currently 2 units for women and 3 for men). However, please discuss this with your endocrinologist when you are prescribed a dopamine agonist.

Patients' stories

One patient's story

I was first diagnosed with a Prolactinoma in 2005. I had recently got married and was planning to start a family as soon as possible. I had been on the contraceptive pill for several years and stopped to try for children. My period never came back. I had noticed a milky discharge from my breasts for several months and had been having a lot of severe migraine type headaches. I was concerned so went to see my GP who took blood tests. I was told I had an increase in my prolactin levels. I had never heard of prolactin! My GP tried to explain what all this meant but all I could focus on was a certain word he used - tumour. Did I have a brain tumour? My referral to the Endocrine clinic was quick and all my worries were put to rest. They carried out various tests (none of them hurt) and I had to go for an MRI scan to confirm a diagnosis of a prolactinoma. A prolactinoma is a benign (not cancerous) growth of the pituitary gland.

I was still concerned about my prospects of starting a family but I was reassured, once on medication my fertility levels should return to normal. My life has not been affected dramatically by the diagnosis. I take medication (Cabergoline) twice a week, usually before my bed-time. I have had no side effects and I get a yearly review at the clinic. My periods came back to normal within 2-3 months, my milk dried up and my severe headaches stopped. I am pleased to say I became pregnant very quickly and had no problems (apart from heartburn and backache!). I have a beautiful and cheeky daughter who is 2½ years old. I stopped my medication whilst pregnant without any problems.

Exciting times ahead again as I am now 6 months pregnant! We are all overjoyed, especially my daughter who wants a baby sister - not a brother!

So having a prolactinoma has not affected my day to day life, and being on medication has helped me achieve my ultimate goal of becoming a mum!

Patients' stories

Another patient's story

No one can be sure when the tumour started growing. It grew so slowly that I did not notice any symptoms until 8 years ago when I began to have a general feeling of lethargy and occasional migraine type headaches. When I caught a cold, my sinuses were blocked and pressure built up causing pain. Sneezing was agony. I learnt to sneeze through my mouth. My left eye became light sensitive and watery and I began to get a pain down the left side of my face to my jaw.

I had an operation to straighten my nose to help my breathing. At the same time, an allergy test was done with no positive result. I had my teeth x-rayed, eliminating the possibility of an impacted wisdom tooth.

My general feeling was of tiredness, discomfort when moving my head and weight increase. When I walked on a pavement with hard-soled shoes, I felt a jarring pain in my neck. I had physiotherapy for a damaged neck. I was taking beta-blockers, antihistamine tablets, anti-migraine tablets and inhalers. I tried a food intolerance diet and got spectacles for reading and for long sight.

The headaches got worse and became more frequent. I would sleep at night, wake in the morning, shower and have to go back to bed where I would sleep until lunchtime. Every month or two the headaches were so severe that I had to have pethidine. I tried acupuncture and homeopathy.

I could not play games with my children. My wife was stressed with the worry. I found it difficult to do simple tasks, and my work suffered.

In February 1996 I asked my ENT specialist for a CT scan. He phoned me afterwards saying that my sinuses were fine, but that I had a prolactinoma. I was so relieved that he had found something that I told him the news was wonderful.

With only two small tablets of Cabergoline a week my life has completely changed. Between March and Christmas 1996, I have had filming trips to The Gambia twice, India twice and Madagascar twice. I feel 20 years younger. My weight has dropped from 12 stone to 10 stone. I have never enjoyed life so much. All the symptoms have gone.

People I meet can't believe how much I have changed. Some people that I have known for years haven't recognised me. My only regret is that at 48 years old, I am just beginning to really enjoy life.

Please support The Pituitary Foundation

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

- ✓ Receive our members' newsletter, *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.
- ✓ 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 **£20.00** for a full year, which is only **£1.66** 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,
86-88 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:	
Address:			
Postcode:			
Telephone No:		Email:	
Please tick (✓) the type of Membership you require:			
Individual	<input type="checkbox"/> £20.00 (annual)	Family	<input type="checkbox"/> £35.00 (annual)
Life Membership	<input type="checkbox"/> £250.00	Concessionary*	<input type="checkbox"/> £10.00 (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).			
Gift Aid: I am a UK Taxpayer. Please treat all membership payments and donations I have made for 6 years prior to this declaration and all that I make from this date, until I notify you otherwise, as qualifying for Gift Aid (please tick) <input type="checkbox"/>			
You must pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6th April one year to 5th April the next) that is at least equal to the amount of tax that the charity will reclaim on your gifts for that tax year.			
Signature:			Date:

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

**86-88 Colston Street,
Bristol, BS1 5BB**

www.pituitary.org.uk

Helpline: 0117 370 1320

Administration Line: 0117 370 1333

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86 Colston Street

Bristol

BS1 5BB

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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 booklet enclosed with your medication or consult your GP or endocrinologist.

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Working to support pituitary patients, their carers & families