

Employment and benefits



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

After diagnosis and treatment, many pituitary patients go on to lead 'normal' or 'near-normal' lives, once achieving good hormone replacement therapy. Indeed, there are those patients who do not even need replacement medication. However, there are others who have different experiences.

Those people with pituitary conditions who may struggle with ongoing symptoms want to continue with their employment or find work. Being able to work can be a positive experience in itself for your own self-esteem and social interaction. Of course, in most cases, employment is a necessity for financial reasons.

However, continuing with your employment or seeking a job after diagnosis and treatment may be fraught due to you as an employee needing some flexibility experiencing possible fatigue, pain, unpredictable symptoms and regular medical appointments and tests.

In this booklet we consider aspects of the workplace for you as a patient and to look at ways you and your employer can engage to enable understanding.



The Equality Act 2010

The Equality Act 2010

(source: www.direct.gov.uk)

The Equality Act 2010 gives rights to employees who have a physical or mental health condition and find it difficult to carry out normal day-today activities. The effect must usually be 'long term' which means one which has lasted, or is expected to last, at least 12 months (or the rest of the person's life if shorter). People with cancer, HIV and multiple sclerosis are covered by the Equality Act from the date of diagnosis.

The Act covers all aspects of employment, including:

- Promotion and training
- Transfer and redeployment
- Career development and retention
- Dismissal and redundancy.

The Equality Act 2010 calls the changes and support to help disabled people do their jobs with 'reasonable adjustments'. What is considered reasonable can depend on the resources and money available to effect a practical solution. Good practice for employers is simply to ask what you need to work to your best and then just offer it if readily achievable, rather than thinking legalistically.

A note on disability and equality in the workplace

Regardless of the fact that many pituitary patients carry on with life as 'normal' post-diagnosis and treatment, there are others who do not. In more extreme cases, pituitary conditions can be considered a disability.

If you feel you are experiencing discrimination due to your condition and if you have thoroughly followed the procedures as identified in your staff handbook, you should contact your local Citizen's Advice, ACAS or your union (contact details are at the end of this booklet). You can learn more about disability at work at www.direct.gov.uk or by contacting the Department of Employment.



Employment



Finding work

Because pituitary conditions are sometimes classed as ‘long-term/life-long illnesses’, they must be declared in the medical section of a job application or during an interview. Failure to do so, either by giving an untrue answer or by avoiding the issue altogether, may render the applicant liable to termination of contract at best, or at worst, to legal action.

Showing a prospective employer The Pituitary Foundation’s booklet *The Pituitary Gland, Its Conditions and Hormones Explained*, or other relevant booklets from The Foundation, may help as some misconceptions exist as to the nature of the condition. It may also help prospective employers gain a better understanding of your condition. If prospective employers request medical information from your GP or hospital specialist, remember that you have a right to view your medical records in the surgery.

If a medical is required for employment purposes, this can be done in two ways.

1. If the examination is performed by your GP, you have the right to view the report within 21 days (there is a box to tick on the form if you wish to see the report before it is sent to prospective employers).
2. If the examination is carried out by the company doctor or an independent physician, details of the finding can be requested via your GP.

At work

If you are employed, or find employment, you should be able to expect the same courtesy, respect and treatment as any ‘fit’ employee. In fact, you may find that certain adjustments and allowances will be made for you. There is no reason, however, why you should have to endure harassment or being made to feel uncomfortable

by management and fellow colleagues.

You are entitled by law to the same sick leave, pension rights and job security as anyone else. These are too complicated to be dealt with in detail here, but basically, what is good for the general public is good for you.

Employers also have rights. They have the right to expect that an employee will fulfil his or her part of the Contract of Employment. If an employer pays for work to be done, that employer has the right to terminate the employment of an employee who is patently unable to do that work.

It is important to note that no one with a pituitary condition, or any other medical condition, should have to experience

unpleasantness because of their condition. If management and fellow workers are aware of the illness, it will do much to avoid suspicion and trouble in the workplace. Education and openness can possibly prevent unpleasant treatment. People with pituitary conditions, which are not easily understood by fellow workers, may find that work life may be difficult. In such a case, you should make an appointment to discuss the matter in confidence with the human resources department, or your line manager, and talk about the problem openly. If you are comfortable, it may be suggested to them that they attempt to educate your colleagues about your condition on your behalf, or you may wish to do this.



Employment



Should I tell my employer?

It may be that your pituitary condition will have little effect on your day-to-day life. However, if newly diagnosed, you may need a variety of tests, consultations and treatments which could mean time away from work.

It is best to be honest with your employer. Education is important. Letting them know about The Foundation booklets and our website (www.pituitary.org.uk) will assist with this and also provide them with credible information about your condition. Further, it will be an indication that, even if your condition is considered 'rare' and not well-known, you are a member of a community that has support and a voice.

You should make an appointment with your line manager or the human resources department and prepare by taking booklets or print outs from The Foundation website. Explain your condition as best you can and detail what might be expected

in future for you to be away from work. It should help a great deal if they know what to expect and you can work together on plans to keep on top of, or, if needed, adjust your workload.

This meeting and your condition should be kept in the strictest of confidence by your employers. Only you have the right to disclose your medical information to colleagues.

What if I don't tell my employer?

If you don't disclose your condition to your employer, they are not obliged to provide suitable adjustment should you need it. If you find you need adjustment in future, and you have not disclosed your condition, this could go badly for you. It is always best to be honest and forthright and doing so will assist you if you should have concerns about your employment in the future.

How much time off am I likely to need?

Every patient is different and it depends on what tests and treatments your medical team orders. You should ask your endocrinologist or endocrine nurse to go through the process with you and advise on what you are likely to expect. Ask for the worst case scenario so that you, and your employers, can anticipate any pitfalls. We find that often patients are not aware of possible recovery times of some of the more arduous tests and treatments, such as surgery, and they may have unrealistic expectations of when they can pick up the strands of life again. As every patient is different, we would suggest that you plan your recovery realistically so that both you and your employer's expectations can be met. The Foundation has a Post Surgery fact

sheet which explains about recovery from pituitary surgery.

If your endocrine clinic does not provide this information to you, please contact The Foundation's Helpline or our Endocrine Nurse Helpline.

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I've had my treatment, how do I plan to return to work?

Again, all patients are different but there are some things you may need to prepare yourself

for, including:

- **Energy levels:** You may not have the energy you had before diagnosis and treatment. Your energy can return, or, if you need hormone replacement therapy, it may take some time for you and your endocrinologist to get your hormone balance right. Inform your employers that this is happening and that you are working with your medical team to balance your levels.
- **Medication timings:** Many hormone replacement therapies come in tablet form, however, there are some injections or nasal sprays and even some treatments where you must return to the clinic and have them administered by your doctor. It might be that you'll need to take your pituitary medications during work hours. If you need privacy to do this, inform your employers and ask if there is a facility available for you, i.e., an unused conference room or an office. It might be that you'll need some time to recover from the effects of medication administration. This should be discussed with your endocrine team to ascertain a schedule that best fits your life. However, if time is needed from work, again, be open with your employers who may be able to provide you with a flexi-schedule to make up work or other suitable adjustment.
- **Transport of medications:** If any of your medications need to be kept refrigerated, a fridge at work could be used. A cool bag with frozen ice blocks would help if there isn't a fridge. Always label your medications with your name.

Employment

If you are finding that the normal level of productivity at work that you used to enjoy is waning due to pituitary conditions, or you have 'pituitary days' where you do not feel yourself, this may cause problems with employers. In most cases, pituitary conditions are not 'visible'. They are also not well-known, unlike diabetes, thyroid, multiple sclerosis or others. Therefore, some employers may not understand some of the physical challenges you may be facing or other challenges such as fatigue, problems with concentration, difficulty multi-tasking or memory problems.

If your employer communicates they are concerned with your performance, in the first instance, attempt to educate them on your experience with the aid of literature from The Pituitary Foundation. You may need to have an honest discussion about reasonable adjustments at work so your employer will be aware of your possible limitations and you will not need to endure the stress of unrealistic expectations.

Reasonable adjustments at work (source:www.gov.uk)

Under the Equality Act 2010, your employer has a duty to make 'reasonable adjustments' to make sure you're not put at a substantial disadvantage by employment arrangements or any physical feature of the workplace. Examples of the sort of adjustments your employer should consider, in consultation with you, include:

- allocating some of your work to someone else
- transferring you to another post or another place of work, such as working from home.

- making adjustments to the buildings where you work
- providing training or retraining if you cannot do your current job any longer
- providing modified equipment
- being flexible about your hours - allowing you to have different core working hours and to be away from the office for assessment and treatment
- making instructions and manuals more accessible
- providing a reader or interpreter



Things to consider at work

You can play an active role in discussing these arrangements with your employer. You might also want to encourage your employer to speak to someone with expertise in providing work-related help for disabled people, such as an

occupational health adviser. Issues for you both to consider include:

- how effective will an adjustment be?
- will it mean that your disability is slightly less of a disadvantage or will it significantly reduce the disadvantage?
- is it practical?
- will it cause much disruption?
- will it help other people in the workplace?
- is it affordable?

You may want to make sure that your employer is aware of the Access to Work programme run by Jobcentre Plus. Through this programme, employers can get advice on appropriate adjustments and possibly some financial help towards the cost of the adjustments.

In many cases, if you have an understanding employer, this will solve the problem. If it does not, your next route is to ask your endocrinologist to send a letter on your behalf. Most endocrinologists will do this and be able to put forward your individual circumstances. If you have trouble getting your endocrinologist to send a letter for you, The Foundation has a proforma letter for consultants which might help. Please see our website or phone our Helpline for details. The Foundation cannot send you this letter, but only send it to your consultant on his or her request. The Foundation also cannot correspond with your employer for you as we are unable to get involved in individual cases.

If this fails to achieve desired results, you may need to seek advice. Employment relations, although not perfect, are improving all the time,



therefore we suggest you do all you can to speak openly about your concerns and seek resolution. If your approach to your line manager does not succeed, then you can take out a formal grievance. If this is not successful and you are not heard with a sympathetic ear, or worse, get the impression that your employer is not doing anything about the situation, you should seek advice externally. It is important to refer to your staff handbook and be certain you've followed the appropriate procedures thoroughly before seeking external advice.

There are a variety of sources that will help including your local **Citizens Advice**, www.citizensadvice.org.uk or **ACAS** www.acas.org.uk. If you belong to a Union, they may be able to work with you, provide advice and help by representing you and attending meetings with you.

The pituitary **impact**

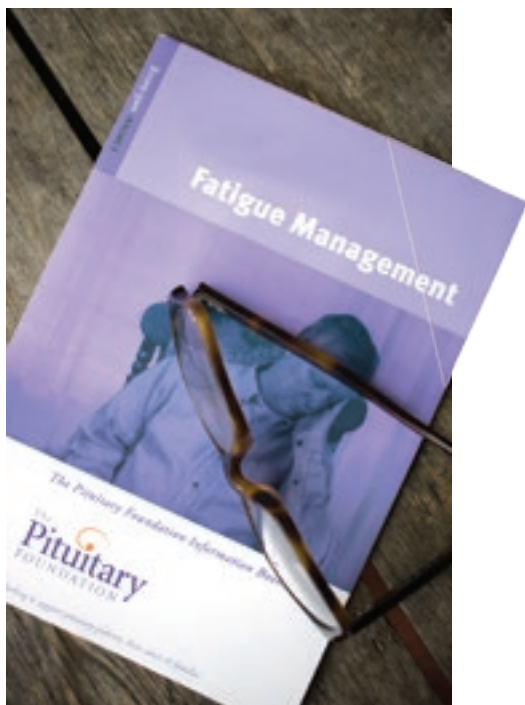
A diagnosis of a pituitary condition may have an impact on your life in more ways than just medically. Again, everyone is different but you may find you are experiencing a variety of emotions such as loss, grief, shock, depression as well as the need to manage life changes. These emotions may affect your home life, your relationships and your work. Dealing with emotional issues alongside attempting to manage your condition and changes to your life may increase your stress including your stress in the workplace.

The Pituitary Foundation has a series of well-being booklets that offer tools to help with these issues. They are available to read or download on-line at our website, www.pituitary.org.uk or you can request them via our Helpline or Helpline email (helpline@pituitary.org.uk). It can also benefit you to talk to our HelpLine operators or Endocrine Nurse about your concerns. Lastly, The Foundation can put you in touch with other patients, you can tell your story to those who understand and get peer support, and often excellent advice, as you travel through your pituitary journey.

Some patients' physical appearances may alter because of their pituitary condition, for example, weight gain, facial changes, etc. This may cause distress if you have to deal with customers, colleagues or even ordering a new uniform. Further, we've had patients report they have feelings of fear that they may be unemployable, or have problems with confidence, or experience

feelings of embarrassment or shame due to their performance level decreasing.

Often, people confuse who they are with what they do. It is important to remember that you are you, not your job or your career. You must give yourself permission to do what you need to do for your health and well-being. If any of these feelings start to overwhelm you, remember there is support available through The Foundation.



Often, when we are experiencing a personal or medical dilemma, we forget that we are interacting with others who have their own ways of communicating or their own agendas and priorities.

Your employment performance has an impact on your employers and colleagues. It also has an impact on business needs. When speaking with your employers, it is advisable that you

are thoughtful, measured and diplomatic in your communications. Before a meeting, take a moment to put yourself in their shoes and try to be open to what they have to say.

Often, managers become managers because they are good at technical skills, but they may not have people management skills. If you experience difficulty, it will be hard to be patient but they may need your understanding as you need theirs.

Strategies

You may find yourself in the position of having to adopt strategies to deal with your life after diagnosis. These could be reasonable adjustments you discuss with your employer or considerations for a life change. Some ideas:

Adapting strategies to discuss with your employer

- Could you (and would your employer consider) a reduction to part-time or a move to flexi-time? You may want to assess if there are any benefit entitlements due to shorter hours or less wages. Contact your local JobCentre Plus for information.
- Can you work for your employer on a retainer or in an advisory role so that you can choose your times of working?
- Can you work from home for all or part of the time?
- Could you move to a lower-key career in the same role or with the same employer?

This may mean less pay and that may seem frightening. But, sometimes in the grand scheme of things, less stress and lifting off the heavy weight of expectations (you of yourself and from others) can offer you a better work/life balance and more quality-of-life which might be more important than earning more money.

Remember, it may be that you simply need to take the pressure off in the short-term. As suggested earlier in this booklet, if you are having problems, be certain to discuss them fully with your endocrine team. It may simply be a matter of hormone replacement adjustment.

Thinking strategies to consider if you need to make a life change

- Is self-employment an option?
- If you are not able to work for a time, consider this as a 'time out' (forced on you of course) to think of things you never had time for before. Reconnect with family and friends, read



books you've always wanted to read, watch films you've always wanted to see, take up a hobby which has always interested you, go outside to take walks, etc. Do something useful to keep socially active, your skills sharp or learn new things. Local charities could almost always use a helping hand. Or, you can take some time to retrain or learn new skills.

- If you are the main breadwinner, can you work with your partner to share the burden or reduce monthly expenses? You may

need to consider some other ideas such as: Taking in lodgers (short-term or long-term). Renting a parking/garage space.

Looking at monthly budgets to improve cash flow.

- Start a journal, not just about employment, but also your experiences, problems and feelings.

These are suggestions from other patients. You may find your own ways to adapt or you may need to discuss your experience with someone else to find creative strategies.

Benefits for pituitary patients and their families

Benefits are changing

Any information on benefits becomes out of date quite rapidly, as all governments change them frequently, often making it more difficult to qualify for benefits related to ill health. In recent years several benefits have disappeared, including incapacity benefit, disability working allowance and family credit. Others are gradually being phased out as universal credit takes the place of six existing benefits in some areas of the country.

What you may be entitled to

Anyone affected by ill health such as a pituitary condition, so that they are no longer able to work, or can only work part time, may be able to claim one or more benefits. Similarly if someone you care for suffers ill health.

The benefits that pituitary people and their families are most likely to claim are:

- Employment Support Allowance (ESA) – if you cannot work full time
- Job Seekers Allowance (JSA) – if you could work
- Carers Allowance (CA) – if you care for someone
- Income support (IS) – as a top up
- Child Tax Credit (CTC) and Working Tax Credit (WTC) – for those on a low income
- Housing Benefit (HB) – help with your rent
- Universal Credit (UC) – a single benefit replacing most of the above in some areas of the country

- Personal Independence Payment (PIP) – if someone needs care or has mobility needs
- Disability Living Allowance (DLA) – if a child has care or mobility needs; also some adults already claim this but will soon be switched to PIP
- Council Tax Benefit (CTB) – help with your council tax.

People over retirement age may claim other benefits such as pension credit and attendance allowance.



Claiming benefits

If you think you may be able to claim some kind of benefit, perhaps because you have lost

your job or you are no longer able to work because of the effects of a pituitary condition, call the benefits helpline on **0800 055 6688**. They will ask questions about your situation and advise you which benefit or benefits you could potentially claim. They may ask you to attend an appointment at your local JobCentre Plus, or if you are so ill that you are unable to travel they may send someone to visit you.

You need to claim as soon as possible, because most benefits cannot be backdated. Also if they send you a form to fill in, ask for other information, or call you for an interview, they will give you a date for this to be done by and you need to do what is needed before the deadline.

If your situation and location are such that they advise you to claim Universal Credit, they may be able to deal with all or most of your situation in one visit. Otherwise you may have to make several claims for the different benefits. For example, to claim for help with your rent and council tax, you will need to contact the local town hall or civic centre to claim from whichever local council sends you your council tax bill.

Before contacting the benefits helpline, it may be worthwhile speaking to a benefits advisor to find out what you might be entitled to. They may also be able to advise you between alternatives, such as whether it is worthwhile to work part-time. It is also possible to make these calculations on line, if you think you know how to do it successfully.

There is not enough space here to write in detail about most of the benefits listed above.

Below is some information about the two benefits that pituitary patients and their families contact The Pituitary Foundation about most frequently - Employment and Support Allowance and Personal Independence Allowance.

Employment and Support Allowance (ESA)

When you ring the benefits helpline on **0800 055 6688** and tell them that you are unable to work due to your health, they will start you on ESA. After asking some questions, they will send you an ESA claim form. If you are not confident about dealing with a complicated form yourself, get help to complete the form from a local Citizens Advice Bureau or welfare benefits centre. Remember to state what your problems will be on a bad day.

ESA is assessed using a points system. Points are awarded for problems with walking, sitting and standing, reaching and moving, communication, understanding, incontinence, anxiety, dealing with other people, behaviour and other difficulties.

After you have sent off the form, they are likely to make an appointment for you to visit a centre where you will be asked about your illness and the problems that it causes. They may also give you a brief physical examination. Remember to state all of your difficulties, including those you have on a bad day, and give examples of when there have been problems. If you are so ill that you are unable to travel they may send someone to visit you. The same applies to having an assessment for PIP.

Personal Independence Payment (PIP), and Disability Living Allowance (DLA) for a child

To start a claim for PIP for an adult ring 0800 917 2222, or if you want to claim DLA for a child then call 03457 123456. In each case they will ask various questions and will send you a form to fill in. As with ESA, if you are not confident about dealing with a complicated form yourself, get help to complete the form from a local Citizens' Advice Bureau or welfare benefits centre.

PIP is assessed using a points system, with points awarded for the help or special equipment you may need for tasks such as preparing food, eating and drinking, managing your health, washing and bathing, getting dressed, dealing with money and walking. This includes needing someone to encourage you or remind you about tasks. DLA for children does not use a points system but it considers topics similar to PIP and others appropriate to children. In general, they consider what support a child would need over and above those of a normal child of the same age.

After you have sent off the form, they are likely to make an appointment for you to visit a centre where you will be asked about your illness and the problems that it causes, as noted above for ESA.

If they turn you down

If they turn you down, ask for a reassessment. They will tell you how to do this in the refusal letter. Then if necessary, put in a formal appeal. Sadly, the assessments are wrong all too often, and many appeals are successful. It may be worthwhile getting help to appeal from a benefits advisor. Or ring The Pituitary Foundation Helpline and ask for benefits advice available.

Sources of information

Your local Citizens Advice bureau and their website

www.citizensadvice.org.uk/benefits

Your local benefits advisor or benefit advice centre

Money Advice Service leaflets and their website **www.moneyadviceservice.org.uk**

Leaflets and websites of the government **www.gov.uk/browse/benefits**

Disability Rights UK website **www.disabilityrightsuk.org**

Resources and links

Pituitary Foundation Support and Information Helpline

0117 370 1320 Monday - Friday
10:00 a.m. - 4:00 p.m.



Pituitary Foundation Endocrine Nurse Helpline

0117 370 1317
Available scheduled hours only.
Or email: helpline@pituitary.org.uk
Website: www.pituitary.org.uk

Advisory, Conciliation and Arbitration Service (ACAS)

Helpline: 0300 123 1100.
Monday - Friday 8:00 a.m. - 6:00 p.m.
Website: www.acas.org.uk

JobCentre Plus

JobCentre Plus is a government agency supporting people of working age from welfare into work, and employers to fill their vacancies. They are a part of the Department of Work and Pensions.
Website: www.jobcentreplus.gov.uk

One patient's experience

Nothing can prepare you for life as a pituitary patient, and diagnosis literally is a life-changing event. Many patients, like me, will find employment becomes harder to maintain as energy levels, the shock of surgery and adjustment to a new medication regime become a reality. I would like to say that my employers were fully supportive, and facilitated a stress-free return to work in what was a very stressful profession. Whilst initially being concerned and allowing me time off to attend medical appointments and hospital visits, they did not expect my period of recovery following surgery to be as long as it was, and their attitude towards me changed significantly.

Having been diagnosed with Cushing's disease after many years of increasing ill-health, by the time I had my surgery I literally had nothing in reserve, and did not work for seven months after my trans-sphenoidal operation. Whilst my employers ensured I had an Occupational Health assessment, a phased return to work and made 'reasonable adjustments' (which is required by law and which I appreciated), their attitude towards me was judgemental and obstructive. I was only capable of working two days a week, and even this was a struggle at times.

I tried my best to provide information about my condition, my changed health status and medication regime, providing them with booklets from The Pituitary Foundation, and holding money-raising events. I also attended several meetings they insisted on calling to discuss my future, only to be told by one senior manager that I did not 'suit their business plan' any longer.

I had worked tirelessly for 17 years in a profession which prides itself on being non-judgemental and accepting, yet discovered this did not extend to their own staff. After four months I decided that I no longer wished to work for an organisation who could not show compassion and understanding in someone's darkest hours, and made the decision to pursue a different career. Fortunately, I was able to retrain and I did eventually leave that employment exactly a year after returning to work. It was incredibly liberating to walk away from the negative attitudes, and feel as if I was in control of my life again.

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).			
<input type="checkbox"/> 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:		

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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www.pituitary.org.uk

Company Limited by Guarantee
Registered in England and Wales
No. 3253584

Registered Office:
86 Colston Street
Bristol BS1 5BB

Registered Charity No. 1058968

A donation from Doyly Carte was kindly made
towards this booklet.

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carer, have any concern about your treatment or any
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enclosed with your medication or consult your GP or
endocrinologist



pit-bklt/04/jun2017

The
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Working to support pituitary patients, their carers & families