

Living with hypopituitarism

For young adults and teens

The questions you ask about diagnosis,
treatment and replacement hormones

About this booklet

This booklet offers answers to common questions about living with hypopituitarism as a teen and young adult. We hope it will help you to better understand your condition and support you in talking about this with your family, friends, and health care team.

Understanding your condition and taking an active part in its management can help you cope with any health issues you might encounter.

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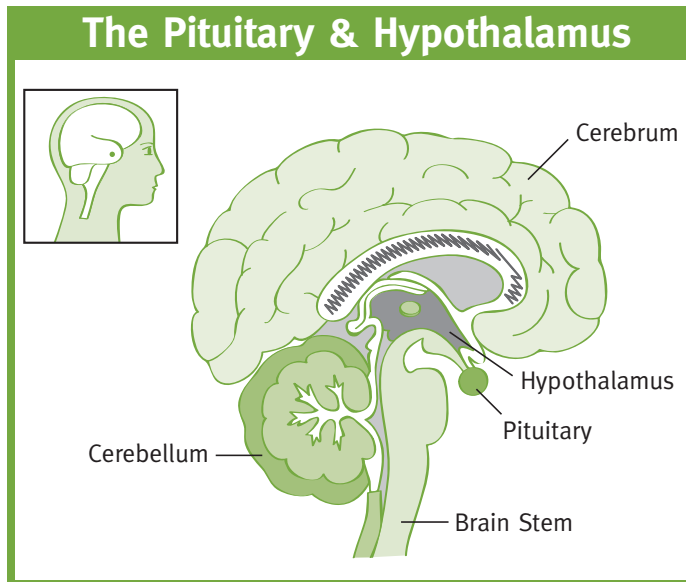
Why me; did I do anything wrong?

It's quite normal to ask these questions. Some pituitary conditions can be congenital (you were born with it) whilst others can occur during childhood, in your teens or as an adult. You certainly wouldn't have done anything wrong to cause your condition.

Diagnosis can seem a bit overwhelming and you will be confronted with all these new medical terms. Remember, your family and friends will be learning with you too. It's bound to feel a bit strange at times but just take one day at a time and remember that you're not the only one going through this and that help and advice is available.



Where is my pituitary gland?



The pituitary gland sits in a bony hollow called the pituitary fossa. This is behind the bridge of the nose and below the base of the brain, close to the optic nerves.

It is usually about the size of a pea and consists of two parts (often called lobes) - a front part, called the anterior pituitary and a back part, called the posterior pituitary.

It is often considered the most important part of the endocrine system because it produces hormones that control many functions of other endocrine glands.

Effects of having hypopituitarism

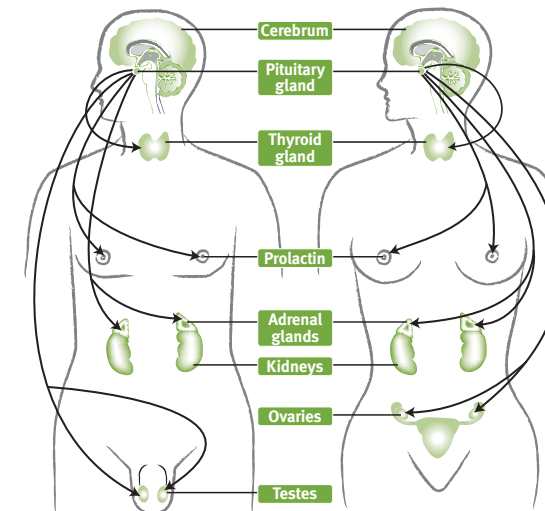
Hypopituitarism means that one or more of your pituitary hormones is not working (deficient). The amount of deficient hormones will vary between individuals.

The signs and symptoms of hypopituitarism depend on which of the pituitary gland hormones are involved, to what extent and for how long. Symptoms may be slow to appear and vague, which may also mimic other more common illnesses.

Symptoms can include, over a variety of deficient hormones:

- Growing less well
- Putting on weight despite eating the same
- Feeling cold when everybody else is warm
- Generally feeling a bit tired
- Feeling sickly, weak or light-headed
- Weeing and drinking a lot, even through the night and your wee is always pale
- Starting puberty before age nine or you have no signs of puberty at age 13
- Fertility problems

The pituitary gland and other glands



What causes hypopituitarism?

There can be several causes, which are explained below:

Congenital hypopituitarism

You might have been diagnosed with hypopituitarism as a baby. This could be a generic cause or an unidentified cause. One of these conditions can be septo-optic dysplasia.

Acquired causes

Craniopharyngioma: This is a type of slow growing, benign brain tumour with 50%

occurring in children under 16 years.

Pituitary adenoma: Although these are the least common cause of hypopituitarism in childhood and adolescent age groups.

Surgery or radiotherapy: This treatment is given to young people who have brain tumours away from the pituitary gland but the radiation can affect the pituitary and cause hypopituitarism.

Severe head injury: This is a rare cause of the pituitary not working, resulting in a lack of production of one or more hormones.



Treating hypopituitarism

All of the hormones produced by the pituitary gland (e.g. growth hormone and anti-diuretic hormone) and those produced by the glands controlled by the pituitary gland (e.g. cortisol, thyroxine and sex hormones) can be readily replaced. Each one is discussed below.

Cortisol: Cortisol is a hormone released by the adrenal glands. It is important for a variety of functions, but is particularly important for helping the body respond to stress. Hydrocortisone is the medication used to replace cortisol.

Our booklets *Hydrocortisone Advice for Patients*, and *Hydrocortisone Advice for Parents* can be downloaded or ordered free of charge from our website. These booklets explain sick day rules, when and how much to increase your tablets, when an emergency injection is needed and when to seek medical help.

Diabetes Insipidus - A condition characterised by great thirst and the constant need to pass urine. It is caused by a reduction in, or lack of response to antidiuretic hormone. It is an entirely different disease to Type I or II Diabetes Mellitus, which has to do with insulin and blood sugar levels. Having DI is probably the most difficult part about

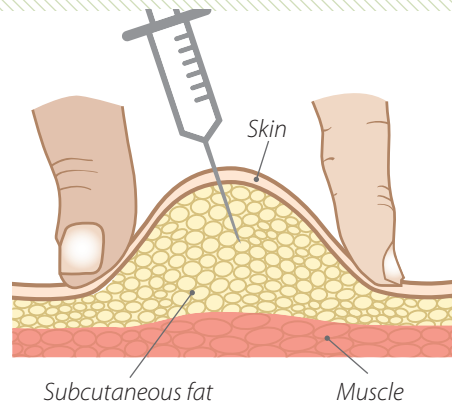
having hypopituitarism. Replacement is with desmopressin to relieve symptoms, and young adults often use DDAVP Melts.

Thyroid stimulating hormone (TSH) - A hormone released by the pituitary gland, telling the thyroid gland to release thyroxine. This is one of the thyroid hormones released by the thyroid gland. It is important for heart and muscle function and the development and maintenance of bones. If deficient, metabolism is affected - your body will run 'slowly', feel cold, gain weight and you may feel depressed. Levothyroxine is the medication used to replace thyroid hormone.

The following hormones will be tested, once the dust has settled, following surgery/radiotherapy:

Growth Hormone (GH) - A hormone released by the pituitary gland which controls the rate of growth. Even after you've finished growing, growth hormone has many important effects during adult life, such as affecting your muscles, bones and energy levels. Your GH levels will be checked through transition and longer term where appropriate. The deficiency in GH is treated with GH injections under your skin (in your thigh or tummy), given through a very thin needle at night. See diagram on page 8.

Treating hypopituitarism



Follicle Stimulating Hormone (FSH) - A hormone released by the pituitary that contributes to sexual development. It works alongside LH in both men and women. In women, it controls ovulation and so is important for a normal menstrual cycle and for fertility. In men, it tells the testes to produce sperm.

Luteinizing hormone (LH) - A hormone released by the pituitary gland that contributes to sexual development. It works alongside FSH in both men and women. In females it controls ovulation and so is important for a normal menstrual cycle and for fertility. In men it stimulates the testes to produce sperm. In women, the combined action of FSH and LH on the ovaries leads to production of oestrogen. In men, LH stimulates the testes to produce testosterone.

Oestrogen - A female hormone which is produced and released by the ovaries. It is important for female sexual development – making a girl's body into a womanly shape, and causing breasts to grow. It is also important in the development of an egg during the menstrual cycle. Oestrogen treatment can be as pills or patches put on the skin.

Testosterone - A steroid hormone from the androgen group of hormones. In men it is produced by the testes (testicles). It is important for the development of male sexual characteristics (like growing pubic hair and developing a deep voice), and plays a key role in reproduction. It is also important for the maintenance of bone density and strength and for muscle growth and strength. Testosterone treatment can be given as injections, gels or tablets.

If you are given replacement hormones, your endocrinologist will regularly check your hormone levels by blood tests.

Treating your tumour

Surgery or radiotherapy

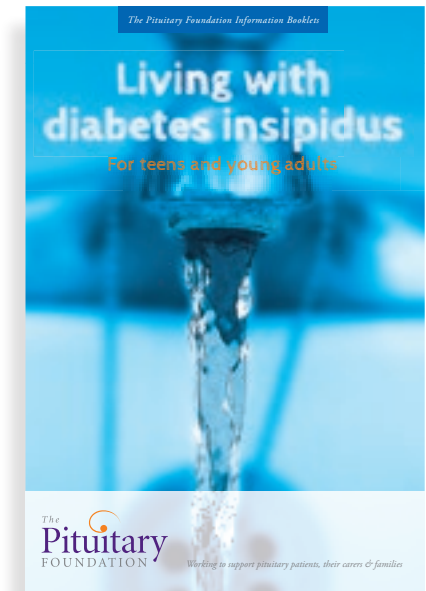
Tumours are one of the causes of hypopituitarism in young people. Most pituitary tumours (they can also be called lumps or a growth) are benign - which means they are not cancerous - but could still require treatment. It is most likely that the tumour you had has been operated on, and you may also have had radiation treatment. Hopefully, that means these treatments will control any further problems with your tumour.

Just been told I will need an operation on my pituitary - I'm afraid!

Your endocrinologist will work in a team which includes a neurosurgeon (usually based in the same hospital or nearby). The neurosurgeon will see you and your parents to discuss the type of surgery he/she will perform, how long it is expected you'll be in hospital and recovery time afterwards. You and your parents will be able to discuss any questions or fears you have at this time.

Will brain surgery affect me in other ways?

No, the pituitary is safely enclosed and tumours or surgery don't impact on the rest of the brain. If you have had any problems with your



eyesight, the aim of surgery is to improve your sight or at least not make it any worse.

Why do they keep checking my sodium?

Sometimes, pituitary surgery affects your ability to retain urine - this condition is called diabetes insipidus (please see our booklet - above - called **Living with Diabetes Insipidus for young adults and teens**). If this occurs, it usually settles down after a few days. However, it may last longer and you would need hormone replacement medication called desmopressin. Blood tests are a fairly quick way of checking your sodium balance.

Treating your tumour

Surgery may cause secondary adrenal insufficiency (AI) which should be explained to you, although you may not feel up to taking this information in if you are suffering from AI. The symptoms of AI to be aware of after your surgery can include feeling sick, dizzy and very tired. Your bloods will be being tested whilst in hospital and would pick this up, but if you have these symptoms once back home and you aren't taking hydrocortisone, you or your parents should contact the ward quickly.

Our **Post-surgery fact sheet** is also available to answer questions you may have following your operation.

I've been told I need radiotherapy – why?

This may be given instead of, or following surgery, or later on if it is necessary. This is a fairly common procedure carried out at a specialist centre (which would be nearest to your home) and can be used to complement surgery. Having radiotherapy does not mean that your pituitary tumour is cancerous. Radiotherapy may make you feel a bit sick or tired. Proton beam therapy, which has only been an option abroad for treating patients, will be available in Manchester in 2018.

Our **Surgery & Radiotherapy booklet** is available from our website and can be ordered or is free to download.

Transition from paediatrics to adult endocrinology

'Transition' is the process of getting ready to be looked after by adult doctors and nurses where you've previously been looked after by children's doctors and nurses.

Transition is a time when you, rather than your parents, begin to take control of managing your hypopituitarism and care – some things will happen naturally, whilst others you may have to work through a plan with your parents or doctors and nurses.

Adult clinics can have some small differences but on the whole are very similar, and there may be things that you prefer about the adult clinic! Some young people (and parents) see going to the adult clinic as a new start. Adult doctors and nurses are just as happy to take time and explain things and be contacted in between clinic visits. You can also still take your parents to adult clinic visits if you want until you get used to the new clinic.

Transfer to adult services should happen when you are well, and at a time which fits in with you. You may want to plan a time which is not too close to doing exams, leaving school or college, going to university and starting your first job. So make sure you tell your doctors and nurses if you are ready or not. Transfer will usually happen between 16 and 19 years of age.

Managing hypopituitarism day-to-day

Travelling

I'm worried about going away from home with my medication

You should be able to go on holidays and travel, as you did before. Taking your hormone medication with you might feel a burden at first, but this is easily carried with you in your hand luggage, or can be safely stored in the car. Some forms of GH will need to be kept in cool temperatures. Purchase or borrow a small cool bag with several freezer blocks. Most GH companies will also supply you with a cool bag free of charge.

Before you travel, call your accommodation (hotel, bed and breakfast) and ask if they have refrigerators in the rooms or, if not, if one can be hired for your room. If they do not have refrigerators, ask if they have a freezer where they can place your freezer blocks on a rota in order that you can keep your cool bag cool.

During travel, place your medication into a cool bag with both frozen blocks - the blocks should keep cool for around 12 hours. If you need to use the hotel's freezer, on arrival, give them one block labelled with your name. Twelve hours later, swap the blocks to ensure you continually have a frozen block to use both day and night in the cool bag.

If you are going on holiday abroad, you should ask your GP or endocrinologist for a



letter about your medication and your doses prescribed. This letter will be helpful should you become unwell and have to see a doctor. It is also useful for you to have this letter whilst going through airport security, in the event that they question your medication. If you have a repeat copy prescription this can also be shown. It is suggested that you have a hydrocortisone 100mg injection kit whilst you are travelling abroad, in case of emergency. If you are to travel to an area where the emergency injection kit may be subject to temperatures exceeding 25°C, then it should be placed in a small cool bag.

All of your medication should be labelled with your name and kept with you at all times during your journey, as part of your hand luggage.

At check-in they will ask if you are carrying anything sharp i.e., needles and you should mention if you are carrying injection needles for your medical condition. If you have any doubts whatsoever regarding airline or airport policies and procedures, please telephone the airport or airline well in advance of your departure. It is wise to take at least an extra two weeks supply of hydrocortisone tablets with you in case you need to increase your usual dose whilst away.

Travel insurance of course is recommended and our website has details of companies that other patients and their families have used successfully.

Camping – how do I keep my medication cool?

You could use your cool bag as above, but most sites now have electric hook-ups for tents and camper vans or caravans usually have fridges. There is a GH injection that doesn't need to be stored in a fridge, called Genotropin Miniquick, by Pfizer. You could ask your endocrinologist if this could be prescribed temporarily for your holiday.

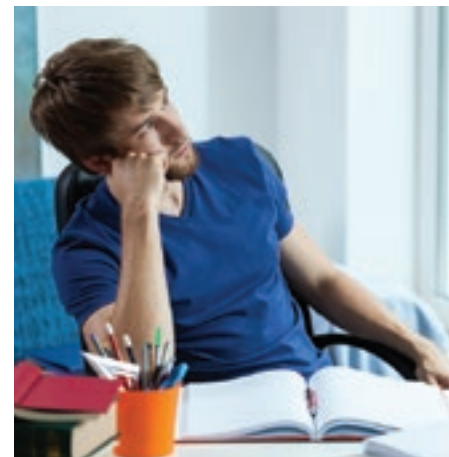
The Foundation has a template travel letter

you can request by emailing helpline@pituitary.org.uk or calling our Helpline on **0117 370 1320**. Your endocrinologist or GP can complete this letter for you.

Working shifts

I work night shifts – will this affect my medication?

This will cause a change in the times you need to take your medication. You can discuss how to do this with your endocrine specialist nurse or call The Foundation's Endocrine Nurse Helpline who can assist with this. Tel: **0117 370 1317** (scheduled hours -see our website for times)



School, college and work

Living with a pituitary condition can sometimes be challenging with regard to going to school, homework, exams and starting work.

Your parents may be able to go to your school to talk to your teachers and classmates about your condition. There may be a nurse who could go into school to explain about your treatment and also what teachers might need to do in case of illness or an emergency. You could find out about a support worker to help you in school or for occasions such as exams.

Going to college or university can be a big change in your life, but can be a positive experience. If full time study isn't appropriate for you, there may be the opportunity to

attend part-time instead. It is important to get a note from your doctor if you are not feeling well, especially if it means that you can't hand work in on time. Your tutor may be able to email or record lectures for you or give you extra time to complete coursework.

The Pituitary Foundation's **School Care Guide** is helpful for teaching staff at your school or college to understand your specific needs if you are ill (also emergency for contacts and hydrocortisone emergency advice) and what they need to be aware of and do for you.

For school, college and starting work, we do recommend that you have a buddy who can support you if you are unwell and could be trained to give you an emergency injection in crisis situations.

Sport and physical activities

Regular exercise can help reduce negative feelings such as depression, tension, confusion and fatigue. Benefits can include increased self-confidence and improved self-esteem. Starting exercise can produce a real mental boost, doing something you didn't necessarily think you'd be able to. That gives you a self-confidence that transfers into other aspects of life, and can feed into your self-esteem and self-perceptions, which is very important for your mental health.

The physical benefits of regular exercise

of course can help weight managing, sleep patterns and help to maintain strong bones, particularly in adolescents. It can also lower stress levels, and can maintain good heart health.

Fatigue can be a real barrier. You might feel worn out, but you might just be experiencing mental fatigue. If you do go out and even gently exercise, you'll find you're invigorated and it will give you more energy. Exercise can help relieve tiredness.

For people who haven't exercised for some time – or if at all – they don't think of themselves as someone who exercises or a sporty person. But there are so many ways of being active; it's just a case of finding something you enjoy. As well as walking, it could be swimming, tennis or badminton; it might be cycling, aqua aerobics or spinning. Often, people don't want to exercise because they think that it's hard work or they start out and feel it's too hard and so they give up. It is much better to start slowly and build up gradually.

Meeting other people with hypopituitarism

Young people mostly like to spend time with people their own age for obvious reasons, more interesting, more fun etc. Finding somebody your own age with a similar condition can be a very positive thing although not for everybody. The good things that it might bring are sharing stories, asking and giving advice and even just relaxing and having a good time. It also lets you know that you are not the only one!

The Pituitary Foundation have an online Younger People's support group, for peer support – see www.pituitary.org.uk/support-for-you/peer-support/younger-people-parents-support-group-uk/

You could also ask the doctors or nurses at your clinic if they run a group for young people, or if they could introduce you to somebody who has a similar condition to you.



I take hydrocortisone and I'm worried about drinking alcohol; all my friends drink and I feel like the odd one out

You do need to stay safe when you are out socialising. Always ensure the people you are out with know that you are steroid dependent and explain to them what it actually means if you become unwell. It is advisable to stay within the recommended safe drinking limits which are 14 units per week for males and females. For example, ½ pint of 4% standard beer or 250ml of a 275 bottle of 4% Alcopop is one unit. Do call and chat with our Endocrine Nurse for practicalities around this.

If you do overindulge, please ensure you have your alarm set for the morning to

take your hydrocortisone as normal. If you oversleep and have a hangover, then taking your hydrocortisone later than normal will only make things worse.

I have DI, should I take my desmopressin before I go out for the evening instead of bedtime?

If you are drinking, you should wait until you get home to take your dose of desmopressin. Alcohol is a diuretic, which means it acts on the kidneys to make you pee out much more than you take in – which is why you need to go to the toilet so often when you drink. Alcohol reduces the production of your vasopressin hormone, which tells your kidneys to reabsorb water rather than flush it out through the bladder. This is of course the

Sex and relationships

hormone (desmopressin) you'll take for your DI. It might seem silly not to take your dose before going out drinking, but it would cause you more problems if you did.

With fluid leaving your body so quickly, dehydration can be a big problem. Though it might seem like even more liquid is the last thing you need, when you're regularly having to dash to the gents/ladies, regular sips of water during and after drinking are what you need to keep yourself hydrated and safe.

Please do discuss this with your endocrine department to advise you more on how to deal with this situation.

I've had a long day and going out until late at night; I will be exhausted but don't want to have to stay in!

This can be a time when you struggle with energy levels, for example going to music festivals and parties. In these situations, providing you are not doing it on a regular basis, then an additional dose of hydrocortisone 5mg can be beneficial at around 9-10pm. This will help maintain your energy levels and ensure you are safe until the morning. You should be able to enjoy a social life like any of your friends and family, but knowing that when you are very tired



and have had enough is quite fine; you should go home even if it's earlier and rest.

How can I help myself feel safe?

Young adults want to be the same as everyone else and do not often wish anyone to know they have a medical condition but if you have steroid dependency/adrenal insufficiency and/or diabetes insipidus, it is imperative you share this important information with your friends. Wearing your medical talisman and carrying your emergency hydrocortisone and/or diabetes insipidus card will help others or medical personnel understand your condition and needs.

Attending college/university/ or starting a new job for the first time and educating the people who are involved with you on a day-to-day-basis really does reassure you that in the event of an emergency/illness, help should be available without delay.

Discussing your condition with friends and colleagues is imperative from a safety point of view when socialising and at your place of education or work. It's a good idea to have a 'HC buddy' - a good friend who can be shown how to give you an emergency HC injection if needed.

Will having this condition stop me having sex or finding a partner?

Some young adults might have to overcome particular barriers because of their condition as it could be harder to get to meet potential partners and difficult to know when (or if) to tell them about their condition. Confidence might be affected by your condition and you may prefer meeting those you already know, rather than having to meet new people. You may also face practical issues about getting tired, lacking confidence and having to be near toilets, for example if you have DI.

Having a pituitary condition does not in itself stop a young person from wanting, or having sex. Hormones and the effects of your condition and hormone replacement (such as tiredness, body image concerns and lack of libido) may be another matter though; it's very reasonable to discuss any concerns you may have with your endocrinologist or nurse.

If you are in a relationship and have concerns, it may be a good idea to discuss this with your partner, who, if they truly care about you, will do their best to understand and support you.

I'm not sure if I'm fertile because of my condition?

Thinking about having children of your own can be important at this time of life although not for everybody. If you needed oestrogen



medication to get through puberty and are still on them you may need to talk through options available. There are always options! Anovulatory failure (a menstrual cycle during which the ovaries do not release an egg) or ovulation disorders can be the main causes of infertility in the female. This is usually caused by an imbalance of hormones - including conditions of the pituitary gland, thyroid gland and raised prolactin levels.

Treatment for these conditions is relatively simple and effective at restoring normal ovulation. Before any treatment can be offered, it's very important to perform certain tests in order to establish the actual cause. These tests include an ultrasound scan of

the ovaries and womb, and blood tests to measure a range of hormones including thyroid, prolactin, follicle-stimulating hormone (FSH), luteinizing hormone (LH), testosterone and other androgens (male hormones).

If you went through puberty on your own and are not on oestrogen medication you may need to take care not to get pregnant if you don't want to. The advice is always to practice safe sex. This is not only for prevention of pregnancy (if appropriate) but also for your safe sexual health and the prevention of sexually transmitted diseases.

If you are taking a contraception pill, it is important that if you have trouble remembering to take this, please do discuss this with your endocrinologist/Endocrine Specialist Nurse. Also to note that whilst taking the combined pill, this can affect serum cortisol levels, so it can affect test results if you are also taking hydrocortisone/ have AI. Contraceptive information and help is available at:

www.brook.org.uk/

www.nhs.uk/Conditions/contraception-guide/Pages/contraception.aspx

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

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- ✓ Become an important part of the only charity in the UK providing support to pituitary patients.
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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:	
Address:					
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Please tick (✓) the type of Membership you require:

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Life Membership <input type="checkbox"/> £250.00	Concessionary* <input type="checkbox"/> £10.00 (annual)

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Helpline

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

0117 370 1320

Endocrine Nurse Helpline

0117 370 1317 (scheduled hours)

Administration line

0117 370 1316

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The Pituitary Foundation

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www.pituitary.org.uk

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The
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Working to support pituitary patients, their carers & families