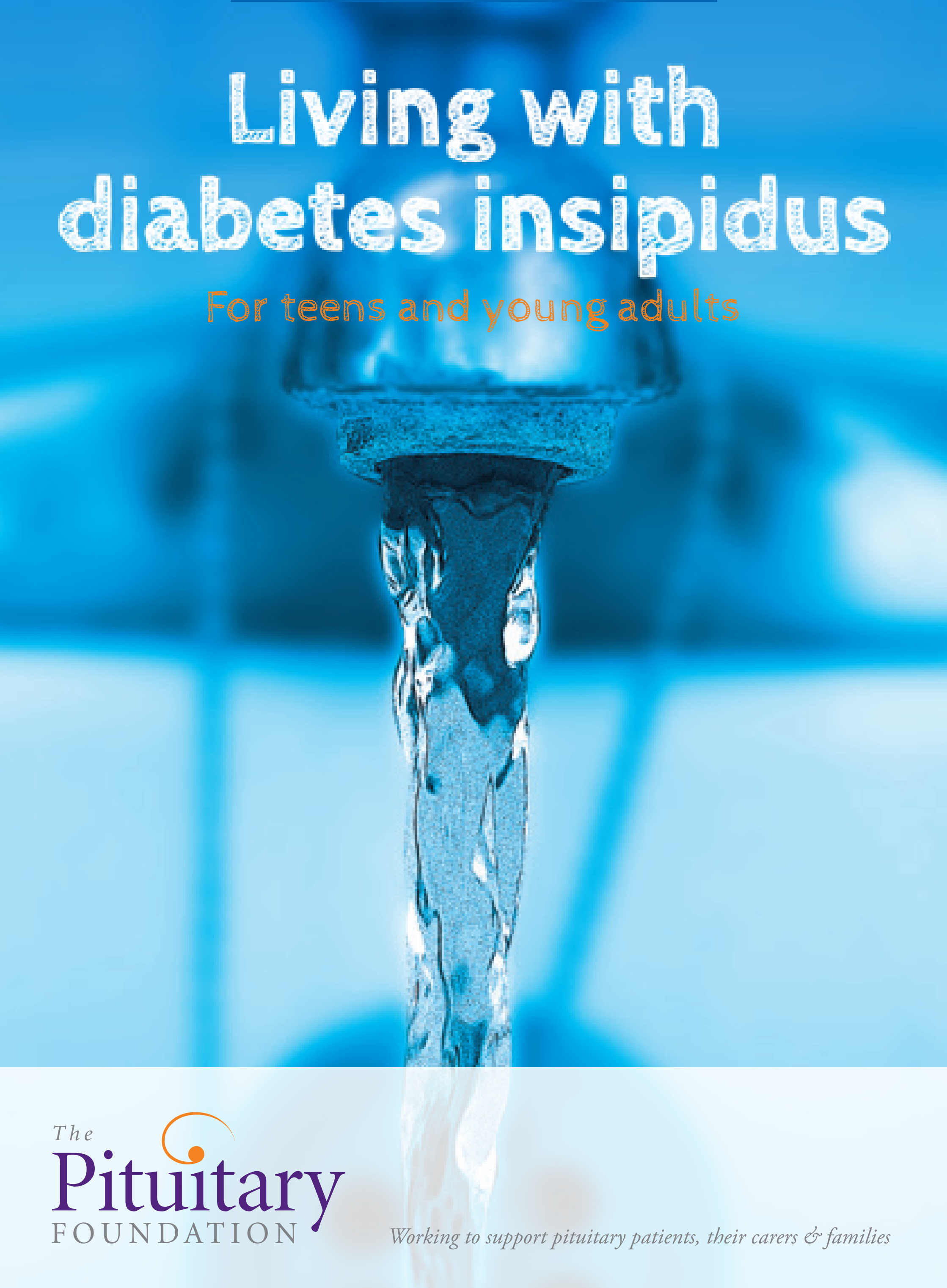
The Pituitary Foundation Information Booklets



Living with diabetes insipidus

For teens and young adults

The Pituitary FOUNDATION

Working to support pituitary patients, their carers & families

About this booklet

This booklet offers information about how to live with diabetes insipidus (DI), as a teen and young adult. We hope it will help you to understand your condition better and support you in talking about DI with your family, friends, and health care team.

What is diabetes insipidus?

Basically, it means passing large amounts of dilute urine. The amount and concentration of your urine are both determined by the hormone vasopressin (ADH or anti-diuretic hormone) secreted by the pituitary gland. In DI, either the pituitary gland is unable to produce this hormone in correct amounts or, (less commonly) the kidneys do not react to the vasopressin produced by the pituitary gland. This causes you to pee out large amounts of urine.

The only way of not becoming dehydrated, and keeping your body in fluid balance, is to drink larger than normal amounts of fluid. Your body 'senses' the need for this automatically. That's why untreated DI can make you can feel thirsty all the time.

The two key parts of this condition are:

1. **Hormone production:** ADH is produced in the back part of your pituitary gland. This hormone circulates in the bloodstream and acts on the kidneys to control the amount of water passed out of the body as urine.
2. **Your thirst action:** This decides the amount of water you want to drink.

The body and water balance

DI is simple. Your body balances fluid in the same way as you would manage a bathtub. You'd want to keep the level of water in the tub just right. The body is the same in wanting to keep the level of water in it just right. With the bathtub, there are two ways the level of water can be altered.

- Water can be **let out** of the bath, by taking the **plug out** *Just as the body lets more water out by passing more urine*
- Water can be **let in** to the bath, by turning the **taps on** *Just as thirst and drinking allows more water into the body.*

> "Ordering a pint of water if I went out for a drink with friends, plus a "normal" drink – because it was impossible for me to sip a drink without downing the water first."

Unlike a bathtub (which can't think for itself), the body is normally very good at sensing the level of water it has on board and doing the right thing to keep things stable. If we do not have enough water and are at risk of dehydration, we do two things: The pituitary gland makes **more** ADH. This acts on the kidney and we make **less** urine (we put the **plug in** the bath). At the same time, our thirst is activated and we drink more (we turn the **taps on**).

On the other hand, if the body senses the level of water on board is too much, the opposite happens. We make **less** ADH, allowing the kidneys to make and pass more urine (we take the **plug out**). At the same time, we feel less thirsty and we drink less (we turn the **taps off**).

Your water balance in DI

So, DI is simple. If you have DI, you have one of two problems:

- You don't make enough ADH (the plug in the bath) or, less commonly:
- You make plenty of ADH but it simply doesn't work as your kidney does respond to it – just that the plug doesn't fit in the bath.

Without treatment, the only way you can keep your fluid levels balanced is to drink enough to match what you are losing - turn the **taps on** to keep up with what is coming out of the bath. Your thirst will make you do this, but the need to constantly go to the loo and drink lots of fluid can have an impact on daily life.

How can I describe to someone what it's like to have DI?

The thirst

You will feel incredibly thirsty, no matter how much water you drink.

Your mouth is so dry it can be compared to having eaten four or five dry cream crackers, one after the other, without a drink. Your family or friends may be able to imagine what that would feel like. You crave icy cold drinks. You'll find it impossible to sip anything and want to 'down' a large amount of water, fast!

Passing large amounts of urine

You will need to pass urine very often (sometimes every 20 to 40 minutes), even through the night. Your journey to school or college (or anywhere) might be planned to make sure there are toilets on the route. Your day-to-day routine can be interrupted with a number of toilet trips and you might feel exhausted from lack of sleep. Going out with your friends and family can be a nightmare - making sure you have access to drinks and there are toilets where you are going. The Pituitary Foundation provides a *Toilet Facilities Access Card* free of charge. You can order this online at **www.pituitary.org.uk**

> "Typically, I'd need to go to the loo at least once every two hours and I was desperate not to draw attention to this."

Treatment

Thankfully, once you are diagnosed, there is treatment to manage your DI and the thirst and running to the toilet can be reduced greatly. You will gradually feel better in yourself once you are taking medication. Your day-to-day activities and quality of life will improve.

The treatment given is called Desmopressin, or DDAVP®. Different types of this medicine are available, each given in a different way. All are effective and it is a matter of finding the best one for each individual, taking into account, convenience and lifestyle.

Name of DDAVP® product	Dosage/strengths available	Recommended initial dose: How it is taken	Comments
DDAVP® Melt (Ferring)	60 mcg; 120 mcg; 240 mcg	1 x 60mcg Melt three times a day. Place under tongue	Dissolves within seconds, no unpleasant taste. Convenient to store, carry and discreet to take. Relieves symptoms within 30 minutes to an hour
Desmospray® Desmopressin nasal spray (Ferring)	100 mcg/ml	1 or 2 sprays (10 -20mcg) once or twice daily, sprayed up the nostril	Does not require storing in a refrigerator. Works within 30 minutes to relieve symptoms
DDAVP®/ desmopressin intranasal solution (Ferring)	100 mcg/ml	10 – 20mcg once or twice daily; using thin rhinyle to 'sniff' the solution up nostril	Does require refrigeration. Dose can be flexible and works within 30 minutes to relieve symptoms
DDAVP® tablets (Ferring)	0.1 mg; 0.2 mg	1 x 0.1mg tablet three times a day. Take orally with water	Convenient to store and carry. A dose might take up to an hour to relieve symptoms as it has to pass through the stomach

Please note: DesmoMelt®, although of the same preparation as DDAVP® Melt, is the product brand name for children or adults who have bed-wetting problems, and not diabetes insipidus. The patient information leaflet inside the pack is different for both types.

Generic versions of DDAVP®

Substitutes are available for the Ferring DDAVP® branded range of medication, made by other companies. These might present some differences for individual patients than their usual DDAVP®. You may find that symptoms of thirst or passing urine 'break through' earlier or later than when taking Ferring DDAVP®. If you experience less stability with a change in medication, then we encourage you to contact your GP or endocrinologist for advice.

Monitoring and changes to your treatment

A good test to check good management of your fluid levels is to weigh yourself each morning.

A varying body weight on a day-to-day basis can help you monitor fluid balance when you start treatment. Remember, that one litre of water weighs one kilogram.

If you carry on drinking large amounts of fluid after starting treatment, you can run into problems even though your urine output has returned to normal. You could develop water overload, leading to a drop in the level of sodium in your blood stream (hyponatraemia). This could be just a passing phase, as your drinking habits adjust over a few days. If it continues, your treatment may need to be re-balanced. The aim is for a daily routine that's the same as others, passing about two litres of urine and with sufficient control of your symptoms through the night for a good night's sleep. You should avoid over-use of DDAVP.

The treatment has very few side effects. Those who use the nasal spray may find some problems with the medicine working when they have a heavy cold. If you use the tablets, some people find that they work less well when they have an upset stomach. A regular blood test for sodium levels should be carried out every three to six months, to check your doses and fluid balance are OK. If you experience any difficulty controlling your DI you should talk to your clinical team.

Living your life with DI

You might have not met or spoken to anyone else who has DI. Your family and friends may find the condition hard to understand. They may not have heard of DI until you speak to them about it and they may confuse diabetes insipidus with diabetes mellitus. (Excessive thirst and peeing are also symptoms of diabetes mellitus but this is caused when blood glucose levels are high and the urine tastes sweet due to the presence of sugar.)

Teens and young adults with DI may experience emotional difficulties. These are common in many young people with long-term conditions, sometimes made worse by the stigma around feeling different and the need to take medication. This can be helped by talking to your family, friends, or your health care team. The Pituitary Foundation has a *Younger People's online support group*, for support and advice; the contact for this group is via: **helpline@pituitary.org.uk.**

School, college and work

You may want to talk to your teachers, tutor or friends about your condition. If your DI is not controlled at the time of key assessments, it's important to engage with the Personal Extenuating Circumstances process that your course will have. If you are going away from home to university or work, a helpful list includes:

- Carry a list of your medications and your doctor's contact number in your purse/ wallet with family emergency contact information

- Keep an up-to-date calendar with your endocrine clinic appointments
- Enter your endocrine clinic's number into your mobile phone

Sport

It is important for your self-esteem and physical well-being to be able to take part in sport. Having DI shouldn't stop you from enjoying this. With physical exercise, your body can lose fluid through sweating. Be guided by your thirst and drink enough water to keep hydrated while avoiding over-drinking. You should not need to adjust your usual dose of DDAVP, simply because of exercise.

Alcohol and the young adult with DI

The good news is that you can still drink moderate amounts of alcohol when you have DI. The bad news…..drinking a lot of it can cause you more problems than it does for others. You need to be especially 'Drink Aware' to keep safe and well when you are out drinking with your friends. Some simple advice:

- **Don't** take a dose of DDAVP before you go out drinking large volumes of beer. This could turn into a 'plug in, taps on full' situation and put you at risk of fluid over-load. Take your dose when you get home.
- **Do** remember that peeing a lot can be a normal part of drinking a lot of alcohol. When you've had some alcohol, it may be harder to think about what your thirst is really telling you. Try to think about your thirst, it can help tell you.
- Peer pressure can be a problem. Remind your friends about your DI and that you may not want to drink as much as them. Good friends will respect your choice.
- **Do** carry a ***DI emergency card*** with you (available for free from The Pituitary Foundation), so that if you were to become unwell, you would be treated appropriately.
- If you have persistent vomiting, **don't** take your DDAVP (even if this is due), until you have stabilised and your sodium level has been checked. The vomiting could be due to the alcohol, but it could also be a sign of fluid overload. It is important to find out which of the two it is.

Transition

This is the process of changing your endocrine (DI) care from paediatrics to adult services. It usually happens between the ages of 16 to 18 years. You might move from your children's hospital to an adolescent unit at 13 or 14 years old, instead of moving straight to an adult hospital.

Sometimes, you can choose a hospital near where you live. Alternatively, you might need to go to a specialist hospital. Your consultant, clinical nurse specialist or family doctor (GP) will be able to recommend which adult hospitals or services are right for you.

The thought of moving to a new hospital and leaving the staff that you've got to know can be difficult. It also comes at a time when you are facing other changes, such as exams, college or university. You might have felt the same way when you moved from primary to secondary school.

One of the main differences between children's and adult health services is the amount of independence you will be given. This means that you will need to learn about your condition, so that you can be more involved in your care and make decisions for yourself. You will need to be able to give information about your condition and know how to keep yourself well and this gives you more control over your health and the care you are given.

Although you, rather than your parents, will be asked to make decisions, you can still ask their advice before making your choice.

At the adult service, during appointments or admissions, doctors, nurses and other staff will spend more time talking to you than to your parents. You will still be allowed to take your parents with you to clinic appointments, but you will be the one to talk about your health and ask or answer questions. Lots of adults take family members or friends along to important appointments for support.

If you go into an appointment on your own, you can still ask your parents for advice on what questions to ask before you go into the clinic room. It can sometimes be useful to bring a written list of your questions with you to appointments.

A young adult's experience

I can't pinpoint exactly when my DI started, but I have a number of significant memories from my first year of A Levels. These include:

Worrying whether I would make it to the end of an exam without needing to leave the exam hall and go to the loo, despite the fact that I'd waited until the last possible moment to go to the loo before the exam had started (and had already been to the loo less than an hour beforehand). I'd be counting down the minutes until the exam finished and would rush out the door as I'd be desperate for the loo.

Rushing to the water machine in the canteen at every break time and drinking a couple of glasses of ice cold water straight down before taking a full glass back to the table. I'd then find any reason to go for at least one refill before the start of the next lesson, even if it was just taking the used glasses back to the counter. If there wasn't time to go to the canteen between lessons, then I'd resort to drinking water from the basin taps, but would make sure that no-one was present to see this.

Ordering a pint of water if I went out for a drink with friends, plus a "normal" drink because it was impossible for me to sip a drink without downing the water first.

If I stayed at someone's house, or they stayed at mine, I remember trying to creep out of the room to go to the loo during the night without making a sound so that I didn't disturb them. Typically, I'd need to go to the loo at least once every two hours and I was desperate not to draw attention to this. I'd always take a pint of water to bed with me and my glass would be filled up each time I went to the loo.

Getting back from an evening out; going to the loo as soon as I'd got in the door, but then drinking a two litre bottle of water taken straight from the fridge without stopping for a single breath. A common dilemma when getting back home was which should come first – going to the loo or getting a drink? If I was able to grab a drink on my way to the loo and take it with me, then that was ideal as it meant I could do both at the same time!

Always having a degree of apprehension when going out for the day, to anywhere I hadn't been before, due to not knowing where the toilets would be, either whilst travelling or when we got to the final destination. And where would I be able to get water from if I needed some?

Going to the GP to ask for advice about the persistent thirst and the need to get to the loo; being tested for diabetes mellitus, which of course came back as negative.

Being told that the reason I needed to go to the loo so much was because I was drinking too much, so I'd try not to drink and then would feel so awful. I remember this feeling of just knowing that I needed water.

My DI was caused by a pituitary tumour but wasn't diagnosed until I was actually in hospital having the tumour removed. I was 22 at the time of the operation, so by then I had had DI for over five years, including the entire time I was at University. During those five (plus) years, I don't remember having a single unbroken night's sleep, but thankfully I could wake up, go to the loo, drink and then fall into bed and go straight back to sleep again. My daily routine was dominated by a need to know where the nearest toilet was and where I could get water from to satisfy my thirst.

When I initially started treatment, it felt very strange not experiencing a constant need to go to the loo and drink. It took a while for my body to get used to the medication and to find the right levels that worked for me. The symptoms soon reduced considerably and although it's fair to say that I still go to the loo and drink more than a non-DI sufferer, my symptoms are now definitely manageable and having DI no longer has as much of a say in my daily routine and how I live my life.

Q: If I just drink less, will I pee out less?

A: No, without your DDAVP, you would continue to pass urine and restricting your fluid could be dangerous (unless medically supervised for a water deprivation test, for example).

Q: What happens if my Desmopressin has been kept out of the fridge?

A: Although intra-nasal Desmopressin can be kept at room temperature for a limited period, long-term exposure to temperatures above 8 °C may reduce the effectiveness. Please contact your doctor or pharmacist for advice if you are concerned that your medication has been left out of the fridge, or if the fridge is broken. Both the Desmotabs and Desmospray are stable at room temperatures; there is no need to store these in a fridge.

Q: What should I do if the spray is blocked or the tube is missing or damaged?

A: You should take the whole product to the chemist who will replace it free of charge.

Q: Can I still use Desmopressin or Desmospray if I have a cold or hay fever that gives rise to a blocked nose?

A: If only one nostril is blocked, then using the clear nostril should give the right

result. If both nostrils are blocked, your doctor may recommend temporary use of the tablets or Melts.

Q: I have been having more headaches than normal recently and seem to be putting on weight. Could this be caused by DDAVP?

A: If you drink large volumes of fluids and take too much DDAVP, your body may become overloaded with fluid, which could result in headaches, dizziness and abnormal weight gain. In turn, this could result in a low sodium level in the blood, which is called hyponatraemia. It is important that you contact your doctor if you experience these symptoms as you may be taking more DDAVP than you need. Your endocrinologist will help you to find the right dose of DDAVP and will advise you on the amount of fluid you should drink.

Q: If I can't remember whether I have taken a dose of DDAVP, should I take another one just in case?

A: It is better to miss a dose than to risk taking twice the amount.

Q: Is it safe to take other prescribed medicines alongside DDAVP?

A: If your doctor prescribes any medicines, you should point out that you are taking DDAVP.

Q: If I have an upset stomach while I am on holiday, what should I do?

A: Mild holiday diarrhoea is no problem. Only if you have any vomiting and/or serious diarrhoea do you need to see a doctor.

Q: Is it OK to take my DDAVP through airport X-ray machines?

A: Yes, it's fine. For travelling with medication, please see our website for information.

Q: What happens if I am in a hot climate or taking strenuous exercise which causes me to sweat?

A: As with anyone else, you should increase your fluid intake in such circumstances; your thirst should prompt you to do this.

Q: My lifestyle means that it is inconvenient to take my DDAVP at the prescribed times and it is also awkward to keep leaving the room to use the toilet. What can I do?

A: If you have any difficulties with your lifestyle due to DI, do contact your endocrinologist, who will be able to advise you about varying the timing of doses. Don't experiment with this yourself, however.

Useful resources and websites

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.

Toilet Facility & Emergency Cards

The Foundation has produced two small credit-sized cards, to help the patient explain about their DI if they are in an emergency situation, or, if they need access to a toilet. Please contact The Foundation if you would like a card or see our website to order these free resources.

National Key Scheme (NKS)

The NKS offers independent access by disabled people to use around 7000 locked public toilets around the country. A National Key Scheme guide is produced for purchase each year, which lists the location of every Radar toilet on record. A smartphone app is also available, with added walking and driving directions. Both are £5. Further details can be found at **https://crm.disabilityrightsuk.org/radar-nks-key** or by calling **020 7250 8191**, Monday to Friday 10.00 to12.30 and 1.30 to 4.00 or email to: **shop@disabilityrightsuk.org**

Male and female travel urinal products

Shewee - female urination device

This is a discreet, portable urinating device for females, allowing you to urinate whilst standing and without removing any clothes. Perfect for camping, festivals, cycling, long car journeys. Shewee is lightweight, reusable and available on NHS prescription for those who receive free prescriptions. The PIP prescription number for it is 343-0394.

Peebol – pocket-sized toilet for male and female urination

This is a private, easy to use, discreet, non-spill, odour free and recyclable. Inside the Peebol are rapid performing absorbent granules that convert fluid into a biodegradable gel. Ideal for car journeys, in a tent or anywhere you get caught short. To remain completely private, ladies could use with or without their Shewee whilst men urinate directly into their Peebol. Can be sealed and opened to use again until full. Holds 1 litre.

http://www.shewee.com/ Sales telephone line: **01539 723091**

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.
- ✔ 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 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	☐ £20.00 (annual)	Family	☐ £35.00 (annual)
Life Membership	☐ £250.00	Concessionary*	☐ £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) ☐

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

Administration line
0117 370 1333

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Working to support pituitary patients, their carers & families