

Weight issues and nutrition for pituitary patients



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 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 about weight issues associated with pituitary conditions, as well as provide some practical advice about nutrition. You may find that not all of the information applies to you in particular, but we hope it helps you to understand weight issues better and offers you a basis for discussion with your GP and endocrinologist.

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Introduction

Weight gain can be a common issue for people with pituitary conditions. It can cause distress and frustration, but with few answers as to why their weight is increasing. The sometimes unhelpful comment of 'you need to diet' can be upsetting for those who already follow a balanced diet and know that they don't eat more than they did before their pituitary condition, or when their treatment started. On the reverse side, and just as miserable, can be the patients who feel much hungrier than they did and know that they are eating more than normal.



Do pituitary or hypothalamus conditions cause us to gain weight?

A common question asked by patients is whether pituitary or hypothalamic disease has been responsible for their unwanted weight gain, or whether weight gain is related to pituitary or hypothalamic disturbances? The answer to this question is usually clear, if there is a history of marked weight gain dating from the time of diagnosis and treatment of pituitary or hypothalamic disease. However, any period of physical inactivity related to illness can also contribute to weight gain. Whereas damage to the pituitary alone is unlikely to contribute to

severe obesity, this is far more likely in the presence of hypothalamic damage, which can sometimes be confirmed by MRI scans of the brain.

Generally, the urge to eat is quite powerful and it is difficult to resist. This urge can be greatly increased in the presence of pituitary and hypothalamic disease. This explains why conditions of the pituitary gland, for example craniopharyngioma, particularly when the adjacent part of the brain (the hypothalamus) is affected, may lead to disturbed appetite, weight gain and sometimes marked obesity.

Can hormones influence weight?

Conditions confined to the pituitary alone, generally cause only relatively minor weight disturbances. Thus, tumours, pituitary surgery or radiotherapy often impair the production of pituitary hormones. Deficiencies of thyroid stimulating hormone (TSH), follicle stimulating hormone (FSH), luteinising hormone (LH) and growth hormone (GH) all have subtle effects on the accumulation of body fat.

Some hormones can have an impact on weight gain, or in fact, weight loss:

- Cortisol, which is produced by the adrenal glands, is responsible for fat cell development. If your cortisol levels are high due to having Cushing's, then weight is usually gained around the trunk and in the face
- If you are taking hydrocortisone or prednisolone as a replacement and the dose is too much, then weight can be gained
- An overactive thyroid gland can cause weight loss, whilst an underactive thyroid can cause weight gain
- Increased prolactin levels can increase food intake
- Lack of testosterone can cause excess inner abdominal fat
- Lack of oestrogen can cause weight gain, as the body lays down additional fat to attempt to increase oestrogen stores
- Growth hormone deficient adults can have 6 to 8 kg excess fat mass; treatment with GH replacement will change this fat mass, but weight can remain the same

- Over-treatment using desmopressin leads to the body retaining fluid and that 1 litre of water weighs 1 kilogram

It is essential that all your pituitary hormones are at satisfactory levels, as even small deficiencies in testosterone, thyroid hormone and growth hormone or over-replacement of your cortisol or desmopressin can make it more difficult to lose weight. If you are under-replaced and consequently feeling tired, you are likely to be less-inclined or less-able to be active and that can lead to weight gain, unless food intake is reduced simultaneously. Regular monitoring with your endocrinologist is important to establish that your hormone levels are satisfactory, but also an opportunity to discuss any weight gained.

Tip: If you have gained weight since your condition started, or after your surgery or treatment, it can be very helpful to take along to your next endocrine appointment some photos of you before. Your endocrinologist will not have known the pre-pituitary person you were and this could help to have a more mutually understanding discussion and reviewing your hormone replacements where appropriate.

Emotional issues of weight gain

There can be many social effects of weight gain and a lot of other disorders associated with it. Overweight people might become self-conscious of their weight and think that people might make fun of them. A lot of emphasis is too often placed on physical appearance. Some of the social effects of obesity might include avoiding social situations, decrease in self-esteem and discrimination.

Many people perceive those who have gained weight to be lazy and gluttonous, which is not always true. They cannot realise the distress this can cause, especially when the weight problem is not the person's entire fault. Physical changes can result in negative comments, reinforcing any negativity you might have about the person you have become.

For the pituitary patient there may be anxiety due to the impact of their diagnosis and/or treatment which can lead to food being a comfort. Exhaustion, pain or discomfort can prohibit even gentle exercise. For help with managing psychological issues, please see our *'Impact of Diagnosis and Treatment booklet'* also our *'Your Journey booklet'*.



> series: well-being

Diagnosis & treatment

The psychological impact of a pituitary condition

> series: well-being

Your Journey

Living with and managing a pituitary condition

Information Booklets

& families

The Pituitary Foundation Information Booklets

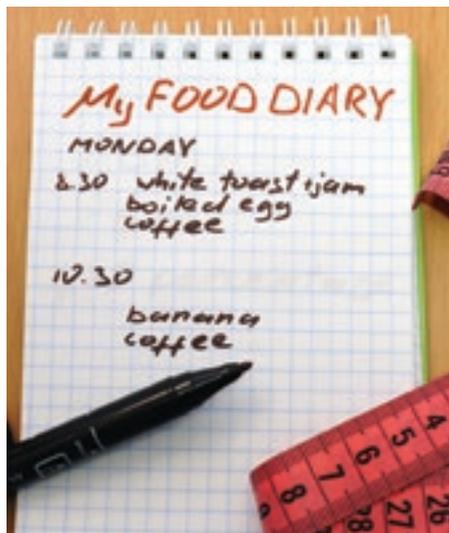
The Pituitary FOUNDATION

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I have a healthy diet but can't lose weight

We can genuinely think that we eat healthily, but in some cases there can be more changes of your current diet made to help you lose weight. Even small changes can give large benefits over time, such as eating 100 calories a day less than your body needs e.g. one slice of bread, two biscuits or one small glass of wine. By removing any of these over a year means 10lb can be lost. Increasing your physical activity by more walking, for example, combining this with small changes to your diet can be more easily kept up over time and really can help.

Tip: Use a food journal, even for a week. Log everything that passes your mouth daily – you may be surprised at what you actually eat and drink in a day! A weekly food journal for you to use can be found at the back of this booklet.



Nutritional advice – healthy eating guidelines

The following guidelines can be helpful to keep your food choices healthy.

- **Start the day with a cup of warm water with a slice of lemon and ginger** – this is a great start for your digestive system and liver, giving it a gentle cleanse before the days eating.
- **Always eat three main meals a day** – breakfast, lunch, dinner. Using whole foods like homemade granola, natural yoghurt and blueberries, soups, salads, ratatouille.
- **Homemade is the best** – take time to make up some batches using whole foods, which you can freeze, for example, vegetable & lentil soup, chickpea dhal, bean burgers, ratatouille which can be served with chicken, fish etc.
- **Always have protein with main meals** – meats, eggs, pulses, as this helps release the energy slowly, allowing you to feel fuller for longer. Serve less on your plate, or use a smaller plate.
- **Eat your greens** – try to incorporate green salads and vegetables with most meals i.e. broccoli, spinach, kale, lettuce and Brussel sprouts. These are packed with vitamins, minerals and fibre (which is great for keeping the bowels moving!)

- **Eat fresh and natural foods** – try your local market or grow your own. Herbs are easy to grow and add flavour and nutrients to dishes.
- **Try new foods** – add a new food into your weekly eating regime. Find out what its main nutrients are i.e. celeriac is great mashed, full of vitamin C and rich in calcium
- **If you need to snack between meals, keep them small** i.e. 10 almonds, an apple, an oatcake with a small bowl of homemade hummus, seeds, or a raw carrot.
- **Keep hydrated** – 1.5 litres of water a day is a good guideline. Make sure you have water with you at all times, in the car, your bag, at your work place. Your urine should be

pale yellow (straw coloured). Note: patients on desmopressin should be aiming for this amount of intake, but this should be balanced with fluid output and thirst.

- **Chew your food well** – eating slowly, take smaller bites and finish one bite before moving onto the next as this will make you feel fuller.
- **Be prepared** – write down a weekly or monthly food plan, plan some time to make batches for the freezer or food cupboard. Make sure you have snacks with you at all times, so you won't be tempted to buy something unhealthy.
- **Gradually make positive lifestyle changes** – such as exercise, maybe start your own 'gentle walking club', or try yoga, meditation or Pilates.

Food portion percentages on a plate



- **Write a food journal** – log all that you eat for the next week or month, this will keep track of what you are eating and drinking, which will motivate you to carry on.
- **Be mindful** – our pace of life is very fast. However, take time to 'just' eat – smell and taste, you'll be amazed at how different food looks and tastes, when you are relaxed and mindful.
- **Do something different** – switch hands when eating, you have to work harder on hand-mouth coordination, so you have to take your time to eat, or try eating with chopsticks!

I find it difficult to exercise because of my condition

There can of course be challenges for some people with a pituitary condition.

Realistically, exercise should be gradual and gentle to accommodate what you can do, rather than what you can't do. Simply becoming more active can be less daunting than actually doing exercise.

- **Chair exercises** will strengthen hips and thighs and improve flexibility.
 - A. Sit upright and away from the back of the chair. Hold on to the sides of the chair.
 - B. Lift your left leg, with your knee bent, as far as is comfortable. Place foot down with control. Repeat with the opposite leg. Do five lifts with each leg.
- **Walk more regularly.** For example, get off the bus a stop earlier, park a bit further away from the shops or work.
- **Go up and down the stairs** a few times.
- **Housework and gardening** can be beneficial as exercise.
- **Gentle 'jogging' on the spot** in the house.



Tips:

Adding perhaps a different, gentle exercise to your routine, such as yoga or pilates. This can help you lose weight *and* feel relaxed without extreme effort. Set small, attainable goals. Don't overwhelm yourself with a lot of goals initially. You will only become frustrated and more likely to stop. Exercise with a friend and you'll be less likely to make excuses not to.

Note: It's important to balance your levels of activity with your fatigue – if you overdo it with activities you are likely to fall into the 'boom and bust' pattern, and spend longer periods being inactive because you are so tired. If you are inactive for longer, your body will assume it doesn't have to produce as much energy, and the metabolism slows down- thus defeating the object.

Will I ever lose some or all of the weight I have put on?

It is possible, depending on the type of pituitary or hypothalamic condition you have, and:

- being mindful of what you eat
- good nutrition (and family support)
- gradual and simple exercise
- hormone adjustments where appropriate
- realistic expectations that it can take time (like all other people trying to lose weight).

NHS: other weight loss services

Your GP surgery may refer you to other services, such as local weight loss groups. These could be provided by the NHS, or may be commercial services that you pay for.

If it's appropriate, you may be referred for exercise classes under the supervision of a qualified trainer. Depending on where you live, the exercise program may be free or offered at a reduced cost.

Weight loss medicines

If you've made changes to your diet and levels of physical activity but you're not losing a significant amount of weight, your GP may recommend medicines that can help.

Medicines are only used if your BMI is at least 30, or 28 if you have other risk factors such as

high blood pressure or type 2 diabetes.

Weight loss surgery

If lifestyle changes and medicines don't work, your GP may talk to you about weight loss surgery. Weight loss surgery is usually only recommended for people with a BMI of at least 40, or 35 if you have a weight-related health condition, such as type 2 diabetes or high blood pressure. Weight loss surgery can be effective but it's a major procedure that comes with health risks of its own.

Ref: <http://www.nhs.uk/Livewell/loseweight/Pages/WhataGPcando.aspx>

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Next review due: 12/04/2018

You don't need to struggle alone

- Use the tips, food journal and weekly meal planner from this booklet.
- Show your GP your 'food journal' diary which can identify for your GP how to help you - from the practice or possible referral to local weight loss services (for example: Slimming World, Weightwatchers).
- Ask your endocrinologist for a dietitian referral within the hospital.
- Speak to one of our Telephone Buddies who will understand.
- Go along to your Local Support Group and meet others who will have similar weight issues.
- Call our Helpline to speak to a friendly operator who can support you.



Do you hate the word 'diet'?

You could use any or all of these phrases to help you instead:

- I am choosing different or new foods to eat.
- I am aiming to lose some weight for me, not for anyone else.
- I know it can take time, but that's OK.
- I want to feel better!

Some quick and easy changes to help you start:

- Change white bread to wholemeal or granary
- Halve any sugar you put in drinks

- Steam or bake
- Fry foods in 'Frylight' or other oil sprays and roast in the oven
- Eat lots of vegetables and salads to fill you up
- If you do want a treat, have it and say "I'm choosing something different".
- Ask for your hormone replacements and timings of these to be checked and any tweaks, tweaked

"If you hear a voice within you say 'you cannot paint', then by all means paint and that voice will be silenced." -Vincent Van Gogh

One patient's experience of weight gain and loss

Before my pituitary surgery, I never had a weight problem - I was very fortunate never to have to think about diets; food to me was fuel and I burnt it off easily. Even whilst pregnant, I only gained two stones, which I lost easily in the following few months.

When I started developing pituitary symptoms and during a lengthy diagnosis, my weight was slightly less than normal, but the week following surgery changed my life quite dramatically for some time to come. I was given high doses of steroids during and after my operation. My usual clothes were brought in on the day I was discharged. I sat on the bed in tears unable to get my jeans over my knees, nor could I fasten

my shirt so off I went home in a dressing gown!

The following weeks were a constant *food fest* for me; I became so ashamed of what I was putting in my mouth, I would lock the bathroom door and gorge on huge bars of chocolate. Any leftovers on plates, I would scoff food secretly in the kitchen whilst washing up. I didn't realise that it was the large amounts of cortisol, causing this voracious appetite, plus other hormone imbalances I didn't know I had at the time. I simply thought that once I recovered from surgery, I would lose this couple of stone I had put on - so I continued to eat!

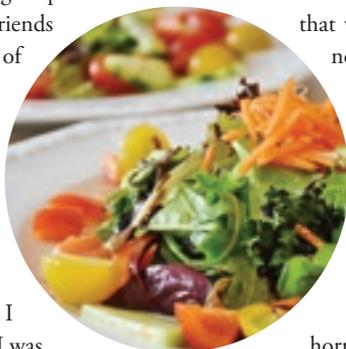
After three months, I had gone from 7½ stone to almost 12 stone; I was horrified when I

looked in a mirror; my clothes wouldn't go near me and I had to wear extra-large tops and stretchy leggings! Family and friends obviously noticed, but sort of acknowledged that I would lose this excess weight soon - that's if I was able to stop eating so much! When I hit almost 12 stone, my endocrinologist ordered me to see a dietician - I was really upset! The dietician went through my daily diet and I was so ashamed at the amount I was eating. Diet sheet in hand, I knew I had to do something, but the miniscule amounts of food I was allowed daily seemed an impossible task. The motivational moment happened when quite a hurtful comment was made about my weight and I said to myself "I'll show you!!"

I started following the diet, to the letter, in early January. The dietician suggested that I start some activity by jogging up and down on the spot gently, in the house, which I did every day.

The diet sheet was simple, based daily on four small slices of wholemeal bread, ½ pint of skimmed milk, salads, lean meat or fish, wholegrain rice or jacket potato, vegetables, fruit and yoghurt. I ate porridge or Weetabix too - sometimes for lunch and breakfast. Two months into the diet, as I had lost some weight, I felt able to start gentle swimming and cycling (slowly and not too far!)

By the end of April, just over three months from starting, I weighed in at 8 stone 13 lbs. I was so delighted and able to wear most of my normal clothes, but this was overshadowed by



the fact that I had to keep up this quite frugal 'diet' and exercise regime forever to retain that weight. No treats, no cheating, no feeling lazy! I was still taking unchanged doses of hormones, so it was even more difficult. In fact, I struggled to keep to such a low calorie diet and gained much of what I'd lost in the following few years. I was constantly hungry!

I was about to be given growth hormone eight years following my surgery, and I took some photos of myself before pituitary surgery to my endocrinologist. He was visibly shocked at who I was then and what I looked like now. Immediately, my thyroxine was increased and my cortisol was reduced, so that my weight struggles were helped and that ravenous hunger diminished a bit. Taking growth hormone enabled me to exercise a bit more, improved my body shape, and gave me a bit more confidence.

However, I wasn't happy at still being bigger than I had always been, so I joined my local Slimming World. I did lose some weight very slowly - it took 18 months to do so, but this helped me to eat more healthily and about portion control.

So, weight loss for me: definitely, the adjusting of hormones, taking reasonable exercise and understanding, then changing, what I eat. I never, ever thought that I could lose weight having a pituitary condition. It is hard, but never say never!

Weekly meal planner



	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Date							
Breakfast	Fruity Porridge Pots	Greek Granola	Crunchy Nut Toast	Quick Berry Smoothie	Fruity Porridge Pots	All In Healthy Grill	Delux Frittata
Lunch	Sandwich & Salad Selection	Soothing Lentil Soup	Smoked Mackerel & Lemon Pâté With Oatcakes	Poached Eggs On Rye Toast	Courgetti Feta Salad Bowl	Green Vegetable Soup	Garlic Hummus & Crunchy Crudités
Dinner	Spicy Beef Burgers & 3 Bean Salsa	Roasted Ratatouille & Wholegrain Rice	Easy Classic Roast Chicken & Vegetables	Delish Fish Pie & Cauli Mash	Quick 5 Spice Pork Stir Fry & Chinese Noodles	Mediterranean Quiche	Crispy Fish & Sweet Potato Chips
Sweet & Savoury Snacks	Baked Almonds	Fruit & Nut Bars	Mixed Seedy Chocolate Bites	Mini Broad bean Falafels	Smoke Roasted Chickpeas	Mixed Nuts & Apple Slices	Warm Ginger Crunch

Weekly food journal

Day	Breakfast	Lunch	Dinner	Snacks
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
Sunday				

Roast chicken dinner



Ingredients

- 1kg potatoes, enough for 4 people
- low calorie cooking spray
- 4 chicken breasts
- selection of vegetables, such as carrots, broccoli, peas or mange tout
- 4 level tsp gravy granules

Method

1. Preheat the oven to 200C, gas mark 6.
2. To make roast potatoes, peel and slice as many as you need into quarters and parboil for 8 minutes. Drain and return to the pan, shaking it to roughen up the edges.
3. Put the potatoes in a roasting tin, spray with low calorie cooking spray and toss to coat well. Roast for 40 to 50 minutes, or until brown and crispy.
4. For the last 30 minutes of the potatoes roasting, spray a non-stick baking sheet with low calorie cooking spray and roast 4 chicken breasts in the oven until fully cooked through.
5. Cook a selection of vegetables such as carrots, broccoli, peas and mange tout in boiling water for 8 -10 minutes or until tender.
6. Measure out 4 level teaspoons gravy granules in a jug and make up the gravy according to the pack instructions.

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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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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