

The Solent and IOW Pituitary Support Group

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The ● Pituitary Foundation

Solent & Isle of Wight
Support Group



Newsletter No. 94, March 2026

Hello everyone,

Welcome to another edition of the Solent and IOW Pituitary Support Group Newsletter, for March 2026.

Thank you to everyone who has contributed, by sending material for the newsletter and giving their encouragement.

We aim to produce a newsletter four times a year, and it is timed to be issued shortly before each of the main support group meetings. **For 2026 these meetings will be at Portchester Parish Hall.** We will no longer be meeting at the Cosham Community Centre. The meeting at Portchester is on Saturday 28 March at 10:30 am. Please note that we are meeting at 10:30, half an hour later than before.

The address of Portchester Parish Hall and directions to get there are given on page 3 of this newsletter.

When we meet in March there will be tea, coffee, juice and biscuits. As our speaker, we are delighted to have Emma Cooper, who is the head (CEO) of the Pituitary Foundation. There will also be time to chat generally, and to give and receive advice and information about pituitary conditions and related matters.

We often welcome new patients and their partners, family or friends at meetings, so if you have recently found out you are a pituitary patient or just found out that we as a support group exist, please get in touch and join us for future meetings and you'll be made very welcome.

Find us on Facebook - The Solent and IOW page is in the form of a group. Together we'll be updating and posting relevant information on there. Anyone that uses Facebook can search and join the group. It is listed as the following: - The Solent & IOW Pituitary Patient Support Group. This is in addition to the main Pituitary Foundation page and other pituitary Facebook groups.

===== Meeting dates for your diary for 2026 – Change of venue =====

Note that in 2026 we will no longer be meeting in Cosham. Instead we will be at Portchester Parish Hall, 1 Assheton Court, Portchester PO16 9PS at the new time of 1030am so enjoy an extra half hour in bed 😊. As usual, we will have tea, coffee, juice and biscuits available. You may bring your own snacks if you wish.

- 2026 dates (all Saturdays at 10:30 am):
- 28 March. We will welcome Emma Cooper, CEO of the Pituitary Foundation for our March meeting
- 27 June. This could have a demonstration and participation in tai chi with Kathryn Pearce. Or a patient-led meeting.
- 18 July. Dr Victor Lawrence will join us for our Isle of Wight meeting. We are still working on finding a suitable venue for the meeting.
- 26 September. We will have Specialist Endocrine nurse Sirbrina Ramharack
- 5 December. Our pre-Christmas meeting with festive food and a quiz

Possible speakers for future meetings include Dr James Lawrence and Dr Smith from Salisbury, a radiographer, a pharmacist, and blood bikers, and on mindfulness, laughing yoga, a life coach etc.

There is always a raffle at the main meetings in Cosham, Portchester and on the Isle of Wight. Prizes gratefully received on the day please.

Receiving your newsletter - If you would rather receive your newsletter by email, please email Howard at: howardpearce1@yahoo.com or Gail at g.weingartner@btinternet.com and let them know. Or let Gail or Howard know if you wish to come off the mailing list altogether.

More than half of the newsletters are now sent out by email. Unfortunately, there are often a few people who have changed their email address, and they do not get their electronic copy. We usually manage to send them a copy by post, but inevitably it is a few days late. If you have changed your email address, please let us know.

The cost of posting the newsletter – Printing and postage of the newsletter for those who do not get their copy by email is a major cost item, around £300 a year, and the price of stamps keeps going up. It would be very much appreciated if those receiving the newsletter by post would make some contribution towards the cost of printing and postage, either by stamps or money, or change to email delivery. Gail and Pam Weingartner and Melissa Reeds are always happy to receive a book of stamps from anyone who receives the newsletter by post. They send a special thank you to everyone who has given stamps or money for this.

It's your newsletter – We would love you to write something for the newsletter. If you have something to share – your experience as a patient, something you have done, some wise words, something to make us laugh, or something that we all ought to know – please send it for the next newsletter, which we are aiming to produce in June 2026.

Donations

Our thanks to our fundraisers for their kind donations and fundraising on our behalf. It is because of the continued support of this kind that we are able to have our quarterly meetings and fund the newsletter. But, **we DO NEED** some proactive fundraising to keep our bank balance in the black, so please give thought to and let one of us know your ideas.

A special thank you to all who contributed to this newsletter.



Stop press – moving from Cosham to Portchester

As you all know, we have been using the Cosham venue for our meetings for many years but recently the service they provide has not been as we would expect. As a result, we have been looking into a change of venue and have visited two possible venues in Portchester, both of which are good, with kitchen access, parking etc.

Following our discussion at the committee meeting recently, and taking into account your valuable feedback, we have decided to change our venue from Cosham to **Portchester Parish Hall (the smaller hall). The address is 1 Assheton Court, Portchester PO16 9PS.** We are impressed with the facilities, the disabled spaces/access/kitchen and adjacent free parking. The change will take place for our meeting on 28 March and the start time will change from 10 am to **10.30 am**. We think this time will be better for everyone. We have been developing plans to make it a great meeting! Portchester Parish Hall is near to Fareham, Portsmouth and Havant with good facilities, disabled access and toilets. Disabled parking is on site at the front of the building

Directions

From Portsmouth/A3M From the A27, turn left into Castle Street (brown sign to Portchester Castle) at the first roundabout when entering Portchester. Take the first right into Assheton Court and you will see the Parish Hall immediately on your left. Continue past the hall and the free car park entrance is just past the hall on the left. Further parking is round the left bend on the right.

From Fareham From the A27, take the right hand exit into Castle Street at the last roundabout (the opposite side of the station signpost). Take the first right into Assheton Court and you will see the Parish Hall immediately on your left. The free car park entrance is just past the hall on the left. Further parking is round the left bend on the right.

As you turn into Castle Street from the A27, the Methodist Church hall is on the right, it's not the Parish Hall, so don't park there!

You will see the Parish Hall on the left as you turn into Assheton Court. The free car park is open to all, so it could get busy on a Saturday. I would advise parking by 10.15 latest if possible.

Public transport: The train station is in the Hillway, off the main roundabout, around 8 minutes walk to the Parish Hall. The bus stop is near the precinct, around 3 minutes walk away.

If you have any questions or concerns please email: jenny.gatland@googlemail.com



Questions for the Doctor

Gail here with a comment or two as usual !

I love reading the questions you submit and the answers from Dr Lawrence, which are always so in-depth. I do feel that sometimes we as patients can be ‘guilty’ of generalising in respect of how we are treated and indeed perceived by, the clinicians within our pituitary world. It is a

difficult one and I’m sure at the end of the day, our Endos do their best for us but sometimes, perhaps it can be beneficial to ask to see a different member of the team or to be referred to a different hospital. Also, it is worth bearing in mind that it can take a while to build up a good relationship with our consultants.



Q 1) I'd like to know why so many of us experience a range of issues, that as part of international support groups are familiar pituitary patient experiences across the globe, but these experiences are routinely met with medics saying our symptoms are unrelated! Fatigue, dizziness, tinnitus, balance issues, mental overwhelmed. All apparently unrelated! This drives me totally crazy. Thanks for listening – Sarah G

Dear Sarah, thank you for your question which raises a very good point that I suspect many readers will identify with. I can certainly understand how this must seem frustrating. In a way, I think this probably overlaps a little with the answer I gave about headache, which is also a commonly reported symptom in a previous issue [Newsletter 91 June 2025]. It's probably worth saying that I don't think doctors have anything to gain from downplaying symptoms or considering them unrelated to a condition a patient has when they are related but I suspect we can nevertheless underestimate the burden that a condition may have on a patient's overall wellbeing and quality of life. I guess sometimes we look for plausible mechanisms and for symptoms that may potentially respond to treatment and may perhaps underestimate symptoms that are less easily explained or less readily treatable. For example, no doctors need convincing of the need to do something about a pituitary tumour that is compressing the optic nerve and causing visual loss, there is a symptom, a mechanism and it will likely respond to treatment. It can be harder to acknowledge symptoms that do not have any clear mechanistic relationship to a known condition and that don't obviously respond to any particular treatment options we might have. Tinnitus could be an example of this. You are absolutely correct to suggest that tinnitus does appear to be reported commonly by people with pituitary conditions. However, it is reported commonly by those without pituitary conditions too. There is a recent study trying to see if it really is more common in patients with pituitary disease coming to surgery compared with patients' partners who were used as the control group. Rates of tinnitus in both groups (42% in the pituitary surgery group and 28% in their partners) were higher than the generally accepted prevalence of tinnitus in the general population or around 15% and we do not know for sure why the partners seemed twice as likely to report it than expected. Although the number of sufferers at first glance looks even higher in the people having pituitary surgery than in their partners, the difference did not reach statistical significance which means that it could have just been this way due to chance (in the same way as you could toss a perfectly fair coin and get 7 heads and 3 tails rather than the 'expected' 5 of each). A larger study would be needed to clarify this. In general, but with a few exceptions, tinnitus did not improve after surgery to reduce/remove the tumour or normalise any hormone overproduction. What this means is that at the moment there is no absolutely clear evidence that pituitary tumours in general cause tinnitus and, except perhaps for massive

tumours or those invading to the side of where the pituitary normally sits, there is no absolutely clear reason why they should assume that all hormone levels are optimally controlled. And yet we must acknowledge that tinnitus is a common experience amongst patients, is a horrible thing to endure and is one of the factors that could contribute to lower overall quality of life amongst pituitary patients. So how should we really make sense of this and proceed? I think firstly, we need to make sure that the tumour is well controlled and that hormone levels are controlled because massive tumours or abnormal hormone secretion (e.g. Cushing's Disease or abnormal thyroid tests) can be associated with tinnitus. If these factors do not apply, we then need to listen and acknowledge a person's symptoms even if we can't explain them or improve them. We should probably remember that having a pituitary condition often increases stress and anxiety and these are absolutely definitely associated with a range of symptoms, including tinnitus. I do wonder whether the fact that partners of people needing operations for pituitary problems had nearly double the normal chance of reporting tinnitus might be explained by the stress of them being anxious about their partner? I think sometimes we can be a bit too mechanistic in our thinking and we as doctors should remember to acknowledge a person's symptoms even if we cannot directly connect them or be able to alter their course. I would be the first to admit we don't always get things right.

[Preoperative and Postoperative Tinnitus in Patients with Sellar Masses: A Patient-Promoted Study - ScienceDirect](#)

Gail again – I have a friend who has quite severe tinnitus and my understanding is that the dizziness and balance issues are definitely a part of this. Here is a useful link to Tinnitus UK [Support for you - Tinnitus UK](#)

Q2) Hello, 8 weeks of Cabergoline has reduced my prolactin from 1800 to 20. So that's good. MRI in May to assess if macro-adenoma is shrinking. My question is how do I manage forgetfulness? Simple things like cooking, now burning foods. Boiling my porridge over or finding switches turned off that I can't remember turning or leaving off. Leaving taps running in the kitchen mainly. Noticing the bathroom light on, when I thought I'd turned it off. Thinking I have locked the back door, only to find it closed but not locked in the morning. A lot of the time, I am a bit freaked out, my cat and me at home, no one else has keys.

Is this prolactinoma related, or Cabergoline related, or stress? I am not rushing about as I have been signed off from work for 6 months to get better. I have been on Cabergoline 8 weeks, 500mg once a week. I told my endocrinology consultant and neurosurgeon today about the side effects, but am continuing the dose so as not to delay the shrinking of the tumour.

What can I do to help me not fret so much about this forgetfulness? Usually, I am pretty sharp; my recall was good with both long, and short term, memory being okay– Thank you Leonie W

Dear Leonie, thank you for your question. There is some evidence that high prolactin levels may affect some aspects of cognitive function, including memory and at least one study has reported being able to show some subtle changes in some relevant brain areas on MRI scanning. The quality of some of these reports is, in my view, a little questionable particularly as people with prolactinomas were often tested as hospital inpatients whereas the comparison group were healthy volunteers (meaning that the prolactinoma group had just been given their diagnosis, were stressed and in a stressful environment and presumably they were not very well as most people do not need to be admitted to hospital just because they have a prolactinoma). I think I would probably keep an open mind until we have better, larger studies about how much prolactinoma actually causes memory issues although it does seem possible. The good news though is that at least one study has retested people 6-12 months after starting cabergoline and found significant recovery in memory and other cognitive function. This might also be a relief to women who are pregnant or breast-feeding who also have very high prolactin levels! Whether it is

cabergoline itself (which affects brain dopamine systems), or lowering prolactin or just having time to adjust again after the diagnosis seems uncertain at the moment but I think this data gives us reassurance that you are not alone in what you are experiencing and that there is every hope for your symptoms to improve over time with the treatment that you are on particularly as you are only above 2 months on from starting treatment. I hope this is helpful to know.

Q 3) On the sick day rules it says to inject 100 mg hydrocortisone before a dental tooth extraction. Could you take 10 x 10mg tablets orally instead? – Derek F

Dear Derek, thanks for your question. As you say, the Pituitary Foundation Guidance [HYDROCORTISONE-SICK-DAY-RULES_Feb-2025-update.pdf](#) does suggest 100 mg by intramuscular injection before induction of anaesthesia under the category of ‘major dental surgery i.e. extractions under general or local anaesthetic’. Root canal treatment is considered a ‘minor’ procedure covered with increased oral hydrocortisone (some may have a view on how ‘minor’ this is in comparison to a simple extraction!). Your question asks whether you could take the hydrocortisone dose orally instead which is a very reasonable thing to ask. To be honest, if it was a simple and easy extraction, there wasn’t much infection, you weren’t very stressed etc, you might get away with just an oral dose although in general we wouldn’t give more than about 40-60 mg by mouth under ordinary circumstances (Covid doses for some may have approached this amount). However, these guidelines are about making sure you will be safe rather than telling you that you ‘might get away with it’. The advantages of intramuscular dosing include:

1. You get reliable absorption into the bloodstream
2. Absorption is almost immediate
3. You get quite long-lasting elevation in blood cortisol levels
4. We know that this prevents adrenal crisis



The problems with oral in this situation are that:

1. Tablets take longer to absorb so you may not get the peak when you actually need it
2. Absorption from the stomach can be very delayed when a person is very stressed (blood flow to the gut is reduced and it contracts more slowly, some of the reasons that people can feel sick under stress).
3. Blood levels are very variable in their height and how long they last with oral stress dosing and may not be sufficient for ‘major’ procedures
4. We would be less certain that this would therefore prevent adrenal crisis.

Ultimately, although you may well get away with it on a good day, the best and safest and most guaranteed way is with an injection as recommended although I think it’s a very good point to raise.

Q 4) I was in hospital recently with very high blood pressure; higher than 200/100, following a stressful event which caused me to panic. The doctors were having difficulty lowering my blood pressure as the anxiety continued. They knew I had adrenal insufficiency but were unsure as to whether I should increase my doses of hydrocortisone, bearing in mind that hydrocortisone raises blood pressure. Unfortunately, it was out of hours, and the endocrine team was unavailable to advise so I wasn't able to take any extra. What would have been the best way forward, please? – Eireen C

Dear Eireen, thank you for this conundrum! It’s not easy to give an absolutely definite answer although the principle is always to give, rather than not give, extra hydrocortisone where there is doubt- it is very hard to think of a situation where doing that, as a one off, would be dangerous. I think it would ultimately depend a little on what had led to your stress. As recommended by the

Pituitary Foundation, general stress generally doesn't require extra hydrocortisone. Much more major stress such as bereavement, a road traffic accident or being a witness to trauma (meaning major physical trauma) can generally be treated with extra oral hydrocortisone (please see [HYDROCORTISONE-SICK-DAY-RULES Feb-2025-update.pdf](#) for details) and the sudden death of an immediate family member may require an emergency injection particularly if signs of adrenal crisis are developing (typically this would be associated with a low rather than high blood pressure). Without knowing what happened to you to cause your stress, it is difficult to be precise. However, clearly it did have a significant effect on your 'physiology' (blood pressure) and I don't think an extra dose of hydrocortisone would have made your blood pressure enormously more difficult to manage so I would probably have given it if your own lived experience made it clear to you that it was the right thing to do or if the event was of the nature described above. I hope this is helpful.

A message from Gail:

A little positive thinking (not always easy)

Love this first one from Leonie Warnick –

- ✓ When you get hit by a bulldozer of a Pituitary diagnosis: Sit, rest, dust yourself off and stay positive.

And, this is a good one too (from Gail)

- ✓ If your day is full of rain, play in the puddles !
- ✓ Although I wish I wasn't a pituitary patient, I can honestly say that I am a nicer person because of it and I have made lovely friends during my pituitary journey defo 😊
- ✓ Today I will do my best and if I have a good day then I will be proud of myself, but if I have a bad day, I will not dwell on it, I will forgive myself, I will put it behind me and I will continue to move forward.
- ✓ You are doing your best so it is OK to be not OK
- ✓ You are capable and stronger than you think but when it feels too much, it is OK to ask for help.
- ✓ Reach out; talking matters and although it may not change things, a different perspective can really help



Ways to stay positive when you have a chronic medical condition:

Why is it that sometimes people only accept disabilities when they can see them with their eyes, but it's the chronic illness that goes undetected that they judge ? When you have an ongoing battle with your health, you become accustomed to people thinking you're not really sick or that it's all in your mind. Suffering from health issues can dampen your spirits and leave you questioning yourself.

Since you have no choice but to keep going, how do you stay positive when your world seems so negative? Is it possible to wear a smile even though you feel like crying? Your mindset is a powerful thing and one of the best defences you have against our ongoing conditions.

1. Count your blessings; things such as friends, partner, family, enjoy your good pituitary days knowing that on a bad day, you have a warm bed to curl up in (some people don't), it is sunny outside, my dog loves me , etc, etc. There is always someone worse off. Be grateful for what you do have.

2. Keep a Diary /Journal; this is an excellent option, which allows you to get things out of your head and release them into the atmosphere. It also helps you to create an account of the battles you fight with your health. If you feel that people are tired of hearing about your bodily woes, you can put things in writing to voice them. It's hard when you feel rough, but you don't want to keep complaining so it is better to put it down in writing and release the negative feelings from your mind. It is also IMPORTANT though, to write down the good things too. Gail interrupting here, which isn't unusual is it 😊 – I am not currently writing a journal but I often read back over the years when I was and even now, it is VERY therapeutic. I must admit to having got fed up with literally hand-writing my journals so I then started typing them, which was lots easier and quicker too.
3. Give Back; Depending on the degree of your pituitary condition, there are days when you will feel like getting out and doing something. Do you have a gift or talent that you can share with the world? Very often with pituitary conditions, one day we feel as if we can 'rule the world' and then the next day, it is a struggle, almost a 'wax and wane'. There are times when you have some energy. Giving back is an essential part of life, and it helps you to feel better. Though you may have limitations that dictate what you can and cannot do, there is always some way that you can assist others who have things worse off than you.
4. Positive affirmations; these are a tool that can help to put you in a better frame of mind. For instance, as soon as you get out of bed, you could say a few affirmations to keep you in a good place. Say these affirmations before you read social media, turn on the news and possibly be filled with all the negativity in the world around us.

Try saying things to yourself like: I am going to have a good day - I'm not going to let my illness define me - I will do my best to accomplish the list/ goals facing me today - no matter how bad things look, I am choosing to stay positive - today I will live life to the best of my ability. Adapt these to suit yourself you get the idea.

5. Humour; there is often something funny to be found in many situations, so have a laugh when you can.

There's nothing great about a chronic medical condition and it can definitely take its toll. However, try not to let your pituitary condition define you. When there are good days, get out and enjoy the sunshine. Consequently, don't push yourself on those bad days. Know your limits and when you need to rest. Remember it won't always rain. There will be times when the clouds break and the sunshine comes beaming through. You can and will find effective coping skills to get you through this 'pituitary storm' in your life.



Now we're all thinking so much more 'positively' 😊, back to basics and some of the very helpful documentation, which is available on the Pituitary Foundation's website. Please see the links below/ over the page. We recognise of course though, that not everyone accesses the internet, so if you'd like copies, either get in touch with Gail or The Foundation to request these.

We have linked below some various resources that may be helpful to you. You can print all these off and it's a good idea to have them in a folder somewhere to take with you in the event you have to go into hospital.

There are a couple of more general forms to fill in about yourself, and add to your bedside notes etc. There are also some info sheets explaining hydrocortisone dependency to health care professionals.

There is also a letter which you can present to a healthcare professional who refuses to give you hydrocortisone - it can make someone think twice about withholding it if they have to sign something to announce they've done this.

NHS Steroid emergency card:

<https://www.pituitary.org.uk/product/nhs-steroid-emergency-card/>

Patient care card:

<https://www.pituitary.org.uk/app/uploads/2024/10/Care-card-June-2024.pdf>

To A&E staff, explaining hydrocortisone dependency:

<https://www.pituitary.org.uk/app/uploads/2023/06/To-AE-and-hospital-ward-staff-%E2%80%93-Adrenal-Insufficiency-patient-2023.pdf>

Patient profile for bed notes: <https://www.pituitary.org.uk/app/uploads/2023/04/Pituitary-Patient-Profile-for-bed-notes-23.pdf>

A letter for the healthcare professional to sign when they refuse to give you hydrocortisone:

<https://www.pituitary.org.uk/app/uploads/2024/10/HC-refusal-letter.pdf>

Hydrocortisone information for ambulance staff:

<https://www.pituitary.org.uk/app/uploads/2025/01/HC-Emerg-Amb-Pers-Factsheet-23.01.24pdf.pdf>

On line events with the Pituitary Foundation

Have you tried any of the on line events arranged by the Pituitary Foundation? They are of two types. First, there are regular meetings for particular groups, for certain conditions: acromegaly, Cushings and prolactinoma, and for particular types of patient: young people and LGBTQIA+. Information is given in the Foundation website www.pituitary.org.uk

There are also regular on-off sessions on particular topics. These usually begin at 6 pm and consist of a talk of about 30 minutes followed by 30 minutes of question and answer. They only tend to advertise these a month or less in advance, so you need to check the Foundation website to find out about them.

There are also about thirty recorded events. Search The Pituitary Foundation on YouTube, or use the link www.youtube.com/@ThePituitaryFoundation/videos

A look to the future

At the London support group (LAPPS) they had a talk about research into the possible use of robots for pituitary surgery. Joachim Starup Hansen gave a presentation about the research he and George Hudson were undertaking on robotic devices. He explained the device goes through the nose – a huge improvement on the current devices. It is minimally invasive, but it takes a long time to train and achieve accuracy and experience. Laboratory studies were used, both old operation and new system. It showed that the robot was better after the learning curve. They also used cadavers and live sheep. In conclusion Joachim Starup said this robotic device was safe, feasible and useful. He invited questions. Hani Marcus, a very experienced pituitary surgeon, was asked how he feels about the idea of using robotics. He immediately replied 'Definitely' and explained he designed a robotic device while studying for his PHD. He hopes every year it will be available and he thinks it will be very soon.

If you're feeling lonely or just fancy a chat, then give Gail a call on either of the numbers shown on the first page. Stay safe and thanks soooo very much for your personal contributions folks.

Gail, Pam, Howard P, Melissa, Jodie, Jenny, Jackie, Eireen & Howard C