The Solent and IOW Pituitary Support Group

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Newsletter No. 91, June 2025

Hello everyone,

Welcome to another edition of the Solent and IOW Pituitary Support Group Newsletter, for June 2025.

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 normally it is timed to be issued shortly before each of the main support group meetings at the Cosham Community Centre. <u>The next meeting is on Saturday 28 June at</u> <u>10 am.</u> There will be tea, coffee, juice and biscuits. And a raffle. Please note that NO nuts or nut derivatives are allowed in the building.

The meeting will not have a designated speaker this time. Instead we will have a patient led meeting, where we can share information about what has worked and what has not worked for us. Similar meetings have been very successful in the past. As usual, everyone will be invited to join in. There will also be time to chat generally, and to give and receive advice and information about pituitary conditions and related matters.

We have in the past, often welcomed 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.

Most meetings at Cosham Community Centre, Wootton Street, Cosham, PO6 3AP

At the Cosham meetings we will have tea, coffee, juice and biscuits available. You may bring your own snacks if you wish, but please note: NO nuts or nut derivatives are allowed in the building. Masks are no longer essential at the meeting, but you may wear one if you wish.

- Saturday 28 June 2025 at 10 am No formal speaker; a patient-led meeting
- Isle of Wight meeting, Saturday 19 July at 10:30 am, with Dr Victor Lawrence. NOT at Lake Community Centre, but at <u>a new venue</u>: Gracellie Hotel, 23-25 Hope Road, Shanklin PO37 6ED. If you wish, you can join some of the committee for lunch at the hotel afterwards
- Saturday 27 September. We would normally have a meeting on this date, and one was arranged. However, the Pituitary Foundation have organised a big get-together meeting in Southampton on this day. So we are cancelling the Cosham meeting and going to Southampton instead. See page 3 for more information.
- Saturday 6 December 2025 Our pre-Christmas meeting, with festive food and a quiz
- 2026 dates (all Saturdays): 28 March, 27 June, 18 July (IoW), 26 September, 5 December

Possible speakers for future meetings include Dr James Lawrence and Dr Smith from Salisbury, the endocrine nurse Sirbrina, a radiographer, a pharmacist, and blood bikers. Also possible speakers on mindfulness, laughing yoga, a life coach and others.

There is always a raffle at the main meetings in Cosham 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: <u>howardpearce1@yahoo.com</u> or Gail at <u>g.weingartner@btinternet.com</u> 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 <u>your</u> 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 September 2025.

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.

Pituitary Foundation meeting in Southampton in September

Join us at the Southampton Get-Together September 2025, an opportunity to hear from medical experts and meet others affected by pituitary conditions!

Saturday 27th September, 2025 Time: 10am - 4pm

Location: Leonardo Royal Hotel Southampton Grand Harbour W Quay Rd, Southampton SO15 1AG

We're coming to Southampton for our next Get-Together! These are our in-person events where you get to hear from incredible speakers and meet others affected by pituitary conditions. We can't wait to bring you all together in the South of England for the first time! We'll have brilliant talks from medical professionals, and you'll also have the opportunity to meet staff and members of The Pituitary Foundation.

About the speakers

Professor John Wass – John is a Professor of Endocrinology at Oxford University and was the head of the Department Endocrinology at the Churchill Hospital Oxford. He is also one of the founders of The Pituitary Foundation! John's talk will include:

- an overview of pituitary conditions within endocrinology
- look at changes in how pituitary conditions can be diagnosed
- changes in the treatment for pituitary conditions
- looking to the future of endocrine care.
- Q&A session

Dr Sue Jackson – Sue is a chartered psychologist who researches endocrine disorders, and how the health service can be improved. She's been involved with The Pituitary Foundation for more than two decades and writes psychological advice for people affected by pituitary conditions. Sue will be running an interactive workshop on relationships and wellbeing. The workshop will include:

- how relationships change when living with a chronic condition
- ways to improve your wellbeing
- opportunities to reflect on certain elements

Aldons Chua – Aldons is an Endocrine Clinical Nurse Specialist, based at Barts Health NHS Trust. Aldons also works part time for The Pituitary Foundation, answering calls on the endocrine nurse helpline, and updating our health information. Aldons has a master's degree in research, and a special interest in adrenal insufficiency. His talk will include:

- Working with your endocrine team
- Preparing for an appointment

The day will also include a chance to hear from others from the community!

The event will be held at Leonardo Royal Hotel Southampton Grand Harbour, West Quay Road, SO15 1AG Southampton. There is car parking available, and it's just a 15 minute walk from Southampton Central Railway Station. The venue is fully accessible.

If you have any more questions about the day and what to expect, please get in touch with the Head Office by calling 01173701333 or emailing: <u>admin@pituitary.org.uk</u>.

Ticket price includes:

- Hot drinks
- Fruit/pastries throughout the day

- Hot Lunch
- Opportunity to hear from medical professionals and pre-submit your questions
- Meeting others from the pituitary community

You will need to arrange your own transport to the venue.

Places are limited, so buy now to ensure you don't miss out! We can't wait to see you there! *If a refund is required, please give a minimum of 72 hours notice prior to the event. We'll do our best to reallocate your tickets so that we can provide you with a refund which will be at our discretion.*

For more information, and to order your ticket (cost £25) see the Pituitary Foundation website or go to <u>https://www.pituitary.org.uk/event/southampton-get-together/</u>

Hi all, see below several very interesting questions, which you our members, have submitted for Dr Victor Lawrence to answer for us. As always, a **<u>BIG THANK YOU</u>** to Dr Lawrence for his time, expertise and thoughtful consideration with his responses. *Q* **1**) Please do you have any familiarity with the new cortisol pump and what do you think of it?



Also, I've been suffering from chronic migraines since surgery.

Have you come across this before and found any solution? I was diagnosed with Cushing's disease age 32. There were multiple micro-adenomas on my pituitary gland. My cortisol levels were sky high. They performed 2 operations, 1st operation 21/3/23 to remove just part of the pituitary but it was unsuccessful. So, on the 23/3/23 a second operation to remove the whole pituitary. I suffered with awful head pain after and was in hospital every 3 weeks with hyponatraemia for the next 8 months. At the time, only morphine tablets could help the pain. I continue to have migraines almost daily and they are completely disabling. Under the care of a headache neurologist I've tried all the triptans, botox in my head, neck and shoulders. nothing works. I'm also allergic to NSAIDS. I'm really desperate for help ! – Charlotte K

Dear Charlotte, I wrote about the cortisol pump in quite a lot of detail in a previous edition of this magazine (March 2024). I think there is definitely preliminary evidence that it may help some people and has some potential advantages over tablets in the way that cortisol (hydrocortisone) is delivered over a 24 hour period. In particular, natural oscillations in cortisol secretion are better replicated by a pump, blood concentrations can be held at slightly more 'physiological' (normal) levels overnight without overdoing it and risking symptoms of Cushing's syndrome and levels can start to be increased before the person wakes up which again is how the body normally does things whereas it is obviously hard to take a tablet an hour or two before waking up! We do not have long term evidence of benefit but there are definitely some people who do feel a significant benefit with a pump. There could be some risks- if the pump disconnects/stops working/runs out of battery etc for any reason (which may or may not be obvious to the user), cortisol levels will fall rapidly and crisis could, at least in theory, supervene quickly. However, the biggest barrier to use is currently the cost (which would be several thousand pounds a year) as pumps are not currently funded by the NHS.

In terms of your headaches, this certainly sounds really awful for you. You mentioned that you are receiving expert care from a neurologist with a special interest in headache. I am unlikely to be able to make a specific diagnosis to help you but can offer some information which I hope may be of some use to you at least in understanding that you are not alone with this. Studies of headache before and after pituitary surgery have quite mixed results but I think it is reasonable to infer from them that 1) headache is common in people before they have pituitary

surgery but in general probably not particularly more common than in the general population 2) a significant proportion of people (but by no means all) with headache before surgery find relief from that headache after pituitary surgery suggesting that, at least for those people, their headache was likely related to their pituitary tumour (although I should emphasise that most pituitary tumours do not cause headache) and 3) a small proportion of people (perhaps around 5%) who did not suffer from severe ('disabling') headaches prior to pituitary surgery may experience them afterwards, in some cases for a prolonged period. There do not appear to be any clear risk factors for predicting who may be affected this way although it might be reasonable to assume that your second operation may well have been 'radical' in the sense that the surgeon is likely to have been particularly focussed on removing all of your tumour(s) rather than simply removing a tumour that was visible on a scan pre-operatively in a more 'conservative' operation. It might seem reasonable to suspect that such an approach may make post operative headache more likely although I am not aware of clear scientific evidence to support this.

There is a specific type of headache that is associated with pituitary surgery for Cushing's Disease as you had. This is called 'idiopathic intracranial hypertension' (in the past it used to be called 'psudotumour cerebri'). This appears to affect children with Cushing's Disease more often than adults although it certainly has been described in adults too. The headache is caused by an increase in pressure in the fluid that bathes the brain (cerebrospinal fluid, CSF) and may be caused in some people due to falling levels of cortisol after successful surgery leading to greater production of this CSF fluid. In general, people who develop this rare condition tend to have signs of pressure on the optic nerve which can sometimes be seen during eye examination or sometimes only detected using scans of the back of the eye (e.g. OCT scans). The diagnosis is confirmed by finding raised pressure of fluid in a lumbar puncture test and treatment is usually with tablets that reduce CSF production. Occasionally a 'shunt' may need to be placed during an operation to drain the excessive fluid away. I suspect that your headache neurologist would be very familiar with this condition and will have considered it already but I mention it here just because it is a specific headache that has a specific (even if rare) association with cure of Cushing's Disease.

Q2) I am interested in the impact of ageing on hormonal replacement therapy, specifically for managing Addison's disease in my own case. It seems to me that this factor for those of us who have lived with/ been managing our conditions for several decades, is rarely addressed by our endocrinologists in our treatment plans. Moreover, I have been unable to find any research in this area. Recently, however, I came across a WAPO vlog (2025 vlog 3) in this area by a US based endocrinologist (Dr S. Aleksic). She has made some interesting points. She said that in older people, normal cortisol production starts earlier in the morning and they exhibit a higher cortisol baseline level during the night than in younger people. I am interested in what the implications of these points might be for our replacement therapy dosage (amount and frequency) as we age. I think she also mentioned that current thinking was to treat older people with lower levels of hydrocortisone because it stayed around longer in the body and to avoid the development of comorbidities (interesting, but even if this is true, I wonder if absorption might also become less effective as we age...)? - Julie W

Dear Julie, Thank you for this interesting question. The whole question of the endocrinology of ageing is a difficult one that we are far from even beginning to unravel or understand. The immediate problem we come up against is this: if a hormone normally changes with ageing, does that make the hormone change responsible for some part of that ageing process and should we therefore try to reverse it? Or, is it the other way around- if we are in the business of trying to make a person's hormones as normal as we can, should we build into that replacement plan a strategy for mimicking natural changes due to ageing even if they may at least conceivably have negative consequences? You can see the problem.

People for a while noted that Growth Hormone falls as we age as, for example, does testosterone in men. Because both of these falls could at least theoretically lead to some of the signs of ageing (e.g. loss of muscle mass, increase in fat mass, loss of bone mass and increased osteoporosis, reduction in sexually motivated behaviour, reduction in strength and vitality etc), there were once enthusiasts for giving all ageing men testosterone and growth hormone supplements. The most vocal of these enthusiasts, unsurprisingly, tended to be the manufacturers who saw a massive new market for their drugs. Those with a more neutral stance probably saw some of the potential risks and before long, studies identified various side effects of GH treatment given to otherwise healthy ageing individuals (as opposed to people with definite growth hormone deficiency), including joint pain, oedema (swelling of the ankles) and carpal tunnel syndrome. Other studies have suggested that high levels of growth hormone in older individuals without growth hormone deficiency is associated with shorter life expectancy and increased risk from diabetes and cancer. Even the increased muscle mass did not appear to lead to any increase in strength and was therefore of little more than cosmetic benefit to the individual. For all these reasons, and more, we currently accept that the age-related fall in growth hormone is probably a good thing and we do seek to replicate this when giving growth hormone replacement to people with severe deficiency (e.g. from pituitary disorders) by reducing the target IGF-1 level to that of an age-matched population.

Less is known about cortisol in ageing but as you rightly say, there is evidence that levels are probably higher beyond the 60's, particularly in the evening and overnight. However, there is reason to suspect, and some evidence to show that higher levels themselves in the 'normal aging population' may be associated with negative effects such as 'sarcopenia' (loss of muscle/ muscle strength) and depression. So knowing that cortisol dynamics (levels and variability of secretion over the 24 hour cycle) changes with age is not necessarily the same thing as knowing whether or not it is a good or bad thing and whether or not we should try to replicate it. I think most of the evidence would suggest that most of the risk to most people is in overly high cortisol levels, particularly in the evening and overnight, rather than the other way around. These dangers, even of subtle cortisol excess, include diabetes, osteoporosis, high blood pressure, high cholesterol and muscle weakness/loss. Of course, this balance is different for people taking replacement than it is for someone who is not but it would be difficult to design a study which would need to give higher doses during the time we suspect them to be most harmful and to follow patients up probably for decades to know what the effects would be. My view, based on what we currently know even if this is still far from perfect, is that the changes we know about in ageing are probably too subtle for us to be able to mimic safely with current treatment although they may inform, for example, how we programme pumps if, in the future, they become mainstream/ NHS funded treatment. I suspect you knew that I wouldn't exactly have an answer to your question as nobody has but I hope this at least gives some helpful context.

Q3) I'd like to ask Dr Lawrence the question about whether you can have radiotherapy twice in the same place, or in fact anywhere on the body ? Thanks - Paul O

Dear Paul, Many thanks for this question. Radiotherapy is incredibly complicated and is really the domain of doctors that are specifically trained in it who have a thorough understanding not only of the tumours they treat but also of the physics behind how particle beams interact with human tissues and DNA. I can only give a non-specialist answer but hopefully it will give you an idea.

The concept with radiotherapy is essentially that high energy 'particles' (those of you who know physics will know that gamma ray photons are not really 'particles' but we will think of them as such for this) will damage cells, particularly those that are more rapidly dividing, and in the case of tumours reduce their size or even kill them completely. The problem is that in order to get the high energy particles to the tumour, they will have to go through normal tissue first (skin, scalp, skill, meninges, brain, blood vessels etc). The radiation delivered to these tissues

must be less than that which would damage them badly/permanently. The problem is that if the beam is weak enough not to harm any of these tissues, then it may not harm the tumour enough either. In pituitary radiotherapy, beams are therefore typically aimed at the tumour from at least 3 sides of the head (sometimes many more) so that the beams cross at the tumour and a much higher dose is delivered there than to anywhere else. However, despite this large dose of radiation to the tumour as intended, there will still be some radiation dose given to nearby tissues (remembering that pituitary tumours tend to be very close to the optic nerves in particular but also to other vital brain areas such as the hypothalamus). The radiotherapist will therefore need to calculate the dose of radiation that is needed for the pituitary tumour and check that this can be given without damaging these nearby structures. Each type of tissue has a known 'tolerance' and the radiotherapist will ensure that this is not exceeded. One of the reasons that radiotherapy is typically given in many 'fractions' (meaning daily sessions, typically 25 for the pituitary, rather than all at once in one session) is that this increases the tolerance of nearby tissues (such as the optic nerves) to the radiation that they will inevitably receive and therefore reduces the risk of them being damaged (<1% risk of damage to the optic nerves with conventional pituitary radiotherapy for example). Ideally, if a tumour has been reduced in size by surgery, subsequent radiotherapy would include the whole original tumour location to make sure that any cells left behind in this area are covered. However, this 'ideal' has to be balanced against any harm from irradiating more area than currently contains visible or known tumour and is not always possible or advisable.

In general, tissues such as tumours which contain cells that are reproducing faster are more damaged than 'normal' tissues which are generally reproducing more slowly. However, radiotherapy does come with some risks even if other tissues are not immediately damaged. Longer term, normal pituitary cells are often affected and hormones may need to be replaced, typically starting several years after treatment. There is some risk from damage to blood vessels (which do contain more rapidly dividing cells) and of the radiotherapy causing 'second tumours' (mostly benign but occasionally malignant). Of course, an approximately 1 in 50 risk of a second tumour developing within 20 years has to be balanced against the more pressing risk from the tumour an individual already has that appears to require radiotherapy to control it.

Given all of this complexity, and I have only really scratched the surface, it is difficult to give a totally specific answer to your question about a second course of radiotherapy. The answer, as so often, is 'it depends'. A second dose can be given if it will not exceed the tolerance of normal tissues as described before so the radiotherapist would work out exactly how much radiation was given in the previous radiotherapy to the normal brain, optic nerves, 'cranial nerves' (which control things like eye movements and facial sensation and travel very close to the pituitary) and calculate how much more may be given to these in any proposed second treatment. A decision would be affected by the risk from the tumour being treated, any other options available (e.g. further surgery, chemotherapy etc.), the acceptable risk of damage in the context of all of the above, the radiotherapy techniques available to treat that person's specific tumour (I have not discussed some of the more recent types of radiotherapy in this brief answer but several do exist which can be considered in particular circumstances) and the patient's own preferences and priorities. Second radiotherapy treatment is not commonly done, the risks do increase but it can be done and sometimes it is the right thing to do.

I hope this is helpful and if this is a decision you are personally facing, I wish you the very best whatever the final decision.

Q4) The hydrocortisone sick day rules when we have Covid are to quadruple your daily dose. When I had Covid I found this helped me combat the infection and speeded my recovery. If I get heavy colds these can often cause a chest infection which, as I am immune-suppressed, can lead to pneumonia if I do not take antibiotics. Is there a case to modify the sick day rules towards a higher multiple than 2 if a viral infection seems to be heading towards chest infection? This could avoid the use of antibiotics and/or possible hospital treatment? - Derek F Dear Derek- thank you for this excellent question. In general, the sick day dosing is really to allow your body to cope with the increased demands that it faces during an infection and therefore to prevent an adrenal crisis from developing rather than in the hope that the steroids themselves will change the outcome of that infection (e.g. prevent it from becoming pneumonia). However, it does turn out that the best treatment we have for Covid (other than immunisation) is actually a steroid called dexamethasone. This was discovered by researchers at Oxford University and first reported as the 'RECOVERY' trial on 6th June 2020, just months after the first lockdown in March 2020. In this short time, they recruited 11,500 patients to their study from over 175 NHS hospitals in the UK, including ours, and this was one of the most incredible and rapid scientific achievements ever performed (in my view). So, specifically for Covid, extra steroids may be beneficial and certainly as you rightly point out, the extent of the recommended dose increase is more than for any other illness.

The question of whether higher doses of steroids are helpful for other infections in general, and for pneumonia in particular, is more difficult. Steroids help to dampen the immune system's response to an infection. In a situation where the immune response itself becomes so aggressive that it threatens the patient's life, we certainly do use high dose steroids (e.g. hydrocortisone 100mg 4 times a day intravenously). The classic situation we use this in is in 'septic shock' (low blood pressure due to an infection that threatens organs and life) that is refractory to other treatments for patients in intensive care. For more 'normal' pneumonia, additional steroids (meaning any steroids to people without adrenal insufficiency and more than double usual steroids for those with it) are not generally beneficial and may even be harmful. Damping down the immune system during an infection- which is what big steroid increases (as opposed to normal dosing or double dosing to avoid adrenal crisis) do is a potentially risky thing to do. In addition to this, high steroid doses during an infection fairly often causes a state of temporary diabetes and this again is probably generally best avoided.

For these reasons, I would recommend that, in general, you limit the dose increases to double unless or until specific information comes to light for a specific infection that you have (as for Covid). I do sometimes wonder whether the massive increases that were absolutely lifesaving in the early days of Covid when we were yet to be immunised and when it was so often a lethal disease are still necessary now it seems so much less dramatic almost all of the time (thankfully). However, until the guidelines change on the basis of evidence, I will definitely stick with that advice which we know works for Covid. I hope this has answered your question.

<u>Gail here</u> – If you require more info in respect of Question 1, please refer to our March 2024 Newsletter or email myself or Howard Pearce and we will email or post you a copy

A message from the Pituitary Foundation

Last year, we shared an update that ambulance trusts would no longer be using 'Red Flagging' to flag addresses where someone with adrenal insufficiency was living. This change was done to improve patient safety and you can read more about the reasons for this change on our website.

Instead of using red flagging to monitor patients with adrenal insufficiency, ambulance trusts will now use Summary Care Records (SCR) to see what conditions someone has, and what treatment they need. In the event of an emergency, call handlers can access your SCR and find details of your medical conditions.

For this reason, it's now important to make sure that your Summary Care Record (SCR) is up-todate and contains details of both your pituitary condition and what medication you require. To help with this, we've collaborated with Addison's Disease Self Help Group to create a template letter that you can share with your GP, to ask them to update your SCR with details of your adrenal insufficiency/steroid-dependency and need for hydrocortisone.

We have two versions of this letter - one related to adrenal insufficiency and one related to AVP-D (formerly known as diabetes insipidus)

How to access this letter:

- You can download a digital version of this letter (for free) from our website shop
- You can purchase a printed version of this letter from our shop

For more information on the move away from red flagging and how to update your SCR, see our website https://www.pituitary.org.uk/ambulance-care-moving-away.../

Further steps you can take

If you are unconscious and your identity cannot be identified, your SCR cannot be accessed. To stop this from happening, there are some good things you can do.

- Always carry medical IDs: Medical ID can include a steroid emergency card or other, specific ID materials like wristbands, keyrings, bracelets and stickers. This helps others to help you! Show your steroid alert card to ambulance staff and any other health care professionals if you need urgent or emergency care.
- 2. List your medical conditions in the Medical ID section of your phone
- 3. Always carry an emergency hydrocortisone kit with you

We have lots of medical alert ID products available in our shop.

Calling an ambulance

If adrenal crisis is suspected, take the following steps:

Step 1: Before calling 999 <u>inject yourself</u>, or the person you are caring for, with your hydrocortisone ampoule (100mg)

Step 2: Seek immediate medical attention - call 999

Step 3: Clearly state to 999 that you are steroid-dependent and having an adrenal crisis AND describe symptoms, e.g., vomiting, diarrhoea, dehydration, injury/shock
Step 4: Be prepared with NHS steroid emergency cards to hand over to paramedics
Step 5: Tell the ambulance crew when they arrive if you have administered extra steroids



What happens when you call 999

Ambulance services will ask specific questions when you call 999. The first questions asked will be if the patient is breathing, awake and if not awake if the patients breathing is noisy. Once these questions have been answered, the location of the emergency will be confirmed and then further questions asked to establish the exact problem.

If you have been told by a medical professional that you must always follow a particular course of action if you suspect an adrenal crisis, make sure you declare that information to the 999-call handler. Additionally, remember the keywords to use are:

• I am steroid dependent

• I am/may be in adrenal crisis

As you give further information about your name, address and date of birth to an ambulance call handler, in England it is likely that you are matched to your NHS number. This will enable, where appropriate, for clinical staff to access your Summary Care Record, and depending on the situation your consent may or may not be asked for first.

You may be informed that a clinician will ring you back. Do not be concerned about this. When you are called back you will be able to give more detailed information about your condition.

Going into hospital

If you're undergoing diagnosis or treatment for a pituitary condition, you may have to spend some time in hospital for tests, surgery or medical treatments. Staying in hospital can be scary - especially if it's your first time.

Below we've shared a list of some things to take with you when staying overnight in hospital, to help make your stay more comfortable. Why not save this post for later, so you can find this list when you next need it? You can also share this post with loved ones who may have a hospital stay coming up

What to pack for your hospital stay:

Comfortable clothes! (Pyjamas, tracksuit bottoms, fluffy socks, dressing gown. Note overhead jumpers/sweaters can be hard to put on, especially if you're having surgery or aren't feeling well. A button up cardigan or zipped hoodie can be a good option!)

- Face/body wipes
- RToothbrush & toothpaste
- Slippers or comfy indoor shoes (non-slip is best)
- 🗢 Lip balm

💼 Lots of hydrating drinks (Lucozade, squash, large water bottle)

- Earplugs (particularly some that are comfortable to sleep in, like foam earplugs)
- ${}^{m{\wp}}$ Snacks & nibbles (ideally ones that won't make too many crumbs in your bed!)
- Cheap pair of flip flops/sliders to use in the shower
- Shower essentials: soap /towel /flannel /shower cap
- Books, magazines, puzzles, sudoku, gaming device, headphones
- Notebook & pen to make a note of what consultants say

Some other tips...

XDon't take jewellery, including wedding rings. Sadly, not everyone is honest

XIt's best to avoid wearing makeup or nail polish if you are having surgery, as the nail beds are a good indication of circulation. It's also helpful for the anaesthetist to see your normal face colour

XDon't have too many people visit you at once - this can be very tiring, especially if you are recovering from surgery. Spreading out your visitors also gives you something to look forward to throughout your stay!

Do you have any tips to share that could help make someone else's hospital stay easier?

From our 'always full of humour' Paul Oastler

Hi all quiet(ish) one here. Hope you are well and are taking your tablets.

Just a quick update on my medical journey.

Well, I hear you ask what's happened to you since my last epistle?

Well here we go, I was thinking of opening up a web site called ask Paul. Bit like ask Jeeves but only medical 😂 .

I've now had my gall bladder removed and if anyone has had gall stones you know how painful it can be. I went into hospital 3 times, twice being discharged as an out-patient and the third time had the operation. I'm no squinney but in the end they had to give me morphine in the A&E. Anyway up and running (more like a slow jog) now. Still got the carpal tunnel and sleep apnoea and now I wear hearing aids. Honestly, it's like a military operation going to bed at night. Tablets, eye drops, hearing aids, carpel tunnel gloves and sleep apnoea machine. OHH!! nearly forgot teeth. Jill my wife has great pleasure getting me to answer the door on Halloween night with that lot going on, I've never seen the kids run so fast.

I'm still working; I'm a strange breed but I do enjoy it. But, only light duties now painting and general maintenance. Free estimates on request and all my work comes with my personal 24 hr guarantee or until the cheque clears !! Right that's it for now, stay healthy you lot and I'll leave you with this thought.

Who thinks Exit signs are on their way out? And, do you think Russian dolls are full of themselves?

I nearly forgot, the other day I super glued my thumb and fore finger together. I was OK for a while. 💍 - Paul

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