Part 2 - For Those **Newly Diagnosed**

Part 2 - For Those **Newly Diagnosed**

MEDICATION NAMES OF VARIOUS TREATMENTS

If you have been given medication to take, this section explains the various names of medication; for what pituitary condition they are given and how they are taken, i.e., tablets, injections, patches, gels, etc.

Please Note: A more comprehensive list of treatments is available on our website.

CONDITION	NAME OF TREATMENT(S)	DELIVERY VERSIONS
ACROMEGALY	Parlodel (Bromocriptine); Dostinex (Cabergoline); Sandostatin; Somatuline; Somavert; Pegvisamont	Tablets and injections
DIABETES INSIPIDUS	DDAVP Intranasal; DesmoSpray; DDAVPMelts; DesmoTabs	Nasal applications, tablets or Melts (placed under the tongue)
GROWTH HORMONE DEFICIENCY	Genotropin; Humatrope; Norditropin; Saizen	Daily injections
RAISED PROLACTIN	Dostinex (Cabergoline); Norprolac; Parlodel (Bromocriptine)	Tablets
HYPOADRENALISM (Cortisol deficiency)	Hydrocortisone; Dexamethasone; Prednisolone	Tablets, injections for emergency purposes
HYPOGONADISM FEMALE (lack of oestrogen)	Various brands of HRT (Full list on our website)	Tablets
HYPOGONADISM MALE (lack of testosterone)	Andropatch; Nebido; Sustanon; Testim Gel; Testogel; Tostran	Injections, patches or gels
HYPOTHYROIDISM (lack of thyroid hormone)	Levothyroxine	Tablets

DDAVP

QUESTIONS YOU MAY WANT TO ASK WHEN YOU START YOUR TREATMENT

- AND WHO TO ASK

It can be difficult to know what questions to ask, or who you ask, especially as you might not have much information about what is going to happen to you at this point. The questions below will be a guide for you to begin discussion with your endocrinologist and/or GP.

Do I have a choice of surgery, radiotherapy or medication and what do you believe would be the best course of action for my particular condition/tumour? **(to endocrinologist)**

Do I have any choice of hospital, surgeon or radiotherapy department? (to GP, endocrinologist or Pituitary Foundation)

Will I remain on replacement hormones for life and how often will I be monitored? (to endocrinologist)

What part will my GP play, with regard to carrying out tests, prescribing my medication and caring for me post surgery? (to endocrinologist)

Will my GP receive my results from your clinic and in what time frame? (to endocrinologist)

If you are taking hydrocortisone: I have heard about a 'cortisol day curve' test; is it appropriate for me to have this test to make sure that I'm on the correct dose? (to endocrinologist)

Note: this applies if your levels of cortisol are monitored by blood tests only.

I haven't felt much benefit from my current dose of thyroxin (after 3 months) can I be tested in case the levels aren't correct?

(to GP or endocrinologist)

If you are a DI patient: Could I have regular sodium (and possibly potassium) tests - 6 or 12 monthly? (to GP or endocrinologist)

I still experience extreme headaches since my surgery; can you investigate these as I'm taking strong painkillers regularly?

I'm having problems with my jaw, these may be related to my headaches; could I see a maxillofacial consultant (a specialist in face, jaw mouth & neck problems) and have an x-ray? (to GP)

Page 11

Pituitary Patients Handbook.indd 11-12 18/1/10 08:48:33

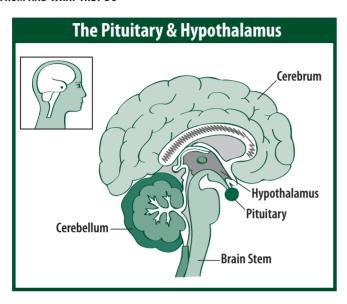
Part 2 - For Those **Newly Diagnosed**

Part 2 - For Those **Newly Diagnosed**

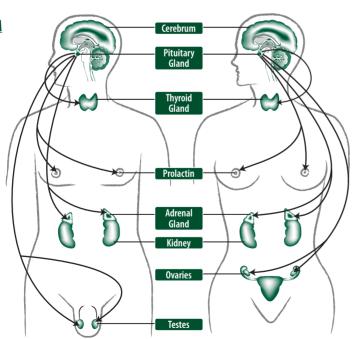
AN EXPLANATION OF HORMONES

- WHERE THEY ARE SECRETED FROM AND WHAT THEY DO

THE PITUITARY GLAND



THE ENDOCRINE SYSTEM



HORMONE	Target	Function
Anterior - FRONT PART Adrenocorticotrophic Hormone (ACTH)	Adrenals	Stimulates the adrenal gland to produce a hormone called cortisol. ACTH is also known as corticotrophin. Cortisol promotes normal metabolism, maintains blood sugar levels and blood pressure. It provides resistance to stress and acts as an inflammatory agent. Cortisol also helps to regulate fluid balance in the body.
Thyroid Stimulating Hormone (TSH)	Thyroid	Stimulates the thyroid gland to secrete its own hormone called thyroxine (T4). TSH is also known as thryrotropin. Another hormone produced from the thyroid is called tri-iodothyronine or T3. Thyroxine controls many bodily functions, including heart rate, temperature and metabolism. It also helps metabolise calcium in the body.
Lutenising Hormone (LH) and Follicle- Stimulating Hormone (FSH)	Ovaries (females) Testes (males)	Control reproduction and sexual characteristics. Stimulate the ovaries to produce oestrogen and progesterone and the testes to produce testosterone and sperm. LH and FSH are also known collectively as gonadatrophins. Oestrogen helps with growth of tissue of the sex organs and reproductive parts. It also strengthens bones and has a positive effect on the heart. Testosterone is responsible for the masculine characteristics including hair growth on the face and body and muscle development. It is essential for producing sperm and strengthening the bones.
Prolactin	Breasts	Stimulates the breasts to produce milk and is secreted in large amounts during pregnancy and breastfeeding. It is however present at all times in both males and females.
Growth Hormone (GH)	All cells in the body	In children this hormone is essential for a normal rate of growth. In adults it controls energy levels and well-being. It is important for maintaining muscle and bone mass and appropriate fat distribution in the body.
HORMONE POSTERIOR - BACK PART	Target	Function
Antidiuretic Hormone (ADH)	Kidneys	Controls the blood fluid and mineral levels in the body by affecting water retention by the kidneys. This hormone is also known as vasopressin.
Oxytocin	Uterus Breasts	Affects the uterine contractions in childbirth and the subsequent release of milk for breast feeding.

Page 13

Pituitary Patients Handbook.indd 13-14 18/1/10 08:48:33

Part 3 - For Those **Diagnosed**

Once you are diagnosed, or have been a patient perhaps for some time, you should find the following sections helpful on your journey.

PITUITARY FUNCTION TESTS EXPLAINED

At the start and throughout your journey, your hormone levels will be monitored through various tests. By regular testing, your clinicians are able to understand how your hormones are working (or not) and ensure you are appropriately treated.

The following sections shows all of the usual tests carried out, but please note that you might not require all of these tests.

Name of Test	WHAT HORMONE IT TESTS?	THE CONDITION IT IS TESTED FOR?	How THE TEST IS GIVEN?	WHAT DO THE RESULTS MEAN?	How Might I Feel?	REGULARITY OF THIS TEST
ACTH	ACTH tested directly	Cushing's (excess cortisol) Or Hypoadrenalism (low cortisol)	Blood sample taken first thing in the morning	Deficiency of ACTH; underactive pituitary; raised/ over production	Normal. Blood test but needs to be done at hospital	When endocrinologist feels it is necessary
Dexamethasone Suppression	Cortisol	Excess cortisol production	Tablet taken at midnight; blood test the following morning	Normal individuals suppress cortisol levels	No side effects	To aid diagnosis
Synacthen (stimulation test)	Cortisol	Low levels of cortisol	An intravenous injection, then a blood test	Poor response shows cortisol deficiency	No side effects	Varies as to how often repeated. 6 monthly, annually dependant on individual circumstances
Day curve	Cortisol and other hormones e.g., growth hormone	Those on hydrocortisone, test done to assess adequate levels achieved pre and post medication	Taking your usual doses, blood is taken several times a day	Shows under or over replacement with medication	No side effects	Varies. Dependant on your centre/ consultant
FSH	Follicle Stimulating Hormone	Stimulates production of sperm in men; stimulates follicle development in the ovary for women	Blood Sample	Depends on age and timing of menstrual cycle (pre/ post/ mid)	No side effects	Varies

Name of T est	What Hormone IT Tests?	THE CONDITION IT IS TESTED FOR?	How THE TEST IS GIVEN?	What do the Results Mean?	How Might I Feel?	REGULARITY OF THIS TEST
Glucose Tolerance	Growth Hormone	To diagnose Acromegaly	After a sugary drink, bloods are taken at 30 minute intervals for 2 hours	Normal Individuals suppress GH levels	Nausea, Headache - although not always!	To make diagnosis and for review purposes; timings vary in centres
IGF-1	Synthetic growth hormone replaced patients. Tests IGF1	To monitor baseline and reviews for patients on replacement GH.	Blood Sample	Guide to overall circulating levels of GH in the blood stream	No side effects	Varies but at least annually when established on GH replacement
Insulin Stress	Gold Standard Test to assess pituitary function for cortisol and GH	To assess correct levels of cortisol and GH	After an injection of insulin, blood is taken every 30 minutes for 2 hours	Body should respond when under stress by secreting cortisol and GH. Lowering the blood sugar causes stress	Because blood sugar is lowered you may feel dizzy and nauseous, sweaty, clammy disorientated, heart racing. These effects are short acting.	Post operative: To assess pituitary function. Diagnosis GH deficiency
LH	H Luteinising Ad Hormone to te in or to occur.		Blood Sample	See FSH	No side effects	Varies
Oestrogen	Oestrogen (females)		Blood sample	See FSH	No side effects	Varies
Testosterone	Testosterone (males)		Blood sample: Morning sample most accurate	Diagnosis deficiency	No side effects	Varies, but required for review purposes
Water Deprivation	ADH Anti Diuretic hormone Serum and Urine Osmolality (ability to concentrate Urine)	Diabetes Insipidus	Patient deprived of any fluids for approx 8 hours. Blood is taken, weight checked and urine tested at regular intervals.	Specialist Interpretation Required	If you have DI this test can be very uncomfortable as you cannot drink anything.	Diagnostic only

Page 15

Pituitary Patients Handbook.indd 15-16 18/1/10 08:48:34

RECOGNISING PRACTICAL AND EMOTIONAL ISSUES

The following issues (in no specific order of importance) may or may not relate to you, but will possibly help you in knowing that other patients experience some of these problems too.

THE PATIENT AND DOCTOR RELATIONSHIP

This relationship can feel unequal to many people. Being a patient and realising you need medical care can be distressing for an individual. You may also feel powerless and you could have expectations that the doctor becomes the powerful one in the relationship. When the doctor is thought of as powerful, the patient's expectations, both realistic and unrealistic, can develop. Remember that the doctor may know more about medicine than you, but you know more about your symptoms and the difficulties that you are experiencing than the doctor.

If you do have unrealistic expectations, you may think that the doctor should realise your concerns, needs and symptoms without you having to communicate these. If the doctor doesn't meet these unrealistic expectations, you may then feel ignored, misunderstood and alone. However, if you have realistic expectations together with feeling able to assist the doctor in your care, this can achieve benefits for both of you to pave the way for good relations and exchange of information.

It is good to remember that the doctor is a human being too.

Although patient care is improving, there may still be problems for some patients. Issues include non-continuity of care, i.e., the patient may be seen by a different doctor at each clinic visit. Patients can, however, request to be seen by a particular consultant upon arrival for their appointment. This might not be possible or this may mean you will have a longer wait, so be prepared (i.e., bring a book or magazine to fill your time).

For many, the regular check up can be unnerving (memories of being told you have 'a brain tumour', re-visiting the hospital site, etc.). It could be helpful (both to you and the doctor seeing you) if you briefly explain why you are anxious or upset at attending clinic.

Blood test results may be delayed for an unacceptable time and sometimes aren't acted upon as quickly as they should be (if hormone levels suggest change of dosage, for instance). It is helpful if your blood can be taken 3 or 4 weeks prior to your hospital visit so that results will be recent and in front of the consultant or doctor at your visit. Ask your consultant for a blood test form before you leave the clinic.

Access to a clinician can be difficult if you need urgent advice. If there is an endocrine nurse at your endocrine clinic you can contact her/him or contact your GP.



PHYSICAL APPEARANCE

Some patients suffer side effects from their condition or treatment. Your clinician may suggest that weight gain is due to overeating, which can be distressing if you are eating a healthy diet. Discuss possible causes (e.g., steroid medication or thyroxin doses) with your consultant. Acromegalics may experience problems with clothing and/or footwear. There are specialist retailers who can provide extended size ranges (you can contact The Foundation for information on retailers). Radiotherapy may cause temporary hair loss in small areas but most hairdressers are experienced and empathetic in restyling for hair loss so don't be afraid to explain to your hairdresser what your needs are.

GPs and consultants can help you to access counseling that help overcome physical and emotional change. The charity, Changing Faces, advises on physical appearance issues. The British Red Cross can provide camouflage make-up for initial scarring post surgery. For more information on these and other organisations, please see our links at the end of this Handbook

The Foundation has a wide range of leaflet available, including our *Well-being* series; the leaflets below could be of help to you:

- For those who have been diagnosed for awhile please see our leaflet called 'Your Journey: Living with and Managing a Pituitary Condition'
- We also produce leaflets called 'Relationships & Communication: with Yourself and with Others' and 'Living with Infertility' that might have information that will be useful to you

GOING IN TO HOSPITAL FOR TESTS

SHORT STAY TESTS

Some tests are carried out over several hours during the day and would usually begin in the morning.

There will be a bed or comfortable arm chair provided for you, and you should be allowed to take someone with you for company. For these tests you won't need to take your nightwear with you, as you'll stay in your clothes throughout. Comfortable clothing is advised, with something to read. Refreshments and drinks are provided as the test allows, and certainly at the end of the test.

If you are having a more intensive test, you might not feel like driving or getting public transport home – ask someone if they can pick you up.

At least the day before you go, it is advised to ask the endocrine unit who will be testing you, if you should take your usual medication at home, for the evening before and on the morning of the test. Also ask if you can eat and drink normally prior to the test; if you aren't allowed to, ask for specific times you should not eat and drink and when you can start eating and drinking again.

Page 17 Page 18

Pituitary Patients Handbook.indd 17-18 18/1/10 08:48:34

Part 3 - For Those **Diagnosed**

Part 3 - For Those **Diagnosed**

GOING IN TO HOSPITAL FOR TESTS

FOR IN-PATIENT STAYS

Patients shared their tips on things to take with them to make the experience as comfortable as possible. These included:

- Three pairs of pyjamas or nightdresses, and/or tracksuit bottoms and loose tops for comfortable day gear
- * Lightweight dressing gown
- * Slippers with non-slip soles
- * Toothbrush and toothpaste
- * Brush or comb
- * Face, or baby wipes
- * Earplugs (wards can be noisy)
- * Eye mask (keeps the bright ward lights out)
- * Notebook and pen
- * Change for buying newspapers, drinks, etc.
- * Small tin of Vaseline or balm (for the lips)
- * Lots of drinks (non-alcoholic naturally, Lucozade or squash)

- * Sanitary items (for ladies only), if required
- * Soft / balm tissues LOTS "the hospital will provide but they are a bit rough"
- * A cheap pair of flip flops for use in the shower
- * Cardigans are better than over the head sweaters in case it gets a bit chilly
- * Nibbles that don't make a mess in your bed
- * Sweets / mints
- * Books / puzzle books
- * Two or three pens
- * List of phone numbers
- * MP3 or an old CD player and two or three of your favourite CDs
- * A couple of cuddly teddies (optional)
- * Don't take jewellery including wedding rings

AND SOME SUGGESTIONS FROM OTHER PATIENTS:

"Go out and buy a nice light perfume or body spray. Not your usual one, because you will probably always associate it with your stay in hospital, so if you throw it away afterwards, it doesn't matter. It makes you feel so much better having a quick 'spritz'. The other daft things I did were things like taking a face pack in with me for when feeling better post-op. I could convince myself it was a spa not a hospital. Being in my own room helped with that one!"

"Designate one person to ring the ward and have a cascade system for letting people know how you are doing. Organising things like that before hand can give you a sense of control."

"Plan something for afterwards. After my hysterectomy, a dear friend came to visit. I was two days post-op and feeling awful and she TOLD me I was going on a trip with her school to a Tapas bar in five weeks time. Seems an odd school trip, but they had been taking Spanish lessons!! Seemed impossible, but I was determined. I went, had a great time with all the children and was so glad I had set myself an achievable target."

"If someone says 'can I do anything?' say yes!! Helps you and makes others feel very worthy. A friend cleaned out my rabbits – just what I needed!"

"I had one day when I was visited by work mates, friends and family – not a good idea and hubby was annoyed as it completely tired me out – stagger the visitors!!! DEFINITELY needed a couple of pens and someone bought me a beautiful journal to keep notes in which were handy when the numerous consultants bombarded me with info."

"I took a photo in of the family and had it on my bedside trolley which was nice to look at."

"Don't wear nail varnish to theatre as the nail bed gives a good indication of the circulation, especially immediately post-op as you are waking up. Face make-up is not a good idea either. The anaesthetist needs to see your normal colour. It has been known for patients to come to theatre with the full works, including hair spray!! Someone forgot to tell them it was an operating theatre they were going to!!"

HOLIDAY AND TRAVEL INFORMATION

It is important that you are able to enjoy a holiday without having undue concern about your pituitary condition. These are some tips to help you whilst travelling:

- When going on holiday, especially abroad, it is important that you obtain from the hospital, or your GP, a letter of confirmation that you are carrying medication, including hydrocortisone for injecting, needles and syringes for your own personal use in an emergency situation relating to your medical condition. This should be on the hospital or GP's letter headed paper.
- Do not place your hydrocortisone emergency kit, Growth Hormone, or any of your medications in your hold baggage - always carry them in your hand luggage. Make sure that you carry your medication in the original pharmacy container it was given to you in by your chemist - with your name on any separate container.
- Tell the check-in staff and also airport security personnel before passing through security (after Passport Control) that you are carrying necessary medications. Have your letter of confirmation available to show them and also have it ready upon arrival at your destination.
- It is important to note that airport policy takes priority over airline policy, i.e., if the airline check-in
 counter personnel tells you that you can carry needles, etc. the airport security may have an issue with
 this. Be certain to make sure you are covered for both the airline and airport policies by checking their
 websites or phoning.
- Take sufficient supplies (7 to 14 days extra amounts) of your hydrocortisone to allow for any increase should you feel unwell, journeys are delayed, or (rarely) if luggage is mislaid. Also take spare supplies (several days) of any other medication you take.
- Be certain to take disposal container for any needles you use.
- Have a written checklist to remind you of the hydrocortisone emergency injection procedure please see our **Hydrocortisone Advice Leaflet** below.
- If you take Growth Hormone, you can store this quite safely whilst travelling in a cool bag with frozen blocks inside until you reach your destination. It is advised to ask if there is a refrigerator in your holiday accommodation, or if there isn't, could you store spare freezer blocks in a hotel freezer (for example). If you can use a freezer, it is best to take spare freezer blocks in your luggage, for rotating the blocks in order to keep your medication cool all of the time in your cool bag. Again, it is recommended that you arrange this **before** travel.
- Carry a *Toilet Access Card* with you if you have Diabetes Insipidus (these can be obtained from The Pituitary Foundation).
- Take and wear your medical information talisman at all times
 during your journey and stay. For further information about medical
 talisman, and companies providing these, please see our website at
 www.pituitary.org.uk. The Foundation provides a Patient Care Card
 which will be helpful too. Please contact us at helpline@pituitary.org.uk
 or 0845 450 0375 for your card.

Would you kindly allow me to use the nearest toilet?

Due to a disorder called Diabetes INSIPIDUS, which prevents my kidneys from retaining water, I need to use a tollow growth at times. An about medical see our website at Patient Care Card

Page 19

Part 4 - For Those **Patients** on **Hydrocortisone**

Part 4 - For Those **Patients** on **Hydrocortisone**

IMPORTANT INFORMATION FOR PATIENTS ON HYDROCORTISONE

HYDROCORTISONE Advice for the Pituitary Patient

What is Hydrocortisone?

Hydrocortisone is a steroid hormone produced by the adrenal gland. It plays a complex role in regulating body functions and is essential for survival.

Hydrocortisone is taken as a replacement for the natural hormone where this is deficient, either because there is a failure of hydrocortisone production by the adrenal gland (Addison's disease), or pituitary deficiency of ACTH (the hormone that stimulates the production of hydrocortisone by the adrenal gland). Replacement therapy is also required for people who have congenital adrenal hyperplasia, which is a birth defect. Hydrocortisone is available as tablets under the trade name Hydrocortone, containing 10mg or 20mg.

An injection containing 100mg Hydrocortisone is available for emergency situations. For children there are lower dose emergency injections available.

How do I take it?

The usual dose is 15 – 20mg orally split over two or three times daily, and depending on your individual endocrinologist's recommendations. For example: 10mg before rising, 5mg at mid-day and 5mg no later than 6pm.

How can I let others know I take replacement hydrocortisone?

When you are prescribed your medication you will be given a 'blue steroid card' from the hospital to carry. The Pituitary Foundation suggests that you purchase and wear a medical necklace or bracelet, such as 'MedicAlert' to show your cortisol replacement therapy. Further, The Pituitary Foundation has a Patient Care Card which is small enough to fit in your bag, or pocket and displays your hydrocortisone needs and information on emergency replacement should you need this. Please contact us if you would like a Care Card; an A5 size SAE with a second class stamp would be appreciated.

Emergency Injections - should I have these at home?

The Foundation does recommend all patients taking hydrocortisone to have a 100mg injection kit in their home for emergency use only. If you don't have one of these already, you can ask your GP, or endocrinologist if they will prescribe this for you. If you have difficulties in obtaining a prescription, we have information available to help you. Please check regularly that these preparations are not expired.

On the following pages are clear instructions on how to inject yourself, or for a relative to do this. Some endocrine clinics will help to show you how to inject, in an emergency.

If you are in an emergency situation and need an ambulance or medical help, we advise that you (or your carer) use the words 'ADRENAL CRISIS' about your HYDROCORTISONE needs. This term is more widely understood and acknowledged within the medical community.

WHEN WOULD I NEED TO TAKE MORE HYDROCORTISONE?

If you become ill then the body would naturally increase the output of steroid from your adrenals. Therefore if you are taking replacement steroid (hydrocortisone) it is essential to mimic the natural response by increasing your dose appropriately.

ILLNESS OR STRESS SITUATION	INCREASE OF USUAL DOSE	For how long?	Is this an Emergency, or when do I seek help?		
Cold with no fever	None necessary				
Fever, flu, infection	Double	For duration of fever	See GP if still unwell after 48 hours		
Vomiting - more than once Also diarrhoea and severe illness	Emergency 100mg injection if extra dose of 10mg-20mg tablets can't be kept down	Resume on usual dose once stable after medical intervention	Phone GP, or go to A&E. If you have injection at home, you, a relative (if able) or GP can administer this. Also an anti –sickness injection may be needed		
Surgical procedures	 Minor (eg: tooth extraction) 20mg before procedure Small op (eg: hernia) 100mg injection every 6 hours for 24 hours Major op (abdomen/chest) 100mg injection or iv every 6 hours for 72 hours 	Resume on usual dose immediately after Reduce rapidly to usual dose	Tell the anaesthetist and surgeon that you take hydrocortisone before the op		
Colnoscopy and Barium Enema	Double your usual dose the day before, when the bowel is cleared out For colnoscopy only -100mg injection 30 minutes before procedure to be given by doctor	Take usual dose on morning of procedure	Drink lots of water to prevent dehydration. Tell the doctor before procedure that you take hydrocortisone		
Cyctoscopy	Double your usual dose day of procedure	Resume as normal	Tell the doctor before procedure that you take hydrocortisone		
Severe shock eg; bereavement or road traffic accident	100 mg injection, or take 20mg as tablets if able	See GP or hospital for further advice	Sudden and severe shock may be classed as emergency —seek medical attention if in doubt		
Long haul flight over 12 hours	Double usual dose on day of flight	One double dose should suffice			
General stress, exams etc	Not usually required		Ask GP if concerned		

Page 21

Pituitary Patients Handbook.indd 21-22 18/1/10 08:48:35

How to Give an Emergency Injection of Hydrocortisone

POWDER VERSION:

SOLU-CORTEF



Wash and dry your hands.

Snap open the sterile water - use a small piece of tissue to protect your fingers.

Attach the green needle to the syringe and remove the cover. Withdraw 2ml of sterile water into the syringe



Remove the cap off the vial of hydrocortisone powder.

Inject the water into the vial of powder.



Swirl the vial until all the powder is mixed with the water.

Withdraw the contents of the vial into the syringe.



Pull the needle and syringe out of the vial

Exchange the green needle for the blue needle Use an alcohol wipe to clean the bare skin at injection site - right or left upper thigh.

Stretch the skin slightly and push the needle in at selected site with a steady motion.

Push plunger down so that all the liquid is injected.



Remove the needle cover and hold the syringe between your thumb and index finger.

Grasp syringe and pull needle out of the thigh.

Apply pressure to the injection site with a clean tissue for 2 minutes.

LIQUID VERSION:

EFCORTESOL

Wash and dry your hands.

Break open the ampoule at the dot, using a small piece of tissue to protect your fingers. Push firmly to attach the needle to the syringe and remove the cover.

Hold the ampoule with your non-dominant hand and draw up the solution into the syringe with your other hand.



Expel any air by pressing the plunger until a drop of liquid forms at the end of the needle.

Use an alcohol wipe to clean the bare skin at injection site - right or left upper thigh.

Remove the needle cover and hold the syringe between your thumb and index finger.



If you are giving yourself the injection, you need to inject yourself on the same side.

eg: right handed
- right thigh.

Grasp syringe and pull needle out of the

Apply pressure to the injection site with a clean tissue for 2 minutes.

DISPOSE OF ALL MATERIALS SAFELY

SEEK MEDICAL HELP IF NOT IMPROVED WITHIN 24 HOURS

Part 4 - For Those **Patients** on **Hydrocortisone**

How do I cope if I'm travelling away from home with Hydrocortisone?

If you are going on holiday abroad you should ask your GP or Endocrinologist for a letter about your medication and your doses prescribed. This letter will be helpful should you become unwell and have to see a doctor. It is also useful for you to have this letter whilst going through airport security, in the event that they question your medication. If you have a repeat copy prescription this can also be shown.

It is suggested that you have a 100mg injection kit — see above — whilst you are travelling abroad, in case of emergency. This injection should be placed in a small cool bag, labelled with your name and kept with you at all times during your journey.

At check in they will ask if you are carrying anything sharp i.e.: needles; please mention if you are carrying injection needles for your medical condition.

At your destination if there is no refrigerator in your accommodation, the hotel may freeze your freezer blocks for you, so do take some spare in your luggage to change around regularly in your cool bag.

It is wise to take an extra 2 weeks supply of hydrocortisone tablets with you in case you need to increase your usual dose whilst away. All medication should be kept in your hand luggage.

If you have any doubts whatsoever regarding airline or airport security and procedures, please telephone the airport or airline before you go.

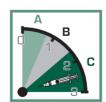
WHEN DO I KNOW THAT I WOULD NEED AN EMERGENCY INJECTION?

If you cannot absorb your tablets, or your usual replacement wasn't sufficient for an acute shock or illness, then gradually or perhaps quite quickly you would feel weak, sickly and light headed.

The cortisol clock below gives approximate times of need for emergency medical help and replacement.

EMERGENCY CORTISOL REPLACEMENT PEAK TIMINGS FOR CLINICAL USE

Pituitary Cortisol Insufficiency



- **A** = period of first feeling unwell (within, or up to, one hour)
- **B** = period of increasing illness (failure to retain oral cortisol) (during 2nd hour)
- **C** = **DANGER ZONE** emergency cortisol injection needed (by the 3rd hour)

The information provided throughout this handbook is general information only. All patients are different and if you have any questions, please contact your consultant or GP.

Page 23

Pituitary Patients Handbook.indd 23-24 18/1/10 08:48:36

Contact Details for Other Organisations

Addison's Disease Self Help Group: www.addisonsdisease.org.uk 201483 830 673

Amarant Trust (Menopause): www.amarantmenopausetrust.org.uk 201293 413 000

British Society for Paediatric Endocrinology and Diabetes: www.bsped.org.uk

British Thyroid Foundation: www.british-thyroid-association.org @0870 770 7933

Diabetes UK: www.diabetes.org.uk 20207 424 1000 (central office) 20845 120 2960 (Careline)

Congenital Adrenal Hyperplasia: www.cah.org.uk 20870 770 0326

Carers UK: www.carersonline.org.uk 20207 490 8818

Changing Faces (living with disfigurement): www.changingfaces.co.uk 20207 706 4232

Child Growth Foundation: www.heightmatters.org.uk @0208 995 0257

Contact a Family (for families of children with a medical condition): www.cafamily.org.uk

20207 608 8700 or (Helpline 20808 808 3555) 3555)

Headway: www.headway.org.uk 20808 800 2244

Impotence Association: www.impotence.org.uk @0870 774 3571

Kallmann's Syndrome (HYPOHH): www.hypohh.net

MedicAlert: www.medicalert.org.uk №0800 581 420

Multiple Endocrine Neoplasia Disorders (MEN): www.amend.org.uk

MEN 1: \$\infty\$01423 712 235 MEN 2: \$\infty\$01892 525 308

National Fertility Association: www.issue.co.uk 201922 722 888

National Osteoporosis Society (NOS): www.nos.org.uk @01761 471 771 (Helpline) @01761 472 721

Premature Menopause: www.daisynetwork.org.uk

Pre-Menstrual Syndrome: www.pms.org.uk @0970 777 2178

Polycystic Ovary Disease: www.verity-pcos.org.uk

Restricted Growth Association: www.rgaonline.org.uk 201308 898 445

RNIB: www.rnib.org.uk @0207 388 1266 or (Helpline) @0845 766 9999

Tall Persons Club: www.tallclub.co.uk @07000 825 512

Thyroid Eye Disease Association: www.thyroid-fed.org/members/TED.html @01797 222 338

Turner's Syndrome Support Society: www.tss.org.uk ≥ 01398 380 385

Also see www.ukselfhelp.info for other useful contacts

Please note: Websites and phone numbers are subject to change from the printing of this leaflet. There are many organisations that provide services on a variety of issues a patient may face and The Pituitary Foundation suggests you utilise these services as they may aid you along your journey. If you don't have a computer at home, you can go to your local library and use their computers to search the internet. Librarians are often helpful in assisting

you to find what you need. You can also call The Pituitary Foundation and if we can't help, we may be able to direct you to someone who can.

Unfortunately, there is also a great deal of untrustworthy information on the internet. To understand the credibility of what you're reading and the support you may receive, we suggest you be aware of such things as an organisation's charity registration (if they exist for charitable purposes, such as patient support, they should have one or be seeking one); the dates on website pages and leaflets (how current is the information?); if medical-based, does the organisation have a medical panel or clinical committee? (with more than one or two members) that reviews their information for accuracy.

Become a member of The Pituitary Foundation Being a subscribed member of The Pituitary Foundation will greatly help our awareness efforts, assist The Foundation's aims to be the 'voice' of the patient and quite simply allow us to do the work that needs to be done. If you would like to become a subscribed member, please complete the form below and send to us at:

The Pituitary Foundation, PO Box 1944, Bristol, BS99 2UB

	Pituitary Foundation - Membership Application Form							
ı	Name: (Mr/Mrs/Ms)							
ı	Address:							
	Postcode:							
	Telephone No:							
ı	Email address:							
ı	Please tick the type of Mem	bership you require:						
ı	Individual	£15 per annum	Family	£25 per annum	Life Membership	£150		
	Please make cheques payable to 'The Pituitary Foundation'							

Donate to The Pituitary Foundation This leaflet was provided free of charge. We hope the information helped you; if you would like to help us, your donation will assist us in continuing this service. Please complete the form below, with your donation and send to: The Pituitary Foundation, PO Box 1944, Bristol, BS99 2UB

Name:							
Address:							
Postcode:							
I enclose a do	onation of	£					
I am a UK tax	payer	YES	/NO				
Please treat all donations that I have made for 6 years prior to this declaration, and all that I make from this date, until I notify you otherwise, as Gift Aid donations							
Signature					Date		
Please make	e cheques	payab	le to ' Th	e Pituitary I	oundation'		You Can Help

Page 25

Pituitary Patients Handbook.indd 25-26 18/1/10 08:48:37