

Diagnosis & treatment

The psychological impact of a pituitary condition



The Pituitary Foundation Information Booklets

The
Pituitary
FOUNDATION

Working to support pituitary patients, their carers & families

The Pituitary Foundation is a charity working in the United Kingdom and Republic of Ireland supporting patients with pituitary conditions, their carers, family and friends.

Our aims are to offer support through the pituitary journey, provide information to the community, and act as the patient voice to raise awareness and improve services.

About this booklet

The aim of this booklet is to provide information about the psychological and social issues associated with diagnosis and treatment of a pituitary condition, as well as provide some practical advice.

You may find that not all of it applies to you. We hope it helps you to understand your condition better, gives you ideas on how to manage emotional issues and offers you a basis for discussion with your GP and endocrinologist.

| | |
|--|-------|
| Introduction | 3 |
| Diagnosis | 4 |
| Dealing with a protracted diagnosis | 4 |
| Dealing with a sudden diagnosis | 5 |
| Dealing with grief and loss | 7 |
| Dealing with post traumatic stress disorder (PTSD) | 9-10 |
| Problems associated with treatment | 11-16 |
| Dealing with radiotherapy / MRI scans | 11 |
| Dealing with needle phobia | 12 |
| Dealing with worries about taking your drugs correctly | 13 |
| Dealing with health care professionals (HCPs) | 14-15 |
| Dealing with other patients | 16 |
| Emotional and psychological aspects of pituitary conditions | 16 |
| Other life events which impact on management of the condition | 17 |
| Stress management techniques | 18-21 |
| Bibliography and other resources | 22 |

Introduction

Being faced with a pituitary condition, with possible life-long implications, can be puzzling. It is neither universal nor predictable. Many people with a pituitary condition have a relatively normal life post-diagnosis, but many will struggle for a variety of reasons.

Even if hormone levels are restored to 'normal' levels with adequate suppression or replacement regimes, there may not be a parallel feeling of being fit and well again.

"I wish I could carry on with my life as normal."

"I had my tumour removed two years ago, have not had Radiotherapy and am not on drugs. I am 'cured' but still get extreme fatigue on any exertion. I have just returned from holiday and am exhausted. I wonder if it is a thing I will have all my life...it is an uphill struggle."

Pituitary conditions can make you feel unwell, with a noticeable feeling of 'flatness' often arising shortly before medication is due. You may feel that key elements of your character (like having boundless energy) have changed. You may not feel like "Me" any more and may feel more emotional and react differently (usually more strongly) to things you find irritating or worrying.

Fundamental unknowns enter your life. The future becomes uncertain; dreams may evaporate.

"Why me?"

"Why did I get this?"

"Is it inherited?"

"Will my children get it?"

"Will it regrow?"

"Will I see my children grow up?"

Diagnosis may have taken a long time. It may have been a difficult experience, as a result relationships may have been strained within the family, at work, and/or with the local GP. Family relationships may have been strained by things like snoring, depression, or tiredness. Sexual relationships may have deteriorated.

"I have suffered from depression in the past, and I now believe this may have been related to the Cushing's."

"Psychologically I suffered quite badly before the diagnosis. Although I had always been sure that something was physically wrong with me, I had continually been treated for stress/mental/ depression-related disorders. The actual diagnosis of a 'Microprolactinoma' (whatever that was) was a great relief and confirmed what I had thought for years."

Because the symptoms are exceptionally varied, non-specific, and often gradual in their appearance, diagnosis of a pituitary condition may be significantly delayed. You may well have puzzled your GP for months or even years with apparently unconnected or inexplicable complaints, or you may have been diagnosed as having carpal tunnel syndrome or depression and treated accordingly with no great success. You may even have been patronised or labelled a hypochondriac.

Diagnosis

dealing with a protracted diagnosis



My problem started in 1997 when I had severe headaches which the doctor told me was very difficult to diagnose. Take a number of paracetamol or whatever. I took these. ...I got the 'flu. ...they thought I had some weird bug and put me in the City Hospital. It was only through the medical detection of a young registrar who had been dealing with somebody with a pituitary tumour who said 'I think I know what is wrong with this lady'...and everything moved from there. I have hypopituitarism and diabetes insipidus. The thing that has really been most difficult to balance was the psychological side of it...you...feel you should always be well and there shouldn't be anything really wrong with you but when you come to terms with that and that is explained out to you, that helps things."

Some individuals feel relieved when they finally find out what their various symptoms add up to. But this can be followed by various very mixed feelings. In some respects the process of adjusting to understanding the implications of the diagnosis can be very similar to the process of grieving or adjusting to a loss. For others it is about accepting that the gradual changes in lifestyle that they have been forced to make are permanent, and understanding how to deal with change can be helpful for some people.

Some things to bear in mind about change:

- It is constant in our lives. Most of the time we try to ignore it but sometimes it is forced on our notice (for example, TV schedules, supermarket reorganisations, road works).
- It is tempting to be judgemental about change saying that it is either "good" or "bad", but in reality change just is. Making judgements does not help in adjusting to the change.
- It is often not logical. It just happens and trying to make sense of it can make the situation more difficult to adjust to.
- Humans have a fondness for order and control but there are some aspects of our life that cannot be controlled. Wanting to control, everything will make adjusting to change difficult.
- Change is good for us. It helps us to deal well with stressful situations because we can adapt to it. Those who fear change experience more stress and anxiety, often to levels that limit their lives.
- Change is best handled with acceptance.

Diagnosis

dealing with a sudden diagnosis

Coping with change

“Trust your desires and trust your heart. You cannot care for anyone else effectively if you are not looking after yourself well. Your body, mind and spirit are going through a rebirth and there will inevitably be some labour pains. Be a good midwife to yourself. Be patient. You have plenty of time to learn.”

Christine Northrup, MD

Developing self-awareness

This is a good way to start the day. It aims to help you to really listen to what is happening with yourself and helps you to make peace with yourself on a daily basis. Find a place where you can be alone and quiet. First just listen to your breathing, then to your body, then to your thoughts, and finally to your emotions. The idea is not that you judge but that you become aware of what your body is trying to tell you.

Refocus your lens

Identify when you are “demanding” that the world be a particular way and learn to stop doing it. Identify when you are deliberately focusing on the negative aspects of a situation or event and try to actively focus on the positive aspects to get a more balanced view. Let go of rating your worth to others based on what you can do and refocus instead on being good enough for just being you.

Learn the art of introspection

Before going to bed, mentally review your day from start to finish. Look at the events and situations that you were in and note what you said and did. What went well? What did you do

well? What didn't go so well? What would you like to do differently next time?

Keep a journal

It will help you to learn to adjust to the change. It can help you chart your progress towards acceptance. It can help you to resolve the problems that you are having. It can help to identify the particular skills that you might need to learn to help you (and your family and friends) to navigate the change.

Dealing with a sudden diagnosis

On the other hand your diagnosis may have come with a sudden and dramatic onset of a pituitary or brain tumour, which resulted in an emergency surgery. For some this experience was both shocking and traumatic, which in some individuals can later present as Post Traumatic Stress Disorder, or severe anxiety. Equally this rapid onset of symptoms and immediate intervention may promote the belief that the problem has been resolved, even cured. However with time the effects of such interventions become apparent as new and unexplained symptoms emerge. This can lead to feelings of frustration, anger and grief at these unwanted changes, (Pituitary Foundation Needs Analysis 2006.) This can also be exacerbated by the fact that the symptoms are no longer managed by the neurosurgical professionals but by the GP and the endocrinology staff.

When you were finally diagnosed correctly, it was probably a relief to find a reason for your

Diagnosis

dealing with a sudden diagnosis

symptoms, but equally you may have felt too shocked and numb to take in what you were told initially. The shock would be heightened if you underwent surgery soon after diagnosis before you had time to come to terms with the situation.

“Diagnosis had a major impact on my life, it makes you address your quality of life and face your own mortality, my life now has little in common with prior to diagnosis.”

As the shock wears off, you begin the coping process; at first, you may deny anything is different, but the longer you avoid facing reality, the longer it will take to adjust.

Secondly, once you accept that your condition is likely to have long-term implications, you may feel many emotions such as anger, guilt, or sadness. These may be particularly intense because your hormonal balance which is altered by most pituitary conditions and medications affects your emotional state.

“...the feelings of failure, that I have fallen short in this life and let myself down are sometime overpowering, lack of drive, enthusiasm, energy, lack of confidence, poor self image and fear are constant...”

Thirdly, you may resolve your grief for the loss of your former state. Remember that grief is normal; it is abnormal not to grieve, even if it is for something you did not enjoy. It was familiar and its loss leaves something unfamiliar in its place, which needs getting used to.

A confiding, supportive relationship is important (for example, with a partner, friend, counsellor, GP or nurse). You should ‘let go’ when you are ready and want to. Also remember that you do not have to keep grieving – it’s all right to stop.

“I don’t know who I am, where I am, bad memory loss...from a support point of view, from an endocrine point of view, I know I am not the same person but I am told in theory that there should be nothing wrong with me, get on with it.”

One of the most helpful steps you can take is to talk with other pituitary patients, either in a formal group or informally for example, to a Pituitary Foundation telephone buddy or on the on-line forum. You will gain reassurance that you are not the only one in such a situation, and you will probably glean useful information as well.

“...its like being in an exclusive club one that you don’t really want to be in but you really don’t have a choice...its this feeling of being completely isolated and alone, and then you realise there are thousands of us across the UK that all have these conditions and there is a spark when you meet someone...”

“I was one of the initial members and actually getting involved and I thought ‘I’m not the only one with a problem’. I didn’t understand half of the other problems, I just knew my own, but it’s amazing how much you learn through the Pituitary Foundation and you know you can use it as you wish, you don’t need to attend every meeting. I think it’s the flexibility...its like everything else, the more you put in the more you get back.”

Dealing with grief and loss



*The following has been adapted from
"On Death and Dying" by E Kubler-Ross*

Coming to terms with grief and/or loss is a process outlined in the stages below but it does not always follow this pattern, people can move back and forward within it.

Stage 1 - denial and isolation *"This cannot be happening to me."* Denial functions as a buffer after the unexpected shocking news. The person may seek second opinions from others or try to continue life as if nothing has happened. With this feeling of denial comes a feeling of being set apart from the rest of the world and fearing the future. At this stage it is important not to try and break through the denial, as full realisation will come in time.

Stage 2 - anger *"Why is this happening to me?"* As the realisation dawns it brings the realisation

and awareness of loss. Anger may be expressed towards God, authority figures, people you have to do things for, or people who are unaffected. This anger is displaced: it actually belongs to the loss of future hopes being fulfilled. This second stage is difficult for family, friends and helpers. It is important for them to realise they are not responsible for this anger.

Stage 3 - bargaining *"If I am good, perhaps it will go away."* Bargaining is an attempt to fight against the event, to buy a reprieve. *"If Only..."* The bargain is often made with God. During this stage there may be associated guilty feelings of having brought about the disaster by having not taken care, not behaving well, not doing something. As with the initial denial family and friends need to listen to and accept these attempts to come to terms with the future.

Stage 4 - depression *"It is happening to me and I can't bear it."* Illusions that everything will be all right collapse and the person and their family and/or support are faced with the unbearable realisation of loss.

There are two kinds of depression at this stage:

Reactive Depression – Mourning what is already lost e.g. the ability to work, care for children, freedom to be independent, and loss of health. This type of depression can be alleviated by reassurances and exploration of how the change in circumstances will be dealt with.

Preparatory depression – Facing a dark future, sadness at facing the end of a life as it had been

Dealing with grief and loss

planned and the uncertainty of the future. The person will often be silent for long periods. This type of depression may show itself as retreat into sleep, drugs, and alcohol. This person may feel they are no use and that there is no hope, that life is futile. It is important for the person and their family and friends to stay with the feelings and be sensitive to the needs they indicate: either to talk or stay with the silences. This type of depression can make the individual, their family and helpers feel impotent and bewildered. No-one can take the depression away it is part of the process of loss.

Stage 5 - acceptance *“I can accept that this is happening to me; I am ready to face it.”* When people reach this stage they are not happy as much as detached from their feelings. Their circle of interests narrows and they may only see people who are close to them. Gradually they may return to a full life: It may be neither better nor worse, but it will be different.

Coping with grief and loss

For some people just understanding the different elements of the process helps. They can identify themselves and some of what they have been feeling starts to make sense. While the process is outlined as having five different stages in reality people move between the different stages, in no particular order. For some individuals it can take a few weeks to negotiate and come to terms with a drastic change in their life circumstances, for others it takes months or years. We are all individuals, there is no set timetable within which this process is expected to take place; it happens, and should be



allowed to happen, at the speed that is right for the individual.

One of the most important coping strategies is learning to be compassionate towards yourself. You have suffered a major shock that will take time to process and come to terms with. Talking negatively to yourself, telling yourself to “pull yourself together” does not help and puts you through more stress. If you can learn to talk to yourself the way your best friend would it will make a huge difference. You just need to be patient and accept that it might take you longer than you might like to come through the process. The time it takes is not important, what is important is allowing yourself the necessary time to deal with the feelings without feeling pressured.

Dealing with Post Traumatic Stress Disorder (PTSD)

Post traumatic stress disorder can occur in patients who have been very shocked by a diagnosis, or by the treatment relating to their diagnosis. Having brain surgery can be traumatic for some individuals and result in PTSD.

Symptoms

Not all of these symptoms need to be present for a diagnosis of PTSD to be made.

- Flashbacks of the traumatic event, which may feel like you are back there and re-experiencing the event.
- Intrusive memories, where thoughts about the event pop into mind during the day without being actively recalled by you.
- Dreams or nightmares about the traumatic events.
- Feeling distressed when you come across something similar and it may feel like your whole body is responding.
- Actively avoiding thoughts, feelings, conversations, activities, places or people that remind them of the trauma.
- Incomplete memories for all or part of the event.
- Feeling detached from other people and an inability to think of yourself living in the future.
- Hyper alert, looking out for anything that may be of danger. You may also have an exaggerated startled response if someone or something makes you jump.

Depression & PTSD

After a traumatic incident, individuals can often feel depressed, down and hopeless. They find they have little interest or pleasure in doing things. They may find it difficult to sleep because

of traumatic memories, or they may find that they sleep too much. They may feel tired and have little energy. They may eat too much or too little. People who are depressed often feel bad about themselves, feeling they are a failure and have let people down. Often they have trouble concentrating, and may find it difficult to read a book or watch TV. They may find that they are slowed down, or the opposite, restless and unable to keep still. Most of all, people who are depressed may feel suicidal and wish they were dead, often to get away from their memories. If you do feel suicidal, please call Samaritans on 116 123.

Anxiety & PTSD

After traumatic events, the brain goes into hyper alert to look out for danger in order to protect you. This becomes generalized into everyday life and soon even everyday things may seem scary. Some people experience extreme anxiety in the form of panic attacks. In the severest form, some people become so anxious that they can no longer leave their home. This is called agoraphobia, or fear of fear.

Anger & PTSD

Irritability and anger can be symptoms of post traumatic stress. People may find they are more irritable mainly because they find they cannot cope with stimuli such as noise, too many people, or too much to do. This is because the brain is so hyper aroused by the traumatic memories that it feels like it cannot cope with anything more. It feels overwhelmed. Intense anger is a way of keeping away from the traumatic memories. Being angry prevents a person from feeling the intense anxiety

Dealing with Post Traumatic Stress Disorder (PTSD)



and helplessness of the situation. While this works for the person in a limited fashion, (it prevents the person from confronting the feared situation) it also prevents the fear reducing in a safe environment, thus delaying the person's recovery.

Coping with PTSD

PTSD is best worked through with a professional rather than trying to attempt a self-help route. Here are some ideas:

- Some people find that counselling helps them. For others talking through the traumatic event just makes them more traumatised than they already are.
- Cognitive-behavioural therapy (CBT) can work very well for PTSD. It works on adjusting the thinking patterns that are helping to maintain the depression, hyper-arousal and anger and helps people move on.
- Emotion skills training can also help individuals with PTSD, this approach teaches individuals how to stay with the emotions associated with the event, rather than avoiding them, thus helping the body to process the memories and the emotions and reducing the impact of them. There are several different types of emotion skills training: EMDR (Eye movement desensitization and re-processing); EFT (Emotional Freedom Technique); the Sedona Method.
- Some individuals find that mindfulness works well for them. Mindfulness is a meditation technique where you learn to live completely in the present moment by training the mind to be able to notice, but not get involved in, thoughts and memories as they pass through the mind.

Problems associated with treatment

Surgical treatment for pituitary conditions may be perceived as threatening and often produces a slower than hoped for improvement in the condition. Patients will be concerned that some of the tumour remains in situ and may regrow. With successful treatment, life expectancy can return to normal and in most cases the tumour will not regrow (although recurrence rate of craniopharyngiomas are higher than pituitary adenomas). A full recovery undoubtedly takes time, and building up unrealistic expectations before treatment hinders rather than helps recovery.

Many aspects of treatment may cause distress; here are some examples:

The thought of having treatment so close to the brain and optic nerves, both surgery and radiotherapy.

“It’s an invasion inside your head.”

“I have experienced and now suffer with dizziness, tinnitus and hearing problems since the radiotherapy treatment. I feel angry that it has done this. I could not cope with treatment, and cannot accept what it has done to me.”

The claustrophobia experienced with MRI scans or with the radiotherapy mask.

“Brain scans [MRI] are absolutely frightening; the experience of going through ‘that tunnel’ leaves me cold.”

When the patient has needle phobia.

“I have and do suffer from psychological problems, needle phobia being most inconvenient because of the nature of the tests. Also I am GH deficient and inject daily - it took me and the specialist nurse almost a year before I was able to get round to injecting myself.”

“On the plus side, my needle phobia is cured, (I used to faint with injections) I now inject myself daily!”

When expectations of treatment are not met or there is difficulty in self-managing the medical regime.

Some suggested strategies for dealing with these issues are outlined on the following pages

Dealing with radiotherapy/MRI scans

Dealing with the claustrophobia associated with radiotherapy and MRI is a case of trial and error of a variety of techniques to find the one that works for you. Below are some suggestions:

Guided imagery/daydreaming

You can take yourself on an imagined journey; enjoy looking around and being in a relaxing place which has particular significance or pleasant calming memories for you. Similarly you can go and do something that you enjoy such as chatting to friends or walking the dog.

Problems associated with treatment

It doesn't matter what it is you imagine as long as it makes you feel good. It takes practice but if you find your mind wandering just bring it back to where you would rather be and it will eventually stay there.

Deep breathing

Most of us take short, shallow breaths, which simply make us feel anxious. Make sure that your arms and legs are uncrossed and that your feet are flat on the floor. If possible breathe in through your nose (if this is not possible for you then breathe in through your mouth) feeling the breath go right down into your stomach, then breathe out through your mouth. Try to avoid forcing the breath out when breathing out. Breathe in for a count of four, breathe out for a count of six (or however long feels comfortable for you). Do this five times. Novice deep breathers should never go above five breaths during the day. You can practice in bed at night where you can increase the number of breaths. Practising in bed creates a kind of anchoring effect where your body remembers doing the exercise and feeling relaxed. What that means is that when you do it during the radiography or MRI scan you only need to do one or two breaths for it to work.

Counting

Counting can really work for some people; numbers can be very soothing and can take your attention away from what your body is experiencing. Count slowly from 1 to 10 in your head, keeping your attention on each number. If you feel your mind wandering (and it will often before you get to three), go back to one and start again. You can also do this technique counting

backwards from 10 to 0. When you get to 0 you imagine yourself somewhere you would like to be where you would be very happy. To come back you count from 0 back up to 10.

Use the sound around you

Instead of trying to shut out external sounds, allow your mind to notice them – whether it's the sound of birdsong, the screech of car brakes, the hum of a machine, the sound of feet on the ground, it really doesn't matter. Don't make judgements about the sounds, and don't become involved in them. Simply notice them. If your attention wavers gently bring it back.

Dealing with needle phobia

A fear of needles is understandable: they hurt and we make strong emotional associations to such things. You can learn to reprogramme your brain to overcome the fear of needles so that you can learn to do your own injections. You need to break the process down into small manageable steps and you have to work through it at your own pace. There is no timetable for how long this will take. If you explain the problem to your health care professionals they should be patient with you and help you with the process. The following steps may help:

1. Touching a wrapped needle for a couple of seconds. (You can then do your usual coping strategy for dealing with the injection – *"I usually look away and concentrate very hard on the floor or on a poster on the wall."*)
2. Touching a wrapped needle and looking at it for a couple of seconds. You need to build

Problems associated with treatment

this up to the point where you can hand the needle to the nurse and watch her unwrap and prepare the medication for injection

3. Next stage is for you to prepare the needle to do the injection but then hand over to the nurse for the final step (injecting you)
4. Ask the nurse to explain how injections have to be done: what is important to get right, etc
5. Take over doing the aftercare of the injection: you prepare the cotton wool/plasters etc and take over as soon as the nurse has completed the injection
6. Reverse roles with the nurse so that you only have to concentrate on doing the injection
7. Do the whole thing yourself from beginning to end
8. The use of technology such as mobiles and watches can have alarms set to remind us when next medication is due.

Remember:

You don't have to go through all the steps above, it's just an idea of how such a process might work. Injecting yourself is only a problem if you believe that it's going to be. You can choose to believe that it will be fine and your brain will do its best to help make it fine for you. You can get ideas from other patients and from the endocrine nurse on how to overcome this problem.

Dealing with worries about taking your drugs correctly

Worrying about it doesn't really address the issue. What you need to do is decide what it is that is bothering you most: Are you going to forget when to take a pill? Are you going

to accidentally take a medication that might affect your pituitary medication? Having decided what the issue is that is bothering you most you next need to ask yourself what it is that you need to do to help you best cope with it. Some of the ideas below might help you:

1. If you are concerned about when to take your medication, drawing up a timetable and sticking it by the bed, on the kitchen wall, wherever it needs to be so that you can clearly see it and understand what you need to take and when can really work for some people.
2. Similarly, you can buy pill pots from the chemist where you have different slots for the different pills you need to take each day. You can set it up at the beginning of each day so that it has the right pills in for you to take each time. There are pill pots small enough for key rings, to enable carrying these with you if out and about.
3. Saying "*I must remember to...*" stresses your mind and body. The best phrase to use is "*How can I remember to...?*" Your mind will not be stressed by the question "*How can I remember...?*" but it will be stressed by your use of the word "must". "Must" is a demanding word which stresses your mind and body because it implies that there will be life-threatening consequences if the demand you are making of yourself, or another, is not met. Dealing with the resultant stress reaction quite often means that you forget whatever it was you wanted to do - distinctly unhelpful.

Problems associated with treatment

Dealing with health care professionals (HCPs)

Depending on your diagnosis experience you will have met (or may meet) a variety of Health Care professionals, including those with and without specialist knowledge regarding the many pituitary conditions.

Individuals are called Health Care professionals if they participate in delivery of health care in some way. Thus, it is a rather broad term including for example, GPs, dentists, nurses, and social workers among many others. A lengthy diagnosis may have introduced you to your GP and/or optician and eventually a consultant endocrinologist. However with a sudden onset, initially you may have been seen by a cancer specialist and/or a neurosurgeon, and then been referred on to see the endocrinologist.

As the name suggests a GP has received a general training in medicine and will have had little or no experience of pituitary conditions, whereas an endocrinologist has undertaken extensive training in the diagnosis and management of pituitary conditions. Equally a neurologist and neurosurgeon have expertise in the anatomy and physiology of the brain and the nervous system, including the effects of brain tumours. However some will have limited understanding of the consequences of these tumours on the hormonal balance within the body and their subsequent management. Where there are teams of professionals managing a patient from diagnosis and initial treatment for a pituitary tumour the care is seamless and positively rated by patients. However where there has been a lengthy diagnosis period involving

several and distinct professionals, the experience can be difficult and achieving a sense of control and mastery over the management of your condition is frustrating and time consuming.

When consulting these professionals you may feel disempowered by the situation or their approach and become unable to get the information you require to make sense of your condition. A situation confounded by short appointment times with a team of staff requiring a multitude of tests to diagnose and/or monitor your condition. This can lead to frustration on your part, you may become angry and distressed at the lack of open communication with these professionals, and because of the symptoms of your condition you may not always remember what information you have been given. The following section may therefore help you to manage your time with the health professionals more effectively.

Ideas to help manage your interactions with your health care team

It helps to be assertive when dealing with health care professionals (HCPs). Assertiveness is the art of being able to communicate how you are feeling and what you need without being disrespectful of the other persons' feelings and needs.

- It helps to be clear about what it is that you want to get out of a consultation. Making a list of questions to take with you is very helpful and means you won't forget what you wanted to ask. If you don't understand the answers you are receiving, be honest and say so. Humans have at least four different ways

Problems associated with treatment

of learning and the one you favour may well not be the same as the one the HCP favours. This mismatch of learning preferences is one of the major reasons for frustrating discussions between HCPs and their patients.

- It can help to keep a diary of your treatment so that you have a document which you can give to the HCP so that they can better understand what you are talking about.
- If you find it difficult to be assertive yourself then get someone to act as an advocate for you. An advocate is someone who spends some time with you finding out what it is exactly that you want from a consultation. They then lead the conversation with the HCP with references back to you (the patient) to check that they are still on track.
- One of the common complaints about HCPs is that they are quite often dismissive and use a lot of jargon when explaining things to patients. HCPs are human too; they find dealing with some aspects of patient care difficult. Faced with a patient who has a list of questions they can start to feel uncomfortable - as though their knowledge or competence to practice is somehow being called into question. When HCPs get stressed they will quite often revert to being rude, dismissive and using jargon. If you can bear with them, they will revert to being human again.
- If you have a lot of questions to ask your HCP then it is helpful to check whether they have

the time to answer them. You could try and list your questions in order of importance to you, as HCPs only have a limited amount of time to talk to patients. It can be worth checking with the Pituitary Foundation as to which HCPs can best answer your questions so you don't waste time asking the incorrect HCPs about issues that are bothering you. Failing that, if possible, ask for a double appointment so that you will have the necessary time to ask the questions that you need answered.

However, do consider a personal anecdote from a local GP about medical knowledge:

“Medical students are taught that 50% of the knowledge they use to treat the human body is wrong at any one time. The trouble is no-one knows which 50% is going to be proved wrong by ongoing research!”
No wonder they get a little defensive when asked lots of questions by patients.

Note: There is a lot to be gained from having a good relationship with your HCPs, and as your condition is ongoing you will be seeing a fair bit of them. If you are unhappy, you may have to reconsider this relationship, perhaps by changing doctors.

Problems associated with treatment

Dealing with other patients

During radiotherapy, relationships build up with other patients waiting for treatment. They mainly have cancer and they may think you have a brain tumour.

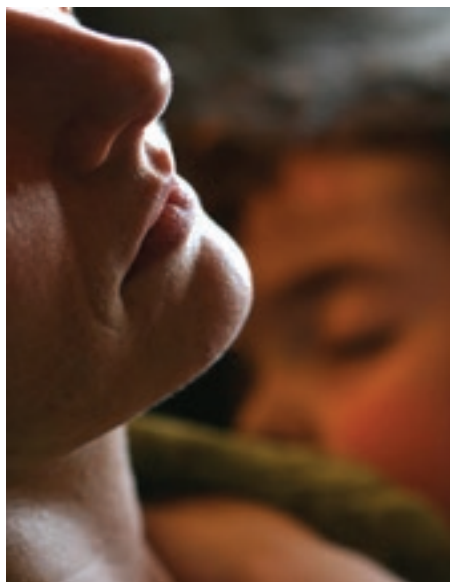
- "I tried to explain it was a benign tumour, but some people thought I was in denial."

This can cause anxiety and distress for you so the following may help you to deal with such situations and how you might deal with family, friends and colleagues:

Insisting that others understand your condition in the way that you understand it yourself is a fruitless task. It is a form of demandingness. You are demanding that the world run itself according to a rule that you have made up - in this case the rule states that everyone you talk to about your condition should come to the same conclusion as the one you hold yourself. In fact, why should they? There is no universal law that says that they should.

Sometimes it's better to accept that other people have different opinions to you (even if they are wrong) and it doesn't really matter. Demanding things of the world is a major cause of stress which just makes difficult situations more difficult. If the individual isn't involved in your care, or in your day-to-day life, ask yourself "Does it really matter what that person thinks? Does it really matter if they don't know about benign brain tumours?" Before you heard of a pituitary condition, did you know about benign brain tumours? Someone who has a malignant brain tumour may not want to know about benign tumours. They are having a tough time

(as you are) and need their coping strategies. Talking about strategies to stay calm during the scans would be more beneficial than trying to make others understand the nature of your condition.



Emotional/psychological aspects of pituitary conditions

People have spoken about the emotional impact of their pituitary condition from (pre) diagnosis through initial treatment and on to ongoing management. Many people talk of experiencing a sense of loss (see earlier) which can lead to changes in mood, sexual problems, fatigue and poor sleep. These changes can impact further on their quality of life and how

Other life events

they adapt to an altered body image, which can be both visible and invisible (Pituitary Foundation: Needs Analysis 2006.) However, the emotional changes many patients experience can be the result of the condition and how it is managed. It is important that you seek and persist with further investigation if you feel that you are coping well with the impact of the condition BUT continue to feel your emotions are erratic, your libido is low and your quality of sleep remains poor.

Fear and loss are the most notable psychological aspects of pituitary conditions, and can occur at any time. One cause of fear is the anticipation of loss.

Both fear and loss are associated with eyesight problems, surgery and radiotherapy, changes to body image, disability or loss of independence, and losing a job or relationship. Furthermore, although most pituitary tumours are benign, the word 'tumour' has frightening connotations.

On the premise that *"uncertainty is worse than reality"*, we recommend you obtain as much information as you need to reduce this uncertainty. You can do this by contacting The Pituitary Foundation, speaking with your Endocrinologist, or an endocrine nurse at an endocrine clinic. Prepare questions in advance to get the best information. If you go to a clinic, take a notebook and write down answers to refer to later or to inform your family and friends.

The Pituitary Foundation have a booklet called *Your Journey-living with and managing a pituitary condition*, which provides a deeper exploration of the long-term psychosocial impact of a pituitary condition (January 2008).

This looks at mood disorders; fear and loss as a

long term process; altered body image; intimacy and sex; and impact on others. It also includes some strategies to help you manage/deal with these concerns. Equally the section on dealing with Grief and Loss in this booklet is useful to read when there is a renewed sense of loss or feelings of grief.

Other life events which impact on management of the condition

Stressful life events have the habit of interfering with the management of most long term conditions (*diabetes mellitus, coronary heart disease etc*) and pituitary conditions are no exception. When we are stressed we feel anxious and perhaps frightened, when the event we are experiencing activates the hypothalamus and the sympathetic nervous system. The body then releases:

adrenalin - when the event is exciting and enjoyable (*laughing, on a roller coaster*); and

noradrenalin - when the event is seen as threatening and you want to run away (*fight or flight response*)

These two hormones increase our heart rate, make us breathe faster and raise our blood glucose and cholesterol levels. This mobilises energy sources around the body so we are able to stand and fight (in war) or run away fast (being chased by a lion). However if the stress continues and is more sustained (e.g. work stress,

Stress management techniques

hassles from neighbours, caring for someone full time), the body then releases cortisol from the adrenal cortex. This hormone is responsible for supporting the metabolic changes needed to support the body under stress. There is a problem however for pituitary patients, especially those who have Cushing's syndrome or who are hydrocortisone dependent. Stress can destabilise your condition and impact on your management regime. Equally your condition and your management of it can create stress and therefore exacerbate your symptoms.

The long term effects of raised cortisol/stress can affect the progression of other diseases: diabetes, coronary heart disease, and hypertension. It can also increase our risk to infection by reducing the effectiveness of the immune system. Equally threat from an infection or disease process can affect the immune system which systematically triggers our stress response to try and help manage the situation.

It is therefore important to try and monitor and manage your stress as effectively as possible to reduce its consequences and maintain stability over your pituitary condition.

Stress management techniques

Most of the techniques mentioned already in this booklet as ways of dealing with particular problems related to pituitary conditions, can also be very successfully used as stress management techniques. The techniques outlined on the following pages may also help you to manage the stress you encounter in your day to day life. You don't need to do all of them.

The best way to choose is to use the ones that you think you will enjoy.

Hand massage



Hold one hand with the palm facing upwards. You need to imagine that you have lines radiating from the base of your palm to the tip of each finger. The aim of the massage is to use your thumb to massage along the lines. So, place the thumb of your other hand at the base of your hand (nearest to your wrist) under your little finger. Massage upwards, in a line, towards your little finger, continuing up it to the tip. Finish by pressing the top of your little finger, then repeat on all your fingers and thumbs on both hands. You need to concentrate on nothing but the massage.

Take care of your feet

It might seem strange but looking after your feet can reduce the stress you experience. Wearing well fitting shoes can reduce foot pain and back problems. Taking time to massage your feet with cream morning and evening will

Stress management techniques



reduce the build-up of hard skin on your feet and is good for your wellbeing.

Learn something

Learning boosts confidence, which improves your wellbeing, which helps you to manage stress better. The more you know about a variety of different things the easier it is to handle change. It doesn't matter what it is you learn. It can be something that someone tells you that you didn't know before, it can be a practical skill, or even reading a new book. You can learn from the television or from other people in a more formal learning environment.

Being a researcher

As adults it can feel as though there is pressure on us to know how to handle all the situations we find ourselves in. A lot of stress is caused by not knowing what to do in particular situations. We can become overly concerned about what others might think of us and it can get in the way of us enjoying ourselves. You can reduce a significant amount of stress by allowing yourself to learn about the situations. A simple technique to try is to imagine you are a researcher who has to collect information for others. Focussing your attention on other people and what is happening in your surroundings will help you project confidence and will prevent you from thinking about yourself too much.

Laughter: the best medicine

Laughter is one of the most powerful things you can use in your stress management. Whenever you laugh your body starts to break down the chemicals your body produces when you are stressed. It also boosts your immune system so it is harder for you to catch the local bugs. Laughter also increases the happy chemicals in your brain making it harder for you to become depressed. You need to make time to do things that make you laugh on your own or with friends. Sometimes it is necessary to think about what things are stopping you from laughing - would it be better to watch a funny video than to listen to the news every day?

Stay hydrated

- Being dehydrated can lead to problems concentrating, increased irritability, and

Stress management techniques



general confusion.

- Staying properly hydrated means that toxins can be efficiently flushed out by your body. It will also improve the efficiency of any medication you might be taking.
- When you are mildly dehydrated (you don't have a dry mouth and sore throat, for example) you might mistake the feeling of being thirsty for being hungry. Have a drink instead of eating something. If you are really hungry you'll be hungry again 15 minutes after your drink.
- Everyone needs to drink different amounts of liquid each day. The simple way to tell if you're drinking enough is to do the "pan check". If your urine is pale yellow you're fine. Any darker and you need to drink something. Two litres of water per day is too much for some people!

- You don't have to drink water you can drink other things instead, just watch the sugar and caffeine levels. Remember: you will also get some liquid from the food you eat each day.

Energy bubble

Imagine that you have a bubble of energy projecting out from your central point and surrounding you like a sort of science fiction force field. Everything stressful that happens outside this bubble just bounces off and away from you, leaving you calm and still inside the bubble.

Anchoring

Your nose does this: smells can evoke memories and feelings. Anchoring is a physical technique with the same aim, the point being that you can recall the memories and feelings without carrying round bottles of perfume. For example: you might decide to use classical music to make yourself feel very calm and relaxed. You would put the CD on and listen until you achieve the intensity of feeling you are after. At this point set your "recall button" e.g. tug your earlobe. The next time you are feeling stressed and want to relax use your recall button, i.e. tug your earlobe, and you will be transported back to feeling calm and relaxed listening to the music. You can use different "recall buttons" to anchor feelings of having lots of energy, or being very happy etc.

Thought stopping

This is a technique where we mentally say "stop" when troublesome thoughts start when we are trying to fall asleep. You can either say this to yourself, or imagine a large sign with "STOP"

Stress management techniques

written on it. The important point is to break the chain of worrying thoughts. Sometimes it helps to find something physical to do that you can concentrate on to make the break in your thoughts last longer.

Colour

Looking at colour stimulates the brain, and warm colours such as a pink, red and orange increase your heart rate and circulation leaving you feeling happier and more energised. Colour therapists use these colours to help patients suffering from depression and mood swings. Cool colours e.g. blues, greens, lilac etc. have a calming effect. If you're not sure which colours work for you, you could visit the paint department in a decorating shop and stand in front of the paint charts.

As you look at the colours you'll find that some you like because they make you feel happier and more energetic, some make you feel calm and relaxed and some you really don't like. See how much of the helpful colours you can have with you. You don't need to paint whole rooms. Just putting a postcard in the front of your diary for you to look at regularly can work wonders.

Smiling

The physical act of smiling causes the "feel-good" chemicals, endorphins, to be released, giving you an instant lift. It doesn't make any difference whether you feel like smiling or not, even if it's a struggle to smile the result will be the same.

Be your own best friend

Many of us have an internal voice that's highly

critical. "You didn't get that job done today," it will say. "You really messed that up." When you talk to yourself in this way, you'll feel a failure, when it should be a positive self-image that you create. Begin noticing when you do well and what you achieve. Praise your own efforts and talk to yourself as though you like and appreciate yourself. Reinforce your positive self-image by looking after yourself and talking to yourself, as you would a valued close friend.

Rituals

The aim of this is to start and end the day in a positive way. The best rituals are simple and soothing. You can create a simple ritual for the time you spend on grooming at the beginning and end of the day. The aim is to create pleasure by using products that smell nice and that help you to be invigorated at the beginning of the day, and relax at the end of the day. You might already have rituals (e.g. the way you make your tea) which you appreciate so you don't need to make up any more, just acknowledge the ones you already do.

For more ideas on stress management the best strategy is to go into a book shop and look at some books. There's nothing much to choose between them, it's down to which one you like the look of.

Resources

British Association for Counselling and Psychotherapy:

Can provide lists of qualified counsellors and psychotherapists in your area.
(01455) 883300; www.bacp.co.uk

Changing Faces: A support group for people whose appearance has changed.

(0300) 012 0275;
www.changingfaces.co.uk;
info@changingfaces.co.uk

Kubler-Ross, E (1990): On death and dying.

Needs Analysis (2006)

www.pituitary.org.uk
London:Routledge

Off the Record Charity: Counselling support for young people

www.offtherecord.org.uk/contact.htm

Relate: Provide relationship counselling, your local branch

will be listed in your phone book.
0300 0030396;
www.relate.org.uk

Royal College of Psychiatrists' Mental Health Information:

Factsheets and leaflets on all mental health issues;
www.rcpsych.ac.uk/info/index.htm

Young Minds Trust (Children's and young People's Mental Health):

(020) 7089 5050;
(0808) 802 5544 (Parent's helpline)
www.youngminds.org.uk

Please support The Pituitary Foundation

Join the The Pituitary Foundation today and enjoy the benefits of membership!

- ✓ Receive our members' magazine, *Pituitary Life*, three times a year full of the latest information, updates and patient stories, to help you better understand, or manage your pituitary condition.
- ✓ Our monthly e-bulletin, which includes the latest pituitary news, information and ways to get involved.
- ✓ Become an important part of the only charity in the UK providing support to pituitary patients.
- ✓ Receive a welcome pack and a membership card and enjoy discounts to Pituitary Foundation events, such as our conferences.
- ✓ Give us a stronger voice to raise awareness, and understanding, of pituitary disorders.

Individual membership costs **£25.00** for a full year, which is only **£2.08** a month!
(Family, concessionary and life membership rates are also available). To become a member, please complete the form below and return to us with your payment (cheques made payable to *The Pituitary Foundation*) to:

The Pituitary Foundation,
86 Colston Street,
Bristol, BS1 5BB

If you would like to pay for your membership by standing order,
please contact **0117 370 1333** or to join online visit **www.pituitary.org.uk**

| | | | |
|---|--|----------------|--|
| I wish to become a Member of THE PITUITARY FOUNDATION | | | |
| Title: | | First Name: | Surname: |
| Home Address: | | | |
| Postcode: | | | |
| Telephone No: | | Email: | |
| Please tick (✓) the type of Membership you require: | | | |
| Individual | <input type="checkbox"/> £25.00 (annual) | Joint | <input type="checkbox"/> £35.00 (annual) |
| Life Membership | <input type="checkbox"/> £350.00 | Concessionary* | <input type="checkbox"/> £15.00 (annual) |
| Additional donation (optional) £ | | | |
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| <input type="checkbox"/> Yes! I want to Gift Aid any donations I have made in the past, present and future to The Pituitary Foundation. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. Please notify The Foundation if you want to cancel this declaration, change your name or full address, or no longer pay sufficient tax on your Income or Capital Gains. | | | |
| Signature: | | | Date: |

Helpline

Monday - Friday 10:00am-4:00pm
0117 370 1320

Endocrine Nurse Helpline

available scheduled hours
0117 370 1317

Website: www.pituitary.org.uk

Email: helpline@pituitary.org.uk

More Information

The Pituitary Foundation publishes a library of booklets on pituitary conditions, treatments and well-being issues. For more information please visit our website, or call our Helpline.

The Pituitary Foundation

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Working to support pituitary patients, their carers & families