

# Your Journey

## Living with and managing 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 the long-term impact of a pituitary condition and its management (both medical and psychological) 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 partner, GP and endocrinologist.

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# Introduction

**Listen to people who have a pituitary condition or any other long-term condition and it becomes clear that your experiences can be likened to being on a journey. A journey, which may start at diagnosis, (for some pre-diagnosis), but will continue throughout the rest of your life with the condition. This journey can be thought of in terms of a trip through the unexpected, unwelcome and sometimes unrecognised terrain of physical and psychological changes. Following initial diagnosis, your path can be sidetracked through unexpected complications and changes, which often delay your attempts to accept and adapt to your medical condition.**

This booklet will consider the journey beyond diagnosis. It has two aims; firstly, to consider the long-term impact of a pituitary condition and its management (both medical and psychological); and secondly, to provide a deeper exploration of the psychosocial impact. This booklet also introduces you to Cognitive Behavioural Therapy (CBT) as well as including practical suggestions for coping with the various aspects of your ongoing journey of adjusting to life with your pituitary condition.

Medical treatment has tended to focus on a recovery journey, but the patient's return to normality remains unsupported. It is commonly assumed that once hormone levels return to within normal parameters patients should experience no further problems, psychological or otherwise. During treatment there can be a transition of care between the neurosurgeon and endocrinologist where communication may be delayed, which can add



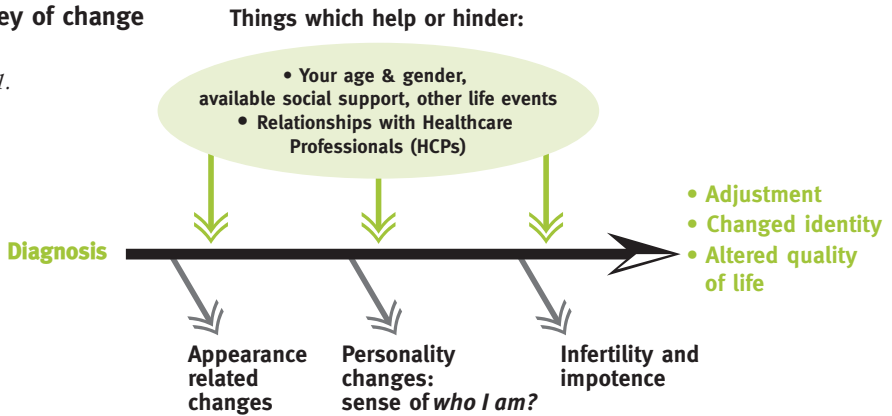
to people's emotional unrest. Aspects of patient care (basic tests and prescribing) will be managed by the GP, however some of you have commented that often GPs do not have the expertise you would like and at times this can increase your frustration as you struggle to make sense of your condition and its impact. This situation is not helped by the fact that pituitary conditions come in a variety of forms some of which are considered rare. No two patients are alike, and are unlikely to respond to treatments in the same way; even having the same condition as someone else does not necessarily mean that you will feel the same either physically or psychologically. This makes management more problematic and ongoing support for patients by healthcare professionals (HCPs) somewhat more challenging. So you shouldn't expect that your experience will be the same as other people's with a pituitary condition, your experience may be quite unique.

# Fear and loss as a long-term process

## The (your) pituitary journey

### Journey of change

figure 1.



We started by talking about your experience of a pituitary condition as a journey. Figure 1 illustrates this journey, starting with diagnosis, which some of you might have experienced as an emergency with immediate treatment (surgery) which can cause great anxiety, intense grief and shock; whereas others of you may have experienced a delayed diagnosis associated with a sense of not being believed, let alone understood. This may have created tension for you with friends, family and colleagues, as well as the healthcare professionals you were brought into contact with; and with the tension may have come a reduced quality-of-life. Progress from diagnosis towards an acceptance of, or adjustment to, the condition can be affected by the physical, social and psychological consequences of the condition and its long-term management which can be experienced as fear and loss.

*"In terms of how I perceive myself I'm not the same and there is some kind of, it's almost like a sense of loss for the life I had before because I was very active and did lots of things, and now my job's in*

*jeopardy, I had to leave my flat. All those things I've given up... I had this life and then it was taken away from me and that makes me sad."*

### A changed me...

Many of you have talked to us about the changes in your appearance as an outward expression of your pituitary journey, as an example of what had been lost or changed as a result of the condition. However, some changes were not visible and as such were ignored. These changes, while difficult to deal with for the individual, leave you looking "normal" and so other people do not understand the impact they have, nor is their significance to you acknowledged. This is especially true of people who might only be meeting you for the first time and know nothing of your condition.

*"Everybody, family and friends, you could see they thought I was going round the bend because they were saying, "You are still here, be thankful for that." And I was, "Excuse me, do you want to look like this?" and they couldn't see it. I could, well they could. They knew it was a vast difference to me"*

Visible differences in appearance included facial and skeletal alterations, obesity and in particular body shapes with some changes being quite dramatic,

*“I looked awful, was 7 stone when I went in 12 when I came out “*

*“I kept thinking of Sinead O’Connor, thinking that will be fine. But it’s not of course. When you’re 8 stone it’s fine, but when you’re 12 (stone), bloated with drugs and with a massive scar it’s not, it’s awful.”*

*“It was all my femininity was robbed in one fell swoop”*

You talked about the possible problems associated with buying clothes and shoes; a situation which can be affected by how others might perceive and interpret your actions:

*“I put on 5 stone, in 2 years, very expensive for clothing. Very embarrassing.”*

These physical changes can result in negative public comments, reinforcing any negativity you might have about the person you have become:

*“Obviously the public perception is that I’m off eating MacDonalds every 5 minutes. That the reason I’m fat is because I eat too much.”*

Changes to levels of self-confidence are often related to appearance and internal bodily changes; this for many of you has produced feelings of low self-esteem and self-worth. With such low confidence trying to accept the changes imposed by the pituitary condition can lead to frustration and mood swings. However the impact of surgery and ongoing treatment can also contribute to a positive mood change, often described by yourselves and others as a personality change:

*“I was producing massive amounts of growth hormones. It made me quite a super woman. I*

*was doing loads and loads of stuff”*

*“My whole character has changed. My whole personality that I am, I think for the better. It’s made me more tolerant and a lot more understanding of other people’s problems. It’s made me a completely different person.”*

How you try and understand who you are shifts during the course of your illness experience. These changes are often difficult to accept:

*“Feelings of being worthless because one is not working and only able to contribute reduced activity in the home/family environment”*

*“I’m always tired, in pain and emotional. I feel a failure that I can’t work and earn income. I hate being overweight...low self esteem...and the future is scary”*

Another aspect of change is being part of a group, “People with a Pituitary Condition” and this for many of you is a group of people that you do not wish to belong to. Some of you told us that you felt a sense of imposed change, a restriction on your life choices that even included the amount of control you feel you have in your lives. However, acceptance of being a part of this new group does provide a much needed source of emotional and information support.

*“It’s like being in an exclusive club, one that you don’t really want to be in but you really don’t have a choice it’s 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”*

*“You put yourself in a rather large bubble and it’s with likeminded people and I think to help each other you take yourself out of normal social life because of your condition.”*

# A beginner's guide to Cognitive Behavioural Therapy (CBT)

*Cognitive Behavioural Therapy (CBT) is a model which can help us understand how the way we feel depends upon our thoughts and beliefs (cognitions) and is influenced by what we do (behaviours). We often think the way we feel is a result of something which has happened to us, for example: someone criticises me and I feel upset. We would then assume that the same event would cause the same feeling in everyone.*

However not everyone who is criticised may feel upset, we can experience different reactions to the same event. So CBT explains the crucial difference is how we interpret the event: it is what the event means to us. All events are filtered by our thoughts and beliefs about them, this is illustrated in the following example: Suppose you were out shopping and someone you know ignores you as they pass by. What would you feel in this situation? There might be several possibilities dependent on your way of thinking:

The behavioural part of CBT suggests that what you do or don't do will affect your thoughts and feelings. So, if we continue with the example above, if you felt anxious you might walk across the road to avoid the person who didn't see you while out shopping, but this behaviour might prompt you to think the person really doesn't like you, which could increase your anxiety and cause you to begin to feel depressed. Alternatively, you might decide on a different course of action; you might walk over and ask them why they seem to be ignoring you. As a result you might find out exactly what was going on and discover that the hangover example (in the table above) is the correct explanation. A hangover has nothing to do with you, so your feelings could change and you could feel more positive. So changing what you do in a situation can have a big impact on how you think and feel. See Figure 2 at right for an example related to managing one aspect of your pituitary condition.

## Thoughts

## Resulting feeling

*"Oh dear, I wonder what I've done wrong, no-one ever seems to want to talk to me, I always lose friends like this"*



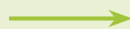
***Depression  
or Sadness***

*"Oh no, what if she sees me and I can't think of anything to say – I'll look an idiot"*



***Worry  
Anxiety***

*"Why is she being so rude and stand-offish?"*



***Irritation***

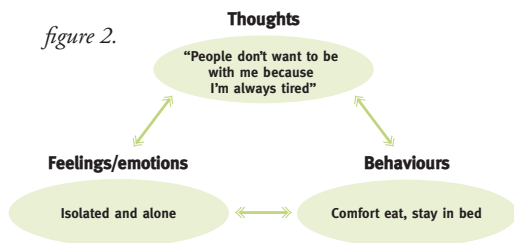
*"She must still be hung over from that party last night"*



***Amusement***

## Thoughts, feelings & behaviour

figure 2.



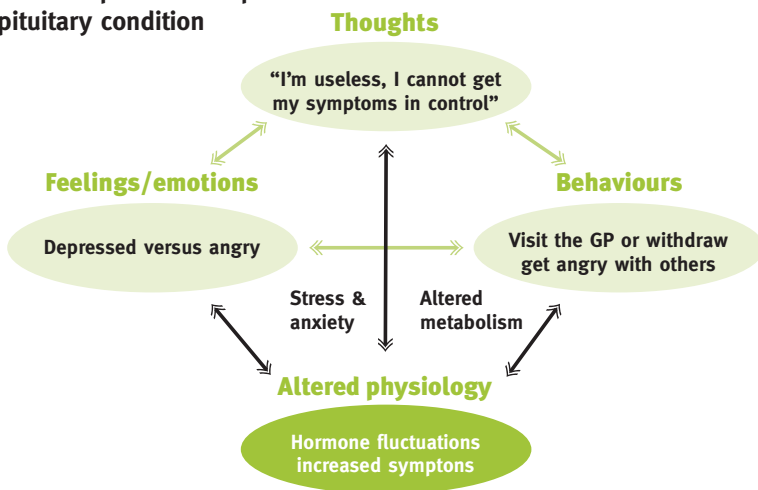
Another aspect to this model is the impact it can have on physiological functioning (i.e. on how your body responds to things) as shown in Figure 3 where how we feel, plus the negative reinforcing thoughts and unhelpful behaviours can increase the risk of a physical stress response. This stress response can take one of two forms:

1. **acute/sudden:** where you have increased heart rate and blood pressure, and rapid breathing, and;
2. **chronic/long-term:** where you have increased levels of cortisol, altered metabolism, and poor sleep patterns.

For the person with pituitary disease this could make management of the condition all the more difficult, especially if you are unable to produce your own cortisol. You might start to think “*I’m useless, I’m not coping*”, you may feel depressed and worried. You may visit your GP or The Foundation website to get some more information or support; or you might feel angry or frustrated and withdraw from the people around you; or if you cannot get away from them you may find yourself expressing your anger and frustration at those around you.

## The possible impact for the person with a pituitary condition

figure 3.



The following sections will take each of these components and introduce skills to help you reduce their impact on you and your condition management.

# Coping with a pituitary condition

Research exploring chronic illnesses states that there needs to be a period of adjustment for the person concerned if they are to attempt to reduce the emotional impact of the condition. To do this you have to learn to cope with a variety of things which are part of the package in managing your pituitary condition as well as maintaining a sense of control over all other aspects of your lives.

Effective coping strategies and skills will help to reduce the emotional impact and help you to come to terms with your condition. Ineffective coping or a limited choice of strategies can delay acceptance and adjustment on your journey of change.

## What do people with a pituitary condition have to deal (cope) with?

**Illness-related tasks (Body)** - tests, medication, treatment, surgery, hospital and

clinic appointments, unexpected changes to the condition and its ongoing management

**Emotional adjustment (Feelings)** - the psychological impact of having a pituitary condition, mood changes, worries about planning for the future

**Cognitive adjustment (Thoughts)** - memory, concentration, negative thinking in respect of ability to cope

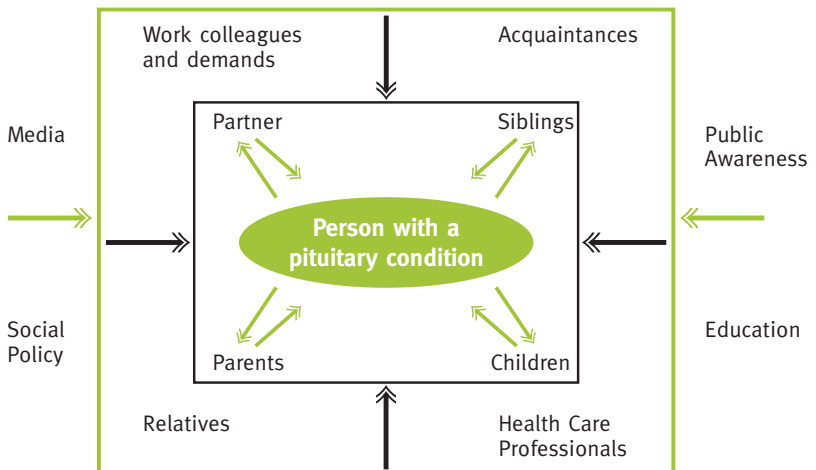
**Social interaction (Behaviours)** - maintaining relationships with colleagues, friends and family, maintaining a job and an income, maintaining interests

**General tasks (Behaviours)** - everyday living, maintaining a job and an income, life events.

Figure 4 below illustrates the many demands (the arrows in the diagram) affecting the person with a pituitary condition or indeed a person with any other long-term condition.

## Coping with a chronic condition

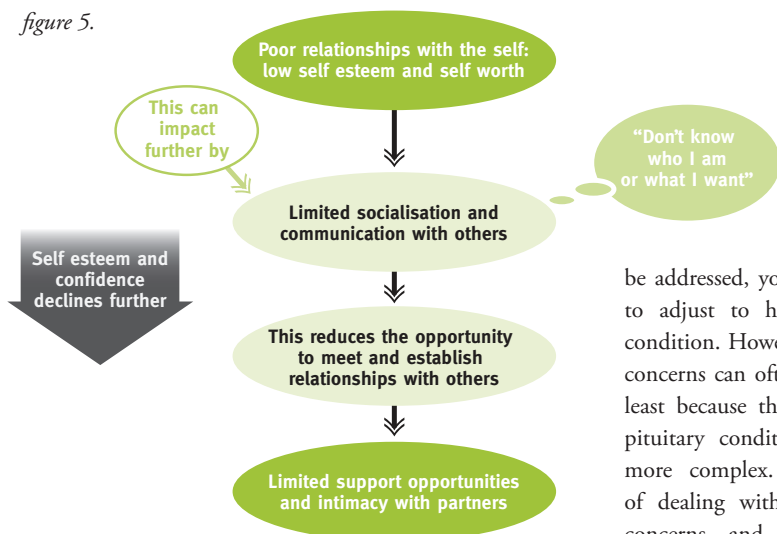
figure 4.





However, core to all of this is the relationship you have with yourself. We all have periods in our life where we are not happy with who we are and this undermines our sense of self impacting on our confidence and esteem. For the person with a pituitary condition this is often precipitated by an imposed change for example, altered appearance and infertility. This is often further complicated by your thought patterns in relation to these imposed changes (as demonstrated in *Figure 5*).

*figure 5.*



be addressed, you hopefully begin to adjust to having a pituitary condition. However new fears and concerns can often then arise, not least because the management of pituitary conditions can become more complex. There are ways of dealing with these fears and concerns and throughout this booklet self-help tasks will be

So establishing a good relationship with yourself is vital if you are to maintain old friendships and develop new relationships as well as enjoy a better quality-of-life.

In the *Psychological Impact of a Pituitary Condition: Diagnosis and Treatment* booklet, we talked about how your condition had significantly impacted on your mood and emotional responses. This included your fear of the future and your need for reassurance; your anxiety about possible surgical treatment; feeling angry and unfairly singled out (“why me?”). But with time and opportunities for your concerns to

included to tackle these.

**If you are newly diagnosed or just starting treatment, you may wish to contact The Pituitary Foundation for the first booklet in the series, *Psychological Impact of a Pituitary Condition: Diagnosis and Treatment*.**

**However, if some time has passed since your diagnosis and initial treatment, and you feel you are still trying to come to terms with it, you should contact your endocrine nurse and/or endocrinologist, or your GP, for a referral to a clinical or counselling psychologist.**

# Understanding and managing emotions and moods

**Research into other long-term conditions confirms what we heard from your journeys, that one of the most difficult aspects of having a pituitary condition is to be able to understand why emotional changes occur and how to manage them more effectively. We need to remember that it is common to experience emotions but it is when the emotion becomes overwhelming (for example, the fear associated with a phobia) that we need to find ways to overcome the emotional impact. Mood and emotion are often used interchangeably but an emotion is situation-specific and immediate, whereas a mood is something which develops to a non-specific series of events and is more long-term.**

This section will focus primarily on four problematic emotional states which affect most people but where those with a long-term condition are more at risk of long-term exposure; these states are anxiety, anger, depression, and apathy. We do sometimes adopt ways of behaving which offer protection against unpleasant feelings, however these can become habitual and block progress towards good adjustment and quality-of-life.

We have also included information on recognising and dealing with **Post Traumatic Stress Disorder (PTSD)** in this section as sometimes some of the emotional disruption you may be feeling may be as a result of as yet undiagnosed PTSD.

## **Anxiety**

Anxiety can be experienced as a feeling of uneasiness where you feel restless and out of control. Some experience fear which is much

more specific and usually directed at a situation (hospital), event (surgery), person (surgeon) or thing (radiotherapy).

*“Even after 18 years of suffering with DI, I’m constantly checking that I have my DDAVP (DI medication) with me when I leave the house – I panic at the mere thought of the terrible thirst and bursting bladder whilst out, in case there isn’t a loo or a drink available.”*

We experience fear when we feel threatened. You may be afraid of many things associated with your condition, for example, the fluctuations in symptoms, meeting people and what they might think and/or say about you. You are likely to feel more negative if your condition changes and your symptoms are not managed effectively; and more positive when the hormone levels are balanced and you feel good. This is perfectly normal. Sometimes even though the condition is stable some people might still feel a little anxious about their symptoms returning. You can recognise this by checking your breathing, which will become short and shallow when you are anxious. Additionally you may notice that



your heart rate might increase so it can feel as though it is racing which can make you feel jittery and shaky and unable to relax.

## Skills to help you manage anxiety using a worry chart

One of the key skills in managing anxiety (although sadly unpopular with many people) is to spend some time working out exactly what it is that you are feeling anxious about. A worry chart is extremely useful in this regard. It can help you to become clear about what is worrying you. It's easy because it doesn't involve you writing a lot and you can use it to help you understand a particular situation, or to help you understand what about your life as a whole is causing a problem. Sometimes we can be beset by a whole raft of little problems. In themselves they are nothing much, but when occurring together they can make life very difficult for us. Where we have a major problem to deal with, a worry chart can give us a way to systematically work through all the different areas of our life. It can provide reassurance that not all areas are equally affected. It can also help us to start to see how we might deal with some of the impact of the major problem by providing a way for us to break it down into chunks.

### Creating your worry chart

On a large piece of paper you need to draw yourself a copy of the diagram (Figure 6) right. You can change the labels against the arrows to more accurately reflect your own life. You work your way round the cloud asking yourself "What is worrying me about my pituitary condition as it relates to... my friends, my family, etc." You

figure 6.



write the results down on your paper. You keep going until you've got it all out of your head. What you do next is up to you. Some people find that just getting it out of their head is enough. Some people find they want to do something about some of the smaller problems so that they have less hassles to deal with. Some people find they need some assistance to help them manage the bigger worries.

### Being rational and compassionate about anxiety

Another good strategy for managing anxiety is trying to be rational about the things that are worrying you. It can be good to imagine that your best friend has just told you about something that is worrying him or her. The something is the thing that you are worried about yourself. Now, human nature being what it is, when someone we care about tells us something that is worrying them we seek to reassure them. We try to help them see the problem rationally, "Is it likely that you are going to lose your job for making one small error on a report?" We will

# Understanding and managing emotions and moods

be kind and understanding. However, when it comes to ourselves, we are quite often very harsh and unsympathetic. This reinforces our negative feelings and makes the anxiety more difficult to deal with. If you can get into the habit of being as rational and compassionate to yourself as you would be for your best friend any anxiety will be easier to manage.

## Strategies for switching your head off

One of the commonest problems reported in relation to anxiety is that the noise in your head is very difficult to switch off. It comes with the additional delight of lying awake at night with your head buzzing. Switching your head off is not difficult. Your brain will have shut up while you are reading this. Any time you are immersed in what you are doing the anxious voice in your head stops. This does not mean you need to turn yourself into a hamster on a wheel, scared of stopping and sitting down because the voice in your head will start again. Paying attention to the tasks you have to perform each day will certainly help you to manage the voice in your head. At other times, such as when you are in bed, you can train your mind to pay attention to other things. So, for example, when I am in bed and my mind won't shut up, firstly I write a list of all the things that are rattling around. Then I make an active decision to relax. I pay attention to my physical self and keep bringing my mind back to pay attention to my breathing. On each out breath I aim to relax my body so that it melts into the mattress. While your brain is helping you with this task, it tends not to focus on your list of things to do. In fact, all those things that rattle round in your head are your

brain doing it's best to help you. All of those things are important to you. It's doing its best to make sure that you don't forget any of them. That's why list-making is such a good strategy for managing this kind of anxiety. It puts your brain at ease, once you have a list it doesn't need to keep nagging you about your list of things to do.



## Anger

Anger is the emotion we feel when we are very annoyed or displeased. It is a strong emotion and so it is important to recognise it to be able to control it and then turn it to your advantage. Anger can be triggered by many things. Your anger might begin with you feeling frustrated or irritated. This is usually the way you feel when things aren't going the way you want them to. You might recognise the following irritations:

- Having to wait to see your doctor when you had an appointment for a specific time
- That despite your best efforts at communicating you are not being understood
- Your friends and family are taking control of your life and telling you what to do and when to do it
- Being forced to do something you don't want to do

These can accumulate and you begin to feel angry. Learning to be aware of why it is you are angry will help you to deal with these negative feelings and help you to understand your reactions.

## **Skills to help you manage your anger**

### **Avoid being demanding**

One of the biggest contributors to anger is our expectations about the way the world ought to be. For example, in your head, everyone is always polite, everyone knows the highway code and obeys it at all times, no-one is ever late, etc. In the real world, people are so lost in their own world they don't always realise that you've held the door open for them and so don't realise that they have not said thank you; people drive to new areas and while knowing the highway code may lane drift simply because they are distracted by trying to work out where they are; people get stuck in traffic and cannot help being late. Demanding that the world run itself according to the rules that you have got in your head is a fast track to feeling permanently irritated, frustrated and angry. If you become aware that you are feeling irritated, get into the habit of asking yourself, "Why am I feeling like this? How did I want this situation to go?" If you can learn to identify what it is that you are hankering after, you can learn to let go of the version of events in your head and you can lose the irritation before it has chance to grow into anger.

### **Look after yourself**

It is never a good idea to try and have certain conversations, or to keep working when you are feeling hungry, thirsty, tired or unwell. Your

capacity for tolerance and for paying attention is greatly reduced at these times. The same is true for all people. Getting into the habit of eating when you are hungry, having a drink when you are thirsty, having a rest when you are tired and not taking on too much when you are unwell can ultimately help you manage your anger. Having a pituitary condition can leave you feeling tired and unwell, but you will have good days and bad days. Your emotions will be more stable if you can stick within your limits on your bad days.

### **Stop criticising and complaining**

When I was introduced to this technique I thought it would be very easy to do. It's turned out to be like the other techniques, you have to practice it. Basically it promotes a generally positive frame of mind, by forcing you to recognise when you are being critical and complaining. This should come with a bit of a warning. There are some situations where it is necessary to complain, however, being constantly critical and complaining about all aspects of you life tends to leave you more vulnerable to emotional upheaval, especially anger and depression.

### **Depression**

Depression, or periods of very low mood, is likely to affect most people with a long-term and/or chronic condition. People with a pituitary condition are no exception. Dealing with the various pituitary conditions can make you feel:

- Completely helpless
- Exhausted
- Socially withdrawn
- Unable to enjoy anything

# Understanding and managing emotions and moods

Many people may not even be aware that they are depressed and often it is friends and family who are the first to notice and comment. Depression is a very unpleasant feeling of despair and can range from being a mild problem to a very severe one. Very depressed individuals may feel that the whole world is against them and life feels like a constant struggle.



## Symptoms of depression include:

- excessive amounts of hopelessness
- anger
- sadness and despair
- inability to eat, or eating too much
- food cravings, especially high fat or high sugar foods
- inability to sleep at night, or sleeping too much
- wanting to burst into tears for no reason
- lacking energy
- not wanting to be around other people at all

The more symptoms you experience the more likely that you are depressed and that you need to take action. A bout of depression can start from one specific thing that makes you unhappy but which then leads on to a chain reaction. So it is important to be able to recognise the process and try and stop the reaction taking you deeper into a depression, from which some find it hard to recover. Being fed up is different from being depressed and it is often difficult to identify which is which at the time. What is important is dealing with it as it happens and this is an essential part of coping; don't wait in the hope it will go away on its own. It might be useful to have a chat to the endocrine nurse or your GP if you feel persistently low.

## Aspects of having a pituitary condition might be causing the depression such as:

- dealing with the impact of the surgery and then radiotherapy
- managing the condition 24/7
- dealing with relationships with others
- dealing with appearance-related changes
- dealing with the long-term consequences: physical, psychological and social
- having to accept your condition is lifelong

## Skills to help you manage depression

### Self knowledge

Learning to identify your early warning signs is key in managing depression. Some people are lucky and only have one episode of depression in their life. However, some are less lucky and having had it once, find that it keeps recurring.

It doesn't really matter what triggers it, what matters is being aware that you are starting to show signs of it and then taking action to prevent it going any further.

### Try to watch your thinking habits

If you are aware that you have a tendency to exaggerate somewhat you might be more at risk of developing depression. Being accurate in your descriptions may not seem like much fun, especially when larger-than life descriptions can make events seem dramatic and important, there are times when this tendency to exaggerate and catastrophise can get you into trouble. It might be a joke to say to your friends, "*You wouldn't believe how bad this was,*" before telling them a story about dropping your mobile phone and breaking it, but if you are habitually thinking this way it can leave your brain feeling constantly overwhelmed and vulnerable to depression. The best thing you can do is to keep your dramatic descriptions for relating stories to your friends and stick to describing your every day life in terms of facts and evidence. For example, "*I had one difficult conversation with the boss at work today*", rather than saying to yourself, "*I had the day from hell.*"

### Use your senses

Pleasing your senses is a very pleasant way to generate positive thoughts and feelings. Here are some suggestions as to how you can do this:

- Find something you like the smell of - there is evidence that this is one of the most powerful mood improving things that you can do
- Listen to some nice music

- Massage your hands and feet
- Do something creative
- Find some photographs or postcards that make you feel happy or positive and pin them up round the house, by your desk, and/or put them in your diary
- Spend some time on your hobby

### Distraction from isolation

One of the symptoms of depression is isolation. You generally don't feel like going out and socialising as it is often requires too much effort. Try these suggestions to be with people:

- Listen to the radio
- Phone a friend and have a ready excuse to end the call when you've had enough (for example, "Got to go, someone has just knocked on my front door.")
- Meet up with a friend to watch a film or DVD
- Do an exercise class or take up a sport where you don't have to talk to others, you can just take part



### Outdoor distractions

It is easy to stay indoors when you feel depressed. This is particularly easy to do in winter when it

# Understanding and managing emotions and moods

is cold outside. Some people get depressed in winter because they do not receive enough sun. This is called Seasonal Affective Disorder (SAD). The following suggestions may be helpful in dealing with this:

- Try and get outside at least once a day
- Spend time in natural surroundings
- Try to walk to the local shops or take your dog for a walk, if you've got one

## Apathy

Do you ever feel you lack interest in things you used to enjoy doing or motivation to engage in social activities? This is defined as a state of indifference - where an individual has an absence of interest or concern to certain aspects of emotional, social, or physical life. It is also referred to in the following ways:

- An absence or suppression of passion, emotion, or excitement
- A lack of interest in or concern for things that others find moving or exciting

You might be more familiar with the term “voter apathy” where politicians find that the general public is so indifferent about the political situation that few people turn out to vote.

## Skills for managing apathy

### Talk to others

Apathy is closely linked to low self-esteem and feelings of low self-worth and often precedes a depressive episode. If you recognise these feelings or someone close comments about how you are behaving, consider talking to someone, a trusted health professional, the endocrine nurse or a good friend and explore why you might be

feeling this way.

Some people find it helpful to ask themselves “*what is good about life?*” and “*what might need improving in my life?*” Using these questions can help them to identify what it is that is making them feel so completely switched off. The next stage is finding ways to address the problem. Often recognising and talking about the problem can help improve your self-confidence and repair your self-esteem.

## Ignite your passion

Learning about something is one of the most powerful things you can do to improve your self-esteem, self-confidence and beat apathy. It doesn't matter what it is you learn, just as long as you are passionate about it. However, you need to get over the idea of doing something to excel at it. People with good levels of self-esteem and self-confidence are open to letting themselves try things, just to have the experience. It's not about how well you do, it's about finding something out about yourself without worrying what other people might think about you. As adults we can find ourselves hampered by this habit of making comparisons with others, and with worrying about what others might think. Since it is a habit, you can choose to change it. So, find something that you are passionate in learning about, whether it's stamp collecting, reading, or steam trains and it will help you overcome your apathy.

## Work on your relationship with yourself

One of the most important relationships we have throughout life is the one with ourselves. You



may well be familiar with the idea that a good marriage requires a lot of work in order to keep the relationship functioning well, and different amounts of work are required at different times. Well, working on your relationship with yourself is also necessary. The simplest description would be to treat yourself with the same love, respect and understanding that you extend to others. This is not about turning yourself into an egotistical maniac, it's about respecting what your body can (and cannot do) and caring for it appropriately, it's about taking the time to identify how you feel about things and respecting your opinions as being as equally important as other people's opinions. More on this topic is available by contacting **The Pituitary Foundation**.

It is important to understand a pituitary tumour can have a profound impact on your ability to function properly and to maintain an appropriate psychological state. For example, altered levels of cortisol can express itself as extreme depression and excess growth hormone can lead to severe mood swings. Hypothyroidism and other neuroendocrine abnormalities are associated with changes in consciousness, impaired mental abilities such as impaired memory and concentration, or sometimes distressing changes in behaviour. Equally fatigue, infertility, sexual dysfunction and other physical symptoms can present as major adjustment challenges.

## **Post Traumatic Stress Disorder (PTSD)**

This can occur in patients who are very shocked by their diagnosis, or treatment, but it may be quite sometime before they actually realises they

need help with this. For example, having brain surgery can be traumatic for some individuals and result in PTSD. The trauma may not be picked up at the time and if untreated the symptoms can cause problems for years.

## **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 the person
- 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 you 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 startle 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

# Understanding and managing emotions and moods

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.

## 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 and helplessness of the situation.

While this works for the person in a limited fashion, it prevents the person from confronting the feared situation and also prevents the fear reducing in a safe environment.

## Coping with PTSD

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

1. Some people find that counselling helps them. For others talking through the traumatic event just makes them more traumatised than they already are.
2. 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.
3. 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.
4. 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.

# Cognitions: impaired Memory and loss of concentration

**Everybody forgets things from time to time. The majority of the time, the things that we tend to forget are the things that we feel do not matter to us. The things that we tend to remember most easily are the things that are important to us - like a special birthday. However, some people seem to have better memories than others and some people are more forgetful than others. For a person with a pituitary condition (in particular hypopituitarism) the loss of key hormones (for example, TSH/Thyroxine and/or ACTH/cortisol) can impair memory and your ability to concentrate. However often treatment for the condition (surgery and radiotherapy) can also affect memory and concentration.**

We know there are certain situations which can affect our memory and make us more forgetful than normal.

These include the following:

## **1. Poor concentration**

If our ability to concentrate is poor then we don't notice things as much, and are unable to retain things as we would normally. Poor concentration can also be a result of simply being bored or tired (fatigue). Equally it can be a symptom of depression and anxiety, as we become preoccupied with negative thoughts.

## **2. Depression**

Some people with depression will have slowed thinking which can make it difficult to:

- retain what people say in conversations;
- find the right words to use; and
- respond to what people might ask you to do

When a person is feeling low or depressed they view the world in a more negative way and they can view their memory functioning in the same way. You could talk to your doctor if you think that you are depressed or you could try one of the self-help strategies listed in the depression section. As mood improves a person's cognitive functioning will also get better.

## **3. Physical illness**

Recovery from surgery and treatment and generally being ill can influence our ability to concentrate and retain memories. An underactive thyroid can slow down the body's functions, including the brain, and can make you more forgetful.

## **4. Age**

Remember as we get older it often becomes harder to remember things, and many people over the age of 50-60 experience this problem, so it's normal and it's not usually the onset of dementia! What happens is, as we get older our ability to process information gets slower. It can become harder to learn new skills and our short-term memory may get worse and will show itself in various ways, the most common being forgetting the names of people we have just met. Evidence suggests that using our brains more may counter this age-related decline in memory function. So, doing things such as reading novels or poetry regularly, doing quizzes and crosswords, socialising with others, and/or learning new skills may help to keep your memory in good shape and improve concentration.

# Cognitions: impaired Memory and loss of concentration

## Strategies to boost memory functioning

What can help our ability to remember? These are some tips that people have tried to manage their memory in their daily lives.

- **Keep routines** - Performing activities on similar days and at similar times can help to reduce forgetfulness.
- **Write things down** - External memory aids such as diaries, calendars and notepads can help to record appointments, social events, and provide somewhere to note down what you want to discuss with your healthcare professionals (HCPs) and what you want to get while you're out at the shops.
- **Electronic devices** - Mobile phones, pagers and electronic organisers can help with organisation of to-do lists, appointments by setting alarms to remind you of when things need doing.
- **Talk to people close to you** - Check with family/friends to see if they have noticed a change in your memory. Find out if there is anyone who could help to prompt you to remember information.
- **Boost concentration** - Try to reduce distractions when learning new skills or information, we do much better when we are in quieter environments for these kind of tasks. Think about what is your best time of the day to do things and when you will not be interrupted.
- **Key facts** - When reading information from books or watching a film ask yourself questions about what you have been reading or watching. The most common questions to use are "who?", "what?" and "where?"
- **Remembering names** - When meeting new people, repeat their name in conversations. Try to use association to make their name more relevant to you such as "Happy Helen".
- **Depression/anxiety strategies** - Strategies to improve mood can be useful for enhancing memory. Exercise, addressing negative thoughts and eating certain foods such as oily fish have also been suggested to improve memory.
- **Medication** - Keep medication in the same place every day. Medication boxes or setting alarms can help people to take multiple tablets each day. To know if you have taken your tablet, it can be handy to put only the tablets out that you need or have a chart to tick off each day once you've taken the pill.



## Useful websites

*MIND:* [www.mind.org.uk/information/booklets](http://www.mind.org.uk/information/booklets)

- Look for "How to cope with memory loss".

*Headway:* [www.headway.org.uk](http://www.headway.org.uk)

- A charity that helps individuals manage any head injury or brain damage.

*Mental Health Foundation:*

[www.mentalhealth.org.uk](http://www.mentalhealth.org.uk) - Look for the healthy eating and depression booklet.

# My body: fatigue, sleep problems & pain



## Fatigue

**You have told us that fatigue is experienced regularly and is possibly the most debilitating consequence of having a pituitary condition. The medical definition of fatigue is a feeling of weariness, tiredness, or lack of energy. It is considered to be different from drowsiness. Drowsiness is described as the need to sleep, while fatigue is a lack of energy and motivation. However drowsiness and apathy (a feeling of indifference or not caring about what happens, see page 14) can be symptoms of depression.**

Fatigue can be a normal and important response to physical exertion, emotional stress, boredom or lack of sleep. However, it can also be a nonspecific sign of a more serious psychological or physical disorder. When fatigue is not relieved by enough sleep, good nutrition or a low-stress environment, alternative explanations and assessments are needed. In fact because fatigue is such a common complaint, sometimes a

potentially serious cause (such as a pituitary condition) may be overlooked.

The pattern of fatigue may help your doctor determine its underlying cause. For example, if you wake up in the morning rested but rapidly develop fatigue with activity, you may have an underactive thyroid or hypopituitarism. Hypopituitarism can also lead to exhaustion on waking. In addition, if you wake up with low energy levels and are fatigued throughout the day, you may well be depressed. Therefore if you are experiencing fatigue it is important to discuss this with your doctor or consultant endocrinologist.

## Skills for dealing with fatigue

it is really important to manage the energy that you do have wisely. The following skills can help you with this.

### Develop some healthy/helpful ways of thinking

The way you choose to think about things influences how you feel about them. The emotions we experience come with energy attached to help us to deal with the situation. The stronger the emotion, the more energy is provided to deal with the situation. If you are routinely increasing your emotional response to situations by exaggerating how you describe things, for example, then it might be helpful to consider adopting the following simple strategies:

1. Stick to describing situations using facts and evidence - boring, but the pay-off in energy conservation makes it well worthwhile.

# My body: fatigue, sleep problems & pain

2. Try to deal with actual situations as they arise. Your new mantra for dealing with situations that are yet to happen, but that are causing you concern: *“I don’t know what will happen, but I can be comfortable with finding out.”*
3. Try to think of yourself as your own best friend. Stick to talking about yourself and others in a way that you would not be ashamed to hear shouted from the rooftops.
4. Practice generating positive thoughts by choosing to focus on the things that you can be grateful for.
5. Stop criticising and complaining except where it is useful and appropriate - it generates a lot of bad feeling and wastes a lot of energy.

## Problem-focused coping strategies

Emotions are information about a situation that basically inform us that there is some action we need to take. If you are feeling a particular way, get into the habit of asking yourself: *“Why am I feeling like this?”* We often experience irritation when things are not going the way that we want them to. If that’s the case, then you need to ask yourself why it’s so important that things happen in a particular way. Most of the time it doesn’t matter how things happen - it’s the end result that is important.

## Clearly identifying your needs

Don’t think about purple elephants - you are, aren’t you? That’s because your brain doesn’t really register the negative, it focuses on the subject of

the sentence. If you say to yourself, *“I don’t want to be angry with Helen”*, your brain hears *“be angry with Helen”*. As a general rule people are very good at saying what they don’t want, but that’s not really a good strategy to adopt. It’s far healthier, and less energy-zapping, to get in the habit of being clear about what it is you do want. It is also a useful strategy to adopt when talking to other people, including children.

## View life as a learning opportunity

If you view life as being a struggle, where other people cannot be trusted and where you are fighting your corner the whole time, it’s anxiety-provoking and energy-zapping. If you view everything that comes your way as an opportunity to learn, then you reduce the amount of energy you are expending. Learning is something that humans are good at. We are naturally curious about the world and how it works, about ourselves and other people. Learning about things is good for your self-esteem and self-confidence and boosts feelings of well-being. Learning increases resilience and makes it easier to deal with the stress associated with the changing world in which we live. Ranting at the Universe because we don’t like something is energy-draining, learning the lesson about what we can cope with, how we are capable of growing and changing and adapting in the face of difficult situations is far more life-affirming and easier to manage.

## Sleep problems

Sleeping can take up about a third of our lives and it varies in amount and quality from one person to the next. There is no pattern which is normal for everyone. However, most adults (aged between 20 and 65) sleep for about 7-8 hours at night. However, there are short sleepers who may only sleep a very few hours a night, and there are long sleepers who may need more than 10 hours per night. Being a short sleeper does not mean you have insomnia, neither does being a long sleeper make you lazy.

Sleep consists of several stages, ranging from very light dozing to very deep sleep, which occur in a cyclical pattern throughout the night. Everyone has several short awakenings during the night, but these are often too short to be remembered, i.e. less than a minute or so. As we get older, i.e. once we are in our thirties, our sleep pattern will change and the awakenings get longer, and so our sleep becomes less “efficient”. Some people have the illusion that they are awake all night because when they wake up they focus on the time on the clock. If you turn the clock away from you, this is much less likely to happen. There are some unfortunate people who dream they are awake and thus wake up in the morning feeling awful. There are also people who dream that their alarm has gone off and they are up and about when in fact they are still in bed. This phenomenon is known as “false awakening”.

If the quality of our sleep is poor this can impact significantly on our daily activities and our overall quality-of-life. Sleep problems in people with pituitary conditions are fairly common, and range from insomnia (difficulty initiating or maintaining sleep, or not getting as



much sleep as you would like) to hypersomnia, or excessive sleepiness during the day.

If you are having problems it can be worth keeping a sleep diary for a month to discuss with your GP to help identify the possible cause of your sleep problems.

## Skills to improve sleep

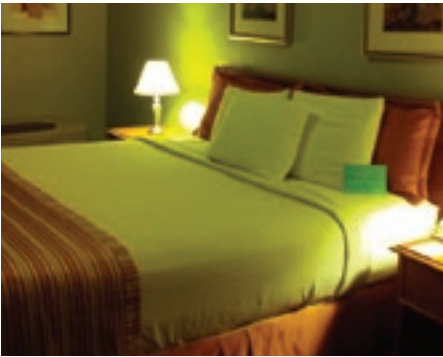
### Consistency

- Go to bed and get up at the same time every day. Your body likes routines. You can programme it by doing the same things when you go to bed each night. Eventually, as you start the routine, your body and brain will recognise it and will start to switch off ready for sleep.
- Stop eating and drinking stimulants such as chocolate and coffee at least 4-5 hours before bed - it can take that long for your body to clear them out of your system. If you've been having a lot of problems sleeping you might want to stop drinking caffeine at lunch time.
- Try and make sure you get enough physical activity during the day so your body and brain are equally fatigued and avoid napping if possible.

# My body: fatigue, sleep problems & pain

## Activities that promote sleep

- Not eating too much during the evening. A small amount of carbohydrate before bed can make you sleepy, for example, a small bowl of cereal.
- Doing things that you enjoy and make you feel generally contented.
- If you're going to exercise in the evening make sure that the more vigorous it is the longer you have to recover before you go to bed.
- Have a warm (not hot) bath, the temperature drop your body experiences after the bath simulates the temperature drop that your body experiences while you sleep.



## Bedroom

Make this room a warm, friendly and inviting place to sleep. Banish unsuitable books, work-related items etc. Avoid being too hot or too cold. You should change your bed or mattress at least every 10 years. Turn the clock away from you if you worry about remaining awake. If you can see it when you wake up your brain will keep registering the time, turn it away and you won't

have anything to focus on when you wake. Keep noise levels to a minimum but if there is noise use it to help you to sleep. If you were already asleep your brain would incorporate the noise into your dreams to keep you sleeping. By listening to the noise and letting your brain play with the sound it can actually help you get off to sleep.

## Mind your language

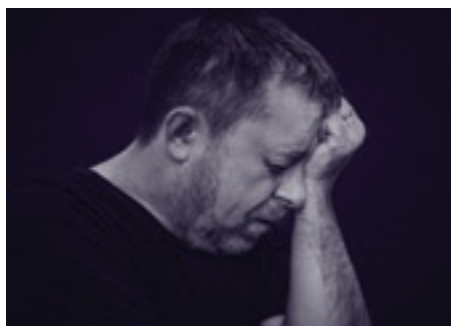
We seem to appreciate a good night's sleep in our society, and yet our sleep can vary depending on what we've done during the day, whether we are fighting off a bug or not, and so on. One of the worst things you can do is to lie in bed saying to yourself, *"I must go to sleep. I've got to be up in the morning. I must go to sleep."* All those musts are a form of demanding language that imply to your brain that if you don't go to sleep some seriously bad consequences will follow. Your brain views this as something that it must protect you from and so it activates your fight and flight response. Not the most helpful thing it can do when you're trying to go to sleep. Once you've activated your stress response it's going to take your body a good 20 minutes to reset itself so that you can go to sleep. So, if this is a habit with you, you need to break it. Stopping and resting is good enough. The less you stress about going to sleep the easier your brain will find it to sort itself out. Don't demand of yourself that you sleep now. Just create the right environment for yourself and enjoy relaxing and resting. The sleep will happen when your brain is ready, and not before.

## Worry hour/de-junking your brain

This is for those people who find that they keep waking up with their minds racing with things



to do. Every few weeks take a piece of paper and divide it into two lengthways. On one half write down all the things that you keep waking up thinking about, it doesn't matter what they are. Against each one, on the other half of the paper, write down one thing that you could do that would start to help sort out the problem. It can be as simple as finding out some information. Your brain will think that you are dealing with the problems and will only wake you with the ones you forgot!



## Pain

### Chronic pain consequences & self management strategies

Pain can be the result of having a pituitary condition or as a consequence of having multiple health problems. Pain may be experienced as a feature in specific parts of the body or as a general pain over the whole body. Some individuals experience tenderness and swelling of the joints making it difficult to walk. The level of pain may vary from day-to-day or even from hour-to-hour. These symptoms can affect a person being able to manage everyday living

activities from going to work, shopping and doing housework. It can be frustrating and distressing to be unable to undertake activities that you used to take for granted. When pain is severe it can affect your ability to concentrate.

The way your pain affects your ability to undertake daily tasks will influence what type of treatment or support you may receive. Your GP will monitor your symptoms for a period of time to determine if the pain will ease. They may give you pain medication to help you manage the pain. If there is no improvement further medical investigations may be necessary to gain more information. Pain clinics are available to support patients with chronic pain, to find effective pain relief and strategies to help cope with the pain.

### Strategies to help you manage pain

- **Pain medication** - Following the guidelines from your GP or pharmacist about medication can prevent severe episodes of pain.
- **Medical treatment** - Ask what is available to help manage your pain from your GP.
- **Pace yourself** - To reduce having good and bad days try to keep to the same level of activity each day. Resist the desire to carry on with tasks as if you are not in pain. Work out how much you can do without increasing your pain.
- **Ask others for help** - If there are tasks that cause pain find out if others will be able to help. For example, when shopping ask the supermarket for someone to help carry the shopping to your car.
- **Acceptance** - One of the most distressing elements of chronic pain is the loss of

# My body: fatigue, sleep problems & pain

functioning and reduced quality-of-life. As such it may be difficult to accept your current limitations and there is the desire to return to normal functioning. This may take time and for some people a return to “normal” functioning becomes an unlikely event. Therefore people need to find a way to manage this uncertainty and establish ways to maintain a sense of control of this new situation.

- **Record Your Pain** - To get a better perspective of the pain intensity and impact on your life, keeping a record of activity and level of pain. Record how you feel after carrying out the activities. This will help to understand what activities may make your pain worse.



## **Mindfulness**

Mostly when we are in pain, we make it worse for ourselves by tensing against the pain. It may seem counterintuitive, but if you can practise focussing your entire attention on the pain it can reduce in intensity. Learning to breathe with the pain and having a dial in your head which you gradually turn down as you breathe can help you to manage the pain. Mindfulness is a useful technique to learn to help you practice focussing your attention and has been proved to be very useful in helping individuals with chronic pain conditions to have reduced pain and increased quality-of-life.

## **Hypnotherapy**

Some people find that hypnotherapy can help them learn to manage pain.

### **Useful websites:**

*The British Pain Society:*

**[www.britishpainsociety.org](http://www.britishpainsociety.org)**

*NHS Choices:* **[www.nhs.uk/livewell](http://www.nhs.uk/livewell)** -

Website that gives information on how to remain healthy.

# Dealing with infertility: impotence & low libido

## Libido & impotence

Having a pituitary condition (in common with most long-term conditions such as diabetes or arthritis) can challenge sexual and or intimate relationships. Sex is something to be enjoyed to provide pleasure, however for those living with a long-term condition it can be something to be feared and avoided. Fear of bringing on a health emergency or increasing fatigue can dampen desire for both partners.

Sex is however more than sexual intercourse; it is the opportunity to share physical and sensual emotionality. Exploring your sensuality with your partner can open up communication and strengthen your relationship. Making love is often spontaneous providing a special intimacy which releases endorphins (the feel good hormones). However for people with a pituitary condition where hormone deficits prevail, the desire for sex (libido) fluctuates and becomes dependent on hormone replacement treatment. This can make the process mechanical and something to be planned. Psychologically this and the loss of fertility can compound the lack of libido.

Emotional and mood disturbances can be major contributory factors to low libido and intimacy levels. Disturbances resulting from the impact of the condition and the continuous management of the symptoms, can affect both you and your partner. Your partner might feel responsible for exacerbating your symptoms and guilty at their perceived selfish behaviour. So open communication and discussion is vital. Also remember that things may have changed for your partner too. Some partners of patients may perceive their partner differently and may



be cooler physically and emotionally. They are trying to adjust too. Desire and/or libido is a two way thing. Pressure in the form of anger, variable moods, frustration and sulking from the non-patient partner can drive any crumb of libido out of the window for the person with the condition. The partner in some cases expects the patient post-surgery and on replacements to be OK now. You need to keep the communications open so that it does not have the chance to escalate into a sheer blank wall of absolutely no libido.

*“as Mrs Nil Libido I have been made to feel extremely guilty over the past six years and have received many accusations of ‘coldness’ etc by my soon to be ex-husband (my choice) and although I am in my late 40’s I would love to have just a smidgen of libido back.....ho hum!”*

A changed self-image and reduced self-confidence can be major barriers to developing/sustaining a person’s sexuality. Altered appearance through hormonal and structural changes to the skeleton; metabolic changes that alter body shape; problems with continence; and loss of fertility can contribute to feelings of being

# Dealing with infertility: impotence & low libido

unattractive. With these perceptions people will avoid sexual situations or even thinking about sex; suppressing thoughts can often lead to depression, which further reduces libido, which can deepen the depression, a vicious cycle. Depression can be managed and there are ways to explore and improve your sensuality and intimacy as well as overcome the fear during sex.

## Ways to help you cope with low libido

- Manage your stress and depression
- Try to share what you are feeling with your partner
- Talk to your endocrine nurse and consultant about what help is available
- Ensure with your endocrinologist's help that your sex hormones are not under-functioning and that your other hormones are balanced

## Get to know (and love) yourself again

Having a pituitary condition may have changed the way you feel about yourself pretty much completely. If you don't take some time to understand how you now feel about yourself and resolve some of the more difficult feelings you might be harbouring towards your body for the way it has been behaving during your treatment then that can cause a sizeable block in your ability to be intimate with anyone else. Can you find a part of your body that you actually do still like (despite all the changes it might have gone through)? Can you learn to extend that liking to the rest of yourself? Can you learn to acknowledge that you are more than just a physical being and that who you are is just as important as what you look like? In order to be able to really love someone else, you need to be able to love yourself.

## (Re-)learning what turns you on

In terms of sex, what turns you on now may well have changed because your body feels different to you in some way. In order to have a sex life you may have to be open to the fact that it will be different than it was before. Different shouldn't imply better or worse. You need to spend some time thinking about what you want and need. If you can't turn yourself on, what hope has your partner got? If you need to spend some time "warming up" with thoughts of Daniel Craig or Halle Berry, your partner doesn't need to know.



## Change your definitions of what counts as sex

We tend to think of sex in terms of full penetrative sexual intercourse, but sex can be whatever you want it to be. Are there things that you could do with your partner that might be classed as sexual? Do you need to find some ideas from a good sex manual or two? Also remember that if you're not in the mood for making love, sometimes just doing it can actually get the right mix of hormones flowing for things to work. Obviously, if you're really angry or resentful it's not going to work.

## Learn to communicate with your partner

Resentment can block desire more effectively than having your mother-in-law in the house! Fear of being rejected can also block any possibility of any action occurring at all. Sex can be a difficult subject to talk about, even more difficult than money. A good use for sex manuals is in starting discussions. The fact that you've gone to buy one will say a lot to your partner about how important this is to you. You can leave the page open or put a post-it note on the page you've been thinking about trying. If you're not sure where to start then try a book by Tracy Cox (there are some suggestions of useful titles below). There aren't any hardcore images, and they are very readable.

### A selection of books by Tracy Cox:

- Supersex
- Hot Sex:  
How to do it
- Kama Sutra
- Hot Relationships:  
How to have one
- Superdate:  
How to be one, how to get one



## Infertility

This can be very difficult emotionally and socially, in fact research indicates that the psychological stress experienced by women with infertility is similar to that of women coping with long-term and life-limiting conditions such as cancer, HIV, and chronic pain. Infertility is therefore not an easy condition to cope with, often hampered by other people's lack of understanding and comments like, "*your anxiety is causing your infertility*". For many people and especially for those with a pituitary condition this is just not true. In fact most recent research studies into the causes of infertility make no connection between levels of anxiety and rates of infertility. Many of you who contributed to the various research projects (2006 UWE/Pituitary Foundation Needs Analysis, the 2006 Infertility Project, and the 2007 Patient Satisfaction Survey) suggested that the emotional impact of being infertile can feel overwhelming and create intense feelings of grief and distress.

### Some of the feelings you have experienced & continue to experience include:

- **Loss:** You may feel a sense of loss for the child or children you imagined having one day. You may also feel that you're missing out on the experience of parenthood or the act of having a biological child. You may feel that life isn't normal and for some there is no purpose to life.

*"I've also been infertile so I found myself in my mid thirties with no job, and no family, so I guess it's a case of well where's my sense of purpose?"*  
*"...the sense of worth, I mean certainly for*

# Dealing with infertility: impotence & low libido

*women...you lose your job, you get married, you don't have children, meeting people through children, well, what am I here for? What's the purpose of life?"*

- **Anger and jealousy:** You may feel angry at life in general. You may also feel angry at or jealous of those able to have children.
- **Shame:** Many women have said that with their diagnosis of infertility they began to feel less feminine; while most men are made to feel less masculine. For some there is a sense of being less perfect than those who can have a child without assistance.
- **Lack of control:** For some this may be associated with a sense of losing control since any treatments offered cannot guarantee a positive outcome and these treatments are dependent on the expertise and skills of others.

Infertility can put tremendous stress on your relationship, with research showing that couples dealing with infertility are more likely to feel unhappy with themselves and their marriages. It can affect your relationship in a number of ways, including:

- **Sexual tension:** During infertility treatment and especially around ovulation, sex may feel more clinical and controlled and not an enjoyable way to express love for each other. Men may experience performance anxiety, reinforcing feelings of guilt or shame.
- **Financial stress and arguments about treatments:** *Fertility treatment is expensive and with limited NHS budgets personal costs can quickly add up.* The decision-making process around how much you're willing to

pay, coping with the financial strain or debt, can create and perpetuate the stress between couples.

- **Fear of abandonment:** For the partner with the infertility diagnosis, there maybe the fear that their partner will want to leave them to have children with someone else.

## Ways to help you cope with fertility

With the complex feelings surrounding infertility, effective coping skills are essential. The tips below may help you to manage and reduce emotional distress you might be experiencing:

- **Acknowledge your feelings:** Holding everything inside does not help. It actually takes more mental energy to hold your feelings back than to express them. Allow yourself time to feel the sadness, anger, and frustration.



- **Seek support:** Whether through friends, professional counselling, groups or online forums, finding somewhere to talk with people who understand and can help you feel less alone.

- **Practice relaxation:** Learning how to relax and calm yourself can help when feelings get intense and during treatments. *Complementary therapies like acupuncture, yoga and relaxation techniques* can be useful in facilitating coping and reducing distress.



- **Talk to your partner:** Talk about your feelings together. Keep in mind, though, that men and women cope with stress in different ways. Women are more likely to express their sadness, while men tend to hold things inside. Neither way is wrong, just different.
- **Learn as much as you can:** The more you know about infertility, including alternatives like adoption or living child-free, the more in control you will feel.
- **Don't let infertility take over your life:** Make sure you fill your life and your relationship with other things. If it seems like infertility is all you talk about together, set a specified time each day for the topic, and use the rest of the day to talk about other things.
- **Keep sex fun:** As mentioned above, sex can

quickly become more like a chore than a fun way to express love for each other. Try to keep things loving and exciting. Light candles, play music, or watch romantic movies, do whatever makes you both feel good.

- **Consider professional help:** Many couples find that professional individual or couples counselling can help them cope with the emotional stress of infertility, and some fertility clinics insist that their patients seek counselling before and during treatment.

*"For couples experiencing infertility, wanting a baby is a craving unlike any other..."*

### Useful websites:

*Resolve- The National Infertility Association:*  
**[www.resolve.org](http://www.resolve.org)**

*Infertility Network UK:*  
**[www.infertilitynetworkuk.com](http://www.infertilitynetworkuk.com)**

*About.com:* **[www.infertility.about.com](http://www.infertility.about.com)**

Fertility Stories:  
**[www.fertilitystories.com](http://www.fertilitystories.com)**



# Taking care of yourself : strategies for acceptance & management

*“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

## **Daily one minute meditation**

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.

## **Be in the moment**

Throughout the day, stop every so often and bring yourself fully into the moment, into the “now”. Truly pay attention to what is happening both to you and around you. Don't judge - just be aware. Gradually extend mindfulness to every part of your life - eat mindfully, walk mindfully, exercise mindfully, shower mindfully.

## **Deep breathing**

All stress experts agree that deep breathing can change your state of mind. Most of us take short, shallow breaths, which simply make us feel anxious. Stop for a minute or two, with your eyes open or closed and begin breathing deeply and evenly. Make sure that your arms and legs are uncrossed and that your feet are flat on the floor. Always

breathe in through your nose to the count of four, feeling the breath go right down into your stomach, then breathe out through your mouth to the count of four. Do this five times. Novice deep breathers should never go above four or five deep breaths during each session of deep breathing during the day. You can practice in bed at night where you can increase the number of breaths and can control the exhalations so that you breathe out to a count of five, then six, then seven, etc.

## **Refocus your lens**

When you identify that you are “demanding” that things in your world need to be a particular way, try and stop yourself. Try and 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.



# Sources of **useful information**

## Useful websites:

### *Related to section:*

#### **Cognitions: impaired memory and loss of concentration**

*MIND:* [www.mind.org.uk/information/booklets](http://www.mind.org.uk/information/booklets) - How to cope with memory loss.

*Headway:* [www.headway.org.uk](http://www.headway.org.uk)

- A charity that helps individuals manage any head injury or brain damage.

*Mental Health Foundation:*

[www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

- Healthy eating and depression booklet.

### *Related to section:*

#### **My body: fatigue, sleep problems and pain**

*The British Pain Society:*

[www.britishpainsociety.org](http://www.britishpainsociety.org)

*NHS Choices:*

[www.nhs.uk/livewell](http://www.nhs.uk/livewell) - Website that gives information on how to remain healthy.

### *Related to section:*

#### **Dealing with infertility, impotence and low libido**

*Resolve:* [www.resolve.org/](http://www.resolve.org/)

*Infertility Network UK:*

[www.infertilitynetworkuk.com/](http://www.infertilitynetworkuk.com/)

*About.com:* [infertility.about.com/od/copingwithinfertility/a/copestress.htm](http://infertility.about.com/od/copingwithinfertility/a/copestress.htm)

*Fertility Stories:*

[www.fertilitystories.com/infertility.htm](http://www.fertilitystories.com/infertility.htm)

### *Mental health websites:*

*The Mental Health Foundation:*

[www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

- The Mental Health Foundation promotes the recovery of mental health.

*The Royal College of Psychiatrists:*

[www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)

*Relate:* [www.relate.org.uk](http://www.relate.org.uk)

- Relate provide services for couples of families who are struggling with situations.

## Useful books

### *A selection of books by Tracy Cox:*

- Supersex
- Hot Sex: How to do it
- Kama Sutra
- Hot Relationships: How to have one
- Superdate: How to be one, how to get one

## References

*Clay, RA* (2006) *Battling the Self-blame of Infertility*. Monitor on Psychology. Volume 37 Number 8.

*Hirsch, AM & Hirsch, SM* (1989) *The Effect of Infertility on Marriage and Self-conception* Journal of Obstetric, Gynaecologic, and Neonatal Nursing Volume 18 Part 1 pages13-20.

*Jaffe J, Diamond D, Diamond M* *Unsung Lullabies: Understanding and Coping with Infertility*. New York, USA: St Martin's Press

*Lukse MP & Vacc NA* (1999) *Grief, Depression, and Coping in Women Undergoing Infertility Treatment*. Obstetrics & Gynecology Volume 93 pages 245-251.

*Northrup, C* (2007) *Wise words in B Brown* (2007) *Living Beauty*. London: Headline Press. Quote from page 128



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**The Pituitary Foundation,  
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## Helpline

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

## Endocrine Nurse Helpline

available scheduled hours  
0117 370 1317

**Website:** [www.pituitary.org.uk](http://www.pituitary.org.uk)

**Email:** [helpline@pituitary.org.uk](mailto: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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