

# Relationships & communication with yourself and with others



*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

This booklet aims to address the process of adjustment you need to make in your relationship with yourself as well as addressing the issues of communication about your condition with others. It aims to provide help and support strategies to aid in developing new, as well as maintaining old relationships post-diagnosis and throughout life with a pituitary condition.

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 adjust to life post-diagnosis, and to manage relationships with others as well as offering you a basis for discussion with your partner, GP and endocrinologist.

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# Introduction

**With the onset of a long-term condition, relationships can change because of the demands the condition imposes on you and your family. The unpredictable nature of symptoms and the demands of the treatment can result in changes to life goals (personal and family). This can necessitate a change in family roles where you move from being a provider and/or carer within the family to a person who becomes dependent and cared for. This change in role can result in confusion for you and for others within your family, as you all attempt to deal with the required role changes and what this might mean for your identity as a person.**

The restrictions imposed by the condition and symptom management can affect relationships with friends and colleagues. They can also reduce the opportunities for, and your willingness to, socialise with others. This booklet aims to address the process of adjustment you need to make in your relationship with yourself, as well as the issues of communication about your condition with others. It suggests strategies to help maintain old relationships and develop new ones, whilst living with a pituitary condition. Communicating about your diagnosis and how you need to manage your condition is dependent upon the degree of

impact a pituitary condition inflicts. It also requires an understanding of the issues that your condition and its management might raise for others in your life. Key to this is helping you to manage the enforced changes and acceptance of the new you.

## How to use this booklet

We have mapped out the people that you are likely to have to communicate with about your condition, its diagnosis and management. We have put some general communication strategies at the beginning of the booklet. There is a section for each of the various people with whom you have to communicate and/or maintain a relationship. Within these sections we have tried to highlight the possible problems from both sides (yours and theirs) as well as identifying some strategies that might help you. Where there are no specific strategies, we would suggest that you read the section on the people concerned, followed by the general communication strategy section in

order to give yourself some ideas about how to manage the issue up for discussion. Section 3 gives you more information on understanding and managing the psychological/emotional impact and may help you to understand and cope with the feelings that both you and your family are experiencing.

### People who I communicate with



# Communication

## Skills to Improve Communication

### Plan what You want to Say

Saying things on the spur of the moment about important topics is never a good idea.

It helps if you spend some time thinking about what you want to gain from talking to the other person. Do you want them to understand how you're feeling about a situation, or do you want them to help you to understand about how you're feeling about something? These are two different things: it's worth being clear at the start of your communication about what the aim is. It also helps to be realistic. Some topics will take time to come to a conclusion and may require revisiting several times.

### Pick your time

Try to avoid important communications when you're feeling hungry, thirsty, very tired or unwell. You also need the person you are talking to be in the best condition themselves. If they are not, then try to make another time to have the conversation. People vary in the times of day that are best for them to do different activities, as in this example:

*"For my husband and I to discuss tricky situations we need to try and stick to afternoons when our energy levels are well matched, early morning is good for me since I'm a lark but no good for my husband who is an owl. Similarly we can't discuss things late at night because I'm a lark and get really ratty if I'm kept up too late."*



### Empathetic listening (Stephen R Covey)

One of the things that causes us stress is the unintentional harm we cause when we talk to each other, especially when we are seeking to solve problems. We typically seek to be understood ourselves. Most people do not listen with the intent to understand; they listen with the intent to reply.

Empathetic listening means understanding that in any situation you already know what you think and feel about the subject up for discussion. However, you don't know what the other person thinks and feels. The aim of listening this way is to find out information from other people without forcing them to listen to your opinions. You are trying to get along side them to understand their point of view. You ask questions and genuinely listen to the answers. Once the listening phase is over you can put their information with your information and make some suggestions that will be appropriate to help solve the problem up for discussion. You might want to have a break from the discussion before you move onto this last step.

# Communication

## The power of language

1. Stick to describing situations using facts and evidence - boring, but it significantly reduces the opportunities for arguments to develop.
2. Don't try and predict what the other person might feel about a situation. It's difficult when you think you know someone really well, but these predictions can get in the way of you having a proper conversation and really hearing someone else's opinions.
3. Try not to criticise and complain except where it is useful and appropriate - it has the power to generate a lot of bad feeling.
4. Take responsibility for how you are feeling about something. No one has the power to make you feel a particular way about something, that's a choice we make ourselves partly determined by the way we think about it for ourselves. For example, if someone has done something and it has annoyed you, you may be choosing to feel annoyed because you think that they did it to annoy you. However, sometimes people do things because the possibility exists that they can do it. They don't think about the consequences of how someone else might perceive it.

## Useful things to remember

- In any communication you've been thinking about making, you may well have been thinking about it for a while, or at least you've been aware of it as an issue for a while. However, your partner may not have been aware of it or been thinking about it at all.
- Other people have their own priorities and other people's priorities at any given time are likely to be very different to your own.
- You can't do it on your own: for a conversation to work you both need to join in and take part.
- For some really tricky conversations, walking and talking can be good, if it's possible for you. The walking seems to create a gentler rhythm for the conversation which can be very helpful, and as we tend to walk side by side it can reduce any potential for confrontation by quite a bit.
- Try not to go into conversations expecting the other person to "get it" the first time. It can take time for someone else to understand what you're saying. They may need time to think about it and come back to you with some questions.



# Communication

## ***Assertiveness - or the art of communicating your needs effectively***

**Assertiveness is the art of treating others with the same love and respect that you would like to have extended to yourself. It's not about forcing your views on other people, or being aggressive towards others. Assertiveness is about taking responsibility for the choices that you make and the consequences that follow from these when communicating with others.**

Assertiveness works best when you are clear about what outcome you would like to achieve from the conversation or situation you find yourself in.

Good negotiation skills are useful; aiming for a situation where both sides gain something (although both sides may have to compromise a little) is far better than trying to bully someone into doing what you want, or being passive and letting someone walk all over you. That said, passivity can be a positive choice in dealing with difficult situations. It's an assertive stance if you are making the decision to be passive and let something go and are willing to accept the consequences from such an action. It is not assertive to just roll over on someone else's demand.

Assertiveness requires that you respect that you have a point of view about a situation, but that someone else's point of view might be different from yours. An assertive person also recognises that someone might well hear what you have to say, but be unable to respond to it at that point in time for reasons that may well be beyond their (and your) control.

## **Communicating assertively**

- You need to take responsibility for how you are feeling (breaking the habit of blaming others for your feelings is a good thing to do) and be able to accept and hear that someone else may be thinking and feeling differently to you.
- You need to accept that even having heard you the other person may not be in a position to respond to your communication at this particular point in time.
- You need to check that they are understanding what you are saying, for example, you can ask them to repeat back to you what it is they think you are trying to communicate. You can then clarify any bits they seem to be misunderstanding. It's helpful to remember that we have a tendency to use words in slightly different ways from each other.
- Mind your language; exaggerating does not help plead your cause, it merely serves to stress the individual that you are trying to converse with resulting in them feeling a need to run away from you rather than help you try and resolve your situation. Similarly getting angry, shouting and swearing also stresses the individual that you are trying to talk to.
- Try to use positive statements identifying what it is that you would like to see as an outcome rather than dwelling on what you don't want which can just lead to confusion.
- You might need several goes to get good at communicating assertively. It doesn't always go according to plan the first few

# Communication

times you try it. When it doesn't, it's just an opportunity to learn how to do it better next time; it doesn't mean that you are bad at communicating with others.

## When normal communications aren't working

- a. **Advocacy/Mediation** - An advocate or mediator is someone who spends some time with you finding out what it is exactly that you want from a consultation. You can have advocates for dealing with work situations as well as for consultations with healthcare professionals. Mediators help in work situations as well as assisting in family issues and in neighbourhood disputes.
- b. **Complaining** - if you need to make a complaint about your healthcare, then you should find that the Patient Advice and Liaison Service (PALS) are able to help you. Their role is to help improve healthcare by taking the complaints that are made to them and helping to find an appropriate solution. The service is free. There should be a PALS office in every hospital that you attend.

When you make a complaint, you have to remember that the person you are complaining about, be it at work or in a healthcare situation, is likely to take the complaint as a personal insult. Because most of us confuse our self-esteem with our self-confidence, complaints about our actions (relating to our skills and therefore linked to our self-confidence) can be felt as criticisms of us as individuals (our self-esteem). For a complaint

to be very effective you need to focus on the problem (or process) that requires to be solved and leave out the (very tempting) character assassination.

## Asking for help

Remember communication works both ways: just as you might feel discomfort about expressing your feelings and asking for help, others may also feel the same way; don't assume that others, *"should know how I'm feeling and what I need..."*

## Having problems saying NO?

1. You can't please everyone - so stop trying.
2. The more things you do for some people, the less they value you and your time. If you can learn to say "no" to requests then your value will rise and others will think more carefully about how they spend the time that you are willing to devote to them.
3. Stop doing things for children and/or other people that they can do for themselves.
4. If you're asked to commit to a task that won't be easy for you, simply say that you are already overcommitted. Alternatively you can ask for time to go away and work out when you can take the task on and do the appropriate amount of work. Give the person the choice between having it done quickly but badly, or later but well.
5. It's perfectly OK to choose when you do things. It's a great compliment and much better to be in the best frame of mind when you see/talk to people than to be short-tempered and tired.

# Managing Relationships

## Managing a relationship with yourself

Central to maintaining and developing relationships with others is ensuring an effective relationship with yourself. We all have periods in our life where we are not happy with who we are and this state can undermine our sense of self, our self-confidence, and our self-esteem. For the person with a pituitary condition this unhappiness with who we are is often precipitated by an imposed change, for example, an altered appearance or infertility. This unhappiness is often complicated by our thought patterns as illustrated in the diagram below:

Establishing a good relationship with yourself is vital if you are to maintain old relationships (and develop new ones) as well as

establishing an optimum quality of life for yourself.

The crux to all of this is understanding that who you are (your self-esteem, best described as how much you love and value yourself) is different to and independent of what you can do (your self-confidence, i.e. the skills that you have and how good at them you are). It is important to be aware of how easy it is for us to judge ourselves negatively when what we are capable of (i.e. what we can do) is limited, or discounted by others. So, when our confidence in our abilities is low, or when we are not capable of doing very many things, our self-esteem quite often takes a battering. This is because most of us confuse who we are (our self-esteem) with what we can do (our confidence) and if our confidence fluctuates then so does our self-esteem. This can lead to a feeling of dissatisfaction with yourself, which for some (if unchecked) can become self-loathing. Once we begin to dislike ourselves we assume everyone else also dislikes us and we therefore become cautious of what we say, how we act, and what we are prepared to do when others are present.

Many people with a pituitary condition at, or after, diagnosis feel they have changed and often ask “*Who am I now?*” After a series of changes we may find ourselves taking stock and asking questions such as: “*What’s been positive?*”, “*How have I changed?*”, “*How do I think or feel other people view me now?*”

What we think and believe about ourselves and how we perceive others to think about us can determine not only how we accept the





# Managing Relationships

pituitary condition but also how we adapt to our 'changed self'.

It can help to remember that another person's opinion about us is not a fact about us, although we often behave as though it is. You need to ask yourself, "Where is the concrete evidence that supports this judgement of me?" It's unpleasant but true that we often judge ourselves post-diagnosis based on the attitudes and beliefs we held prior to the onset of our condition, and so we assume that everyone else will be judging us based on that out-of-date set of attitudes, too. For example, you might have believed that someone who allows others to care for them is basically a weakling and somewhat inadequate. The truth is far different to that, as you now know, but we don't often update our attitudes until someone gets us thinking about what we believe about ourselves.

What can often exacerbate this is the fact that the treatment you need for your condition can take control away from you. It might prove to be crucial to you to take the control back from healthcare professionals and family members. The idea behind this is the attempt to gain a sense of normality by getting back into a more familiar routine.

## **The effects of an altered body image and identity**

What is a person? It's an interesting question and one that is very pertinent to individuals whose self-esteem and self-confidence have taken a hammering because of a change

in their identity, be that through physical changes as a result of a health condition, or through job loss, retirement, or sudden increase (or decrease) in wealth. A person is made up of more than just the way they look (their physical appearance). A person is a collection of various factors of which their body is just one aspect. Other important facets that make up a person are the mind and how this expresses itself through intelligence, wit, thoughts and ideas; personality; and moods and emotions. It's easy to forget the role that personal history and experience plays in our understanding of both ourselves and other people. Similarly, we often forget the spiritual aspect of what it means to be a person. So, a person is potentially a complex mix of many factors.

We have a tendency as humans to focus on what we don't want, on what is missing rather than on what we are and what we have got. This negative focus is very unhelpful in dealing with a changed identity. It is useful to reflect on the fact that different does not have to mean better or worse, and yet we tend to think in these very all-or-nothing and quite judgemental ways. Different can just mean different, being neither better nor worse. So, in coming to terms with a changed identity we would argue that one of the first changes it is necessary to make is this shift in judgements. Can you get to a place where different is just that, different, and not better or worse than you were before?

# Managing Relationships

## Working on a 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 aim would be to treat yourself with the same love, respect and understanding that you extend to others. This is not about turning yourself into a mirror-kissing, 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 those of other people.

## Physical attributes

What aspects of your physical self do you like and value? Do you have nice hands or feet? Do you like your nose? Remember, this is not about what other people think, it's about what you like about yourself. Even if it's only the nail on one hand that you like about yourself, it's a place to start. Once you can feel something positive for one aspect of your physical self, you can then start to extend that to the rest of yourself. If you go through your life hating the way you are physically put together then you can miss out on some important information about yourself. Your physical self is just one way that you communicate with yourself, your thoughts and feelings are two others.

## Pay attention to your needs

It's really important when you're working on building a good relationship with yourself to be aware of the things that really matter to you. This is a good habit to get into; being aware of what you would like or need in different situations. Generally as humans we are brilliant at identifying what we don't want, we are not very good at identifying what we do want. *"As a child I found adults very confusing. Telling me that they didn't want me to do something left umpteen choices for behaviour and did not leave me any the wiser as to what it was they actually wanted."*

## Things you do for yourself

What things do you do for yourself that you really value? Is it only you that knows how to make a cup of tea or coffee just the way you like it? Do you know what your favourite grooming products are and do you make the effort to buy them for yourself, just because you like them? What other secret likes do you have that you can make the time to recognise and act on?

## Choosing when you're with others

It's very easy when you have low self-esteem or a poor relationship with yourself to refuse to make good choices for yourself when you are with other people. If you are at a friend's house and they offer you a drink, you might say *"I'll have whatever you're having."* We do it to make life easier, but in reality it's another way of undervaluing yourself. If you would like a glass of water then saying so reaffirms your self-esteem and improves your relationship with yourself. It's a small thing, but when working on improving your relationship with yourself these small things matter.

# Managing Relationships



## **Making friends with yourself - 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.*" It's very easy to be harsh and critical and to keep on repeating unpleasant things about yourself in your head. If you can find a positive way of describing yourself that makes you feel good about yourself then that can be a major step forward. Describing yourself as "*a work in progress*" could be an improvement on repeating whatever ugly names that you've learned to use. Also, 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.

## **Power minute**

The point of this technique is that it stops stress building up during the day. It also aims to keep you generally calm by making you listen to yourself. Approximately once an hour you need to ask yourself two questions:

1. How am I feeling?
2. What do I need?

The answers to the first question will vary from: I need the toilet/drink/snack, my shoulders/back/head is hurting, I'm going too fast, I'm bored, etc.

The point of the second question is that you think of something that is quick and easy that will answer the need you have just identified. If you need to go to the toilet, go! If you need a drink, have one. Little niggles can end up being big problems if you don't deal with them promptly.

# Managing Relationships

## One minute meditation

To do this you need to find a place where you can be alone and quiet. During one minute, bring your focus first 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 and mind are trying to tell you in their various ways. After the session write down how you felt at each of the different points during the meditation:

1. Did your breathing tell you anything? Was your breathing shallow or deep? Were you aware of your breathing changing during the meditation?
2. What was your body saying to you? Was there any pain or discomfort that you became aware of during the meditation?
3. What were your thoughts telling you? Was it a list of things to do? Were there more worries hiding under the list of things to do? Is there a problem hovering in the background but that was difficult to pin down because of all the other noise?
4. What about your emotions? How did you feel during each of the sections above? Was it easy to get started on the meditation, or difficult? How are you feeling now that the meditation is over?

## Thought stopping

This is a technique where we mentally say “stop” when troublesome thoughts start either during the day or when we are trying to fall asleep. You can either say this to yourself in your head, or say it out loud whilst simultaneously clapping

your hands sharply once, or imagine a large sign with “STOP” 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.



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## Communicating with family members

**People do not live in social isolation with only their pituitary condition for company; they often interact daily with partners, family, friends, and colleagues, and less frequently with healthcare professionals. Coping with a long-term condition often involves maintaining a sense of who we are but also the need to maintain and develop relationships with others. Changes within existing relationships at the onset of a long-term condition are very common and pituitary conditions are no exception to this. As the full consequences of the condition become apparent, relationships can be threatened further.**

Changes to how you see yourself, specifically in relation to fatigue, mean for many the loss of a role within the family and home. The loss of social roles can affect self-esteem and exacerbate the emotional impact.

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

*“you feel inadequate in some ways at home”*

You may well need to think about the process of diagnosis and the ongoing condition management after diagnosis as two separate stages requiring different management. If the person with the pituitary condition was hospitalised in an emergency it is likely that everyone in the family is suffering from shock to a greater or lesser extent. However, if the diagnosis has taken a long time then that presents different challenges to the dynamics within a family. You might have been told that you're OK by your GP, or been subjected to lots

of tests over a long period of time, but in the mean time have been suffering periods of not feeling right and have probably been unable to do all the things that you would normally do without thinking about it. Not only do you find this difficult to cope with, but it also unsettles family members. The lack of understanding of the situation can lead people to veer between feeling sorry that you're not feeling well, to feeling irritation that it's happening again and that they are left carrying the burden of running the house.

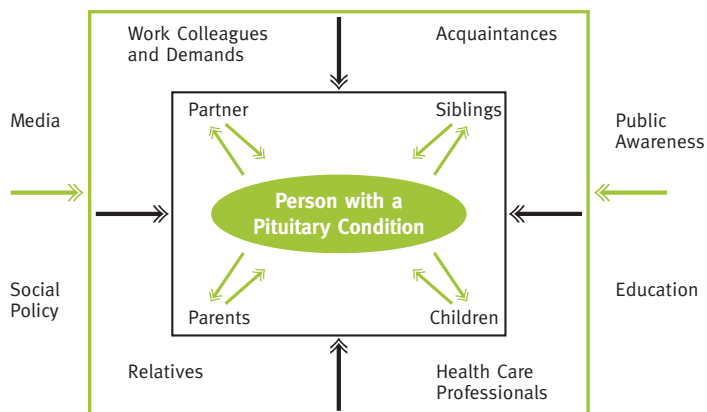
You need to remember that your family members do not necessarily have the same understanding of your condition that you do. They certainly cannot control your condition any better than you do. However, control can become a barrier between couples and family members and quite often it can feel like a battle to be won or lost. Family members can be very concerned that you are looking after yourself properly. They may be carrying an unspoken dread that you are going to die and abandon them and they may have no way of telling you this. This can fuel their anxiety and manifest itself in nagging about your medication, the time you're going to bed, what you choose to eat, whether you have your medical kit with you when you go out, what time you're going to be home. The list is endless and requires managing if the situation is not going to deteriorate to the point where you are all shouting at each other out of fear and frustration.

Unfortunately, explanations and education about the condition are focussed on the individual with the pituitary condition firmly

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in the domain of the healthcare professional-patient relationship leaving the family uninformed, scared, frustrated and possibly angry. Open communication is vital if the emotional impact of a pituitary condition on the family is to be reduced and relationships are not negatively affected in the long term.

## Coping with a chronic condition



become very challenging as both you and your family become increasingly aware of the reality of a restricted life with a condition which is unpredictable. For some, the process of managing the re-evaluation of life goals can activate the grieving process. You might have had lots of ideas about things that you would like to do with your life and letting go of these can be painful. We can start to see things as

being “good” or “bad”, “better” or “worse”. Negotiating change can be very difficult and can affect both partners and other family members. Partners can also feel that their life goals also require re-evaluating and changing and this can activate the grieving process for what might have been for them. This does not mean that they no longer love you,

## Partners

### Domestic

The onset of a pituitary condition and the demands placed upon you in terms of symptom management may well require that you change or re-evaluate your life goals. This may not only be true for you, but also for your partner and family. This process can

or care about you. Just that their aspirations may need to undergo a change as the full extent of what you can and cannot do is understood. Managing this process takes time and patience. We have put some information on managing change in Section 3 of this booklet. There is no magic cure, just tolerance for the fact that you are human beings doing your best to navigate a difficult situation.

# Managing Relationships

*"My relationship with my husband is changing, I have very little sex drive at all. I get very disheartened at times, I have added diabetes and heart problems to my list of illnesses, and it just seems so unfair. I am going through a difficult time accepting that this is an ongoing situation."*

*"No magic cure, just ongoing levels of illness"*

*"...Change in relationship with husband and lack of sex drive has meant a big change"*

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 may feel guilty and selfish for wanting sex. 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 libido are two-way things. 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 intimacy of any kind.

*"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 and 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 unattractive. With these perceptions of themselves firmly in place people will avoid sexual situations or even thinking about sex.

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However, suppressing sexual thoughts can often lead to depression, which further reduces libido, which can deepen the depression; a truly vicious cycle. Depression can be managed (see Section 3 of this booklet) and there are ways to explore and improve your sensuality and intimacy as well as overcome any fears you may have during sex.

## Partners

### ways to help you cope with low libido

- Try to share what you are feeling with your partner (see the communication strategies at the start of this booklet);
- 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;
- Manage your stress and depression (see Section 3, page 29).

### 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.



# Managing Relationships

## **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 on the next page). 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
- Super date: How to be one, how to get one

## **Sexual Dysfunction**

Pituitary disorders are a common cause of sexual dysfunction. However steroid-induced diabetes mellitus can exacerbate the problem, with men experiencing problems with erection and women experiencing pain during intercourse. There can be failure in achieving orgasm and reduced desire and arousal.

Sexual function can be affected by cigarette smoking, drinking too much alcohol, the use of some recreational drugs, and a lack of exercise, so by addressing these lifestyle behaviours you

may experience improved sexual function.

However, one of the most common causes of sexual dysfunction in men and women is psychological distress manifesting as tiredness and fatigue, anxiety, stress, depression, feelings of inadequacy, poor self-image, (for men) embarrassment about the size of their penis and the possibility of premature ejaculation, guilt, and anger. Addressing these through counselling or self-management strategies (see Section 3) could be something to consider.

There are treatments available to help with sexual dysfunction which include sex therapy (your GP and endocrine nurse specialist should be able to recommend a sex therapist); and Sensate Focussing which is available through RELATE.

## **Children**

What do children need to know? The literature and research related to other long-term conditions suggests that children are affected by a parent's illness. They need information to understand what is happening and the changes that are taking place. Ideally, they should be provided with information which is relevant to them and age appropriate for them presented as and when they ask for it. You need to be open and honest with children without worrying them in the process. Remember, if you are worried about talking to your child about your condition, they will pick up on the anxiety and may feel that they are doing something wrong and are somehow to blame for what you are telling them. You need to try and be

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as comfortable as possible with what you need to communicate to your child, or failing that acknowledge how you are feeling and make that part of the discussion about your condition.

Many young children can feel that in some way they are responsible for their parent's ill health or that their behaviour makes their symptoms worse. This belief is based on the fact that the parent may be irritable or withdrawn from family activities, or the child may have been told by another adult that, *"they have tired mummy out and now they should be quiet"*.

Older children are often given the responsibility of caring for their younger siblings but actually don't have the authority to care for them, and can find themselves being blamed for their sibling's misbehaviour. If the partner works then a child will in effect take on the role as carer. This has a huge impact on child who may mature very quickly into a mini-adult, different to their peers. This can mean that the child no longer sees their friends in the same light. They can feel that they have no time for fun and games and that playing is a pointless activity. They can feel very shut off from other people, with adults patronising them, and their peers making fun of them. There is a need for families to draw on other support systems allowing children to be children, a necessity for a normal relationship to resume. Failing that, the child with the responsibility for their siblings or as a carer requires a mentor who can help them unravel their feelings and deal with the situation so that it doesn't overwhelm them.

## Communicating with other people

### Parents/siblings/wider family

The impact of a pituitary condition, like most long-term conditions, has wider implications beyond the immediate family to include parents, siblings, etc. So as a person with the condition, or as their partner, understanding the issues that your condition might raise for these people needs attention to enable you to manage your and their expectations of you and what you are able to achieve since the condition developed.

Sometimes it can feel like you have to manage everyone else's reaction to your condition. It can help to approach the process of dissemination slowly. It's OK to tell people when you feel ready to, or when you feel you need to tell them. Families can be very political. You might have to tell certain people before you tell others if you want to avoid offending them. The truth is that while people may appear to be adults, in families childish behaviour can reappear unexpectedly. You may have noticed this at family gatherings where you and your siblings (should you have any) revert to behaviour that you used to do when you lived together. Having a sibling diagnosed with a health condition can sometimes cause these old behaviours to reappear. Especially if your parents or other family members step in to help with childcare and/or financial assistance. You can find siblings moaning that *"it's not fair"* just as they did 20 or 30 years ago!

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## Friends

We choose our friends to reflect different aspects of ourselves. So, we have different types of friends, for example, the “*party animal*”, the “*surrogate sister*”, some where you support them, some where you provide the support. Some will have a deeper understanding of you and your life whereas others are for you to have fun with. Because of this we tend not to talk about the same things with all our friends, in fact we may not even communicate with them the same way.

Understanding the issues that your condition might raise for these people to enable you to manage your and their expectations is important. A life interrupted by daily fatigue or an altered appearance will reduce the desire and opportunity for partying, so the party animal may not phone as they find it difficult to deal with the imposed changes. While a surrogate sister might offer much needed emotional support with or without an understanding of the condition because they accept you for you. You may therefore decide to tell some of your friends and not others. You might find that this is a period in your life where your friendships start to change and where some of the friendships naturally finish whilst others flourish.

If we allow it, our negative beliefs, low self-esteem and confidence, and mood disruption can feed our inaccurate assumptions and perceptions that people do not want to be with us.

## Work

For many people, the work that they do makes up a significant part of how they define

themselves as a person. Having work to do, going to a job, it gives us a sense of value, of making a contribution, whether that is in the workplace or in the home. Problems can arise when this is challenged in some way for example because of redundancy, retirement, accident or illness. Not having a contribution to make can lead you to feel as though you are on the scrapheap of life, that no-one wants you anymore and that you are worthless. These feelings link back to what we were talking about at the beginning of this booklet; the confusion that many of us make between the relationship we have with ourselves (our self-esteem) and what we are capable of doing (our self-confidence).

For those who cannot return to work, or have to stop working, there are problems to be overcome.

*“Stress is a big problem day to day.  
Mine is due to being on benefit (not  
being able to work).  
Money does not cover needs... makes  
me feel very depressed, frightened,  
anxious and I don't tell people  
because I am embarrassed to.”*



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Finding others who will support you is good for you. Trying to bear the burden of difficulties on your own is not good for you and can make the mental health consequences of anxiety and depression more severe. There are centres where you can get advice and support, such as the Citizens Advice Bureau. There are also places where you can go and get other forms of support, a trip to your local Library may give you lots of ideas. You can also get support from **The Pituitary Foundation**.

For those who can or do return to work there are different problems to be faced and dealt with. There are the issues related to how you are going to be able to stick to your treatment regime and do the necessary things that are required as part of your condition management. The **Pituitary Foundation** has an **Employment Booklet** which provides hints and tips on managing the physical aspects of a pituitary condition in the workplace.

The next issue is, *“who needs to know?”* Some people are naturally very private and would rather chew glass than tell anyone any private details about themselves. They do not want a label and may actively resent having to play the *“sick card”*.

*“I went through all the worry and horror on my own, didn’t want to tell anybody the thought of being the only one in the world...I wanted to understand what was happening inside my head and in my body and the specialist didn’t have the time (laughs) to explain “*

However, there are some people that you may well need to tell about your condition and the treatment regime that you need to stick to. Large companies may well have an occupational health department whose job is to make sure that you are fit to work and that your employer can provide adequate resources for you. Where occupational health centres exist, people can find them a great source of help and support.

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*"I did get good support actually with the job I was in at the time. They had an occupational health service... She came and saw me in September and said, "Don't go back until after Christmas, you're in no fit state... Just thinking about it brings tears to my eyes. That was just so supportive, to have some one say, "You can't cope with this, and why should you?"*

Smaller companies may well not have any occupational health department. This may mean that you are dealing primarily with your boss and the **HR (Personnel) Department**. HR (Human Resources) Departments vary hugely in how good they are at dealing with employee problems. Some of them are very good and you will get as much support as you would from a good occupational health service. However, others are not so good, and can give the impression that you are a nuisance that they would rather not be dealing with. Some HR Departments largely have their roles restricted to "hiring and firing", and managing returns to work is a bolt-on aspect of their job for which they have not been trained. They may well be struggling to know what to do and how to deal with you and lack the confidence to be seen to be asking for assistance in helping you make the return to work. In this situation you may find that the onus is on you to determine how your return to work is managed. You can see your GP who can give you advice on when to return to work and how it can be managed. They can provide you with the necessary paperwork for your workplace. There is a role for the community of the members of **The Pituitary**

**Foundation** here, you can get a lot of ideas from others who have had both good and bad experiences of managing the return to work and then pick what would help you the most.

The return to work can lead to some very mixed feelings. Some people find it very difficult to return, not least because of the need to manage the depression and mood swings which can be a result of having a pituitary condition.

*"We've all had it you know, clinical depression. You're knocked out your job, you got the label. Its difficult to come back... just difficult. Everything's more and more difficult."*

The current situation as regards the workplace is that you need to be honest with your employer about your condition and what it takes for you to manage it. You need to manage your own expectations of yourself and what you can and cannot do, and you need to manage your boss's and colleagues' expectations about what you can and cannot do.

*"I would say I probably hide what's wrong with me in a way, because you don't want people to know you are different, because you don't really look different apart from the fact that you are fat and my face has changed... in a way I feel it's wrong to hide it, but it's right because I don't want to be suffering"*

If it is possible, building up slowly is a good thing to do. Many people returning to work after a break find that they don't feel very confident in their ability to do their old job. Making a list of the various things that you used to do and then making a decision about where it would be sensible to start back can

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be helpful. So you might prefer to start out doing the quieter jobs that keep you at your desk, rather than being launched straight back into the hurly burly of meetings with lots of people present. It can be a good idea to have a diary where you write down the things that you would like to achieve that day, then as you do each one, tick them off and give yourself some praise for having achieved the task.



It can help if by the end of the day you have at least three things where you feel satisfied that you met your own minimum requirement for doing the job.

There is a world of difference in being trained to do a job and actually being able to continue doing the job. It's a tough decision but you may find that at some point you have to take the decision as to whether you can really do all aspects of your previous job. It can be very

scary, not least because if you lose your current job, then you may have concerns about whether you will ever find any other work again.

*"any future employer will look at my sickness records and my health and take one look at me and go, thank you very much but no thank you"*

It's a tough thing to do, but you need to be honest with both yourself and your employer about what you are able to do, and those things where you need more support.

*"you don't want people to know that you are different because you don't really look different apart from the fact you are fat and my face has changed...I feel it is wrong to hide it but its right because you don't want to be suffering for my employer taking it out on me as it were...disadvantage"*

Some employers are willing to negotiate and to help reassign aspects of tasks that are now proving difficult for you to do. Remember, your pituitary condition may well have affected your memory (see page 17 of **Your Journey: Living with and Managing a Pituitary Condition**, a booklet produced by **The Pituitary Foundation**) so while you still know how to do your job, some of the detail may be escaping you. You can come up with ways of dealing with this, such as developing protocols for the aspects of the job that you are struggling with. A protocol is a list of all the steps, from start to finish, that you have to complete in order to do a particular task. A protocol can act as a prompt for the more detailed aspects of your job that you may be struggling with. Similarly, you might find that you need to try and keep

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more notes to remind yourself of conversations with people and what was agreed in meetings. It's better to manage your vulnerabilities than to be a victim of them. The need for protocols and notebooks is not a sign of weakness, but a sensible coping strategy. Using a problem-solving approach rather than getting mad at yourself when you can't do things will make the process of returning to work easier for you. Rising irritation, anger, anxiety and depression are all messages that your body and mind are sending to you that there is a problem that needs to be solved. The stronger the emotion, the greater the energy required to solve the problem. If you can learn to ask yourself some questions, such as, *"why am I feeling like this?"* *"What is it that I need to do to manage this better?"* *"What can I try to do next time that might give me a better outcome than the one I managed this time?"* you might find that it makes it easier for you to manage the process

of returning to work. Expecting to be able to do all aspects of your job and have things be exactly as they were before is unrealistic. It will take time to manage the return.

However, it may be that with the best will in the world, there is no way that you can do all the aspects of your job anymore. This is sad, but it's better for you to realise it and own it for yourself, rather than having your boss point it out and make the decision for you about when you will leave.

## Dealing with your boss

You need to remember that business works in a bit of a strange way in the UK. We promote people who are very skilled at certain tasks to the position of manager where they inevitably have to manage people. Just because you are a very skilled engineer, accountant, computer technician, etc, does not mean that you are going to be good at managing a department of





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other people. Having promoted such skilled individuals to management posts, UK business fails to train them in how to manage people. Some managers are very people-oriented. They like others and enjoy being a manager. However, not all managers are like this. There are some who just want to be doing their old job and don't enjoy the responsibilities that come with a department of people. They may feel scared, that they don't have what it takes to manage certain situations, such as an employee crying in their office. Many managers complain that they are expected to manage their staff's stress levels, but have no training in how to recognise when someone is becoming stressed and needing assistance. If you have a people-oriented boss, things may well be easier for you in managing your return to work. They may well be very supportive, and go in to bat for you with HR and your colleagues to help you to manage your return to work. If you don't have a good manager, then the situation can be tricky to manage. If poorly managed, you can end up feeling disempowered and depressed by the lack of support which can then result in damaged communications.

Your boss needs to understand that there is a need for both yourself and others to have patience and to wait and see what you are now capable of. You may find that your boss is stressed because in your absence he/she has been having to manage the department with a person missing. They have targets to meet and may feel that they want you to be back in the saddle as quickly as possible.

However, you need to be honest with

your boss about where you feel you can start. Between you, you need to agree a strategy for your return to work. The strategy agreed, you need to keep some records of how you are keeping your side of the deal. You will need to have regular reviews with your boss/supervisor. You need to be honest about those areas where you are struggling, because there may well be some help that can be provided to you.

If it becomes apparent that you need to alter your working patterns to accommodate your treatment regime for your pituitary condition, then you need to discuss this with your boss. It may be that some days you really struggle with big meetings in the afternoon - there is too much going on and your fatigue means that you can't track all the different people speaking. You can communicate this to your boss, and between you it may be possible to devise a way of working round this. However, you cannot expect others to be willing or able to manage your condition for you. They certainly are not going to be able to manage your condition any better than you do yourself. You need to be honest about how you sometimes find it difficult to know what you can do each day.

## Dealing with colleagues & peers

Your colleagues may have very mixed feelings about your return to work. They may not understand why you have been off because the boss hasn't told them. They may have lots of questions about why you have been away and how you are feeling but may be prevented from asking you any questions because they are scared of upsetting you. They may also



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be prevented from talking to you due to the pressures of work - opportunities to talk in some workplaces are very limited. You may have some friends at work who are very supportive and with whom you feel comfortable sharing how you are feeling and managing your return to work. There may be other workers with whom this approach would be completely inappropriate for you.

Remember that in your absence, your colleagues may well have been having to work longer hours and take on various aspects of your work for you. It can help to take the time to find out who has been doing what, and also take the time to thank them. You may need to explain your graded return to work in order to manage their expectations of what you can and cannot do. You are going to need their continuing support. This can be best managed by being honest about how things are going with you. Again, you may decide to share this with your colleagues who are also your friends and let them go to bat for you with other co-workers rather than taking on doing all the communication yourself. Where communication is poor, colleagues can get the impression that you are *“swinging the lead”* and using your condition as a way of skiving off work which they are having to do, but that you are being paid for!

Long absences from work can lead to power struggles on your return. If some aspects of your role and responsibility have been redistributed, taking control back from others who might be ambitious for their own careers can be difficult to do. You may need some assistance and support

from your manager to be able to manage this without there being any bad feelings.



## Strangers

Some of the people that you come across each day are going to be strangers. You may only ever meet them once in this lifetime. Does every person you meet really need to understand your pituitary condition as you understand it? Unfortunately, your head is not your friend in these situations. If your appearance has changed, particularly with regard to weight gain, you may have concerns about what others might think of you. This is not just true in relation to close family and friends, but to those that we meet casually. We may have strong beliefs about what it means to be fat, e.g. fat people eat too much. Because we hold these beliefs ourselves, we assume that others (including strangers) also hold these same beliefs.

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*"yes it does bother me sometimes that I have to shop in Evans and I'm a size 22 because obviously public perception is that I'm offeating MacDonald's every 5 minutes, that the reason I'm fat is because I eat too much"*

*"...all he saw was some fat bird who'd parked in the disabled space"*

Going through life thinking that others hold negative views of you is not good for your relationship with yourself (your self-esteem). The truth is that you are projecting your beliefs onto other people. Others may not immediately jump to the conclusion that you are fat because you eat too much. They may not notice you at all, and be thinking only about themselves and their own problems. Your beliefs can lead you to interpret the looks and glances from others in a very particular way. You can get to the point where you are effectively wearing blinkers, unable to see that the majority of people are not reacting negatively to you. The blinkers create the illusion that everyone is judging you, when the truth is that you are the source of some of the problem.

Some of the stress and anxiety can arise, in part, through a general lack of awareness and understanding from others.

*"People don't know what it entails [the illness]. Your life is restricted or changed by those things ... I feel like I need to try and explain to people,"*

*"No, but I look alright to you now, but you don't understand what it's like when I go home. You don't know what I struggle to do just to get here"*

*"I have to wear my \* mask everyday...I feel much better with a mask on"*

*"Trying to find female shoes size 10, they just look*

*at you as if, you know, "What's wrong with you?" "Stress, pain and anxiety. Verbal abuse from small children and small-minded adults, "You big fat pouff."*

Remember other people's opinions about us are not facts about us. However, our mind-reading and thought projection habits die hard!



## Health care professionals (HCPs)

Depending on your diagnosis experience you will have met (or may meet) a variety of HCPs, 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

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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 onto 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 elicit 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/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. As patients we often shy away from explaining all of our symptoms because we think the clinician will not want to be bothered with it, or that it isn't important enough, etc. We often divide what we feel are symptoms that can be "dealt with" compared to those that are in the "other" category. However, with pituitary problems, symptoms in the "other" category can be due to physical/hormonal changes, such as mood-swings, loss of libido, poor concentration. So it is important that we explain and discuss all our symptoms and let the clinicians decide what they can help with and what they can't. They need to know the whole person not selected bits! The following section may therefore help you to manage your time with the health professionals more effectively:

**It helps to be assertive when dealing with HCPs (see Section 1 of this booklet). Some of the following ideas might help you in managing your interactions and how you communicate with your health care team.**

1. 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

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ways 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.

2. 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.
3. 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 to check that they are still on track (Please see page 6).
4. 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.
5. 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 question 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.*

Relationships with health professionals need to be effective to allow for full, frank and honest communication to ensure management of the condition is optimal. So there is a need for a functional relationship with the health professionals even if you wouldn't chose them as a friend! While this relationship will provide effective support and management of the physical health it does not always address our emotional and social health. However support for psychological well-being is essential if you are to effectively manage the impact of your condition.

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## Body & Behaviour versus Thoughts & Emotions

**Remember:** Needing help with understanding your thoughts and emotions does not make you mad (or a nutter). So where can you get this help? **The Pituitary Foundation** provides booklets specific to psychological well-being, as well as the Endocrine Nurse, The Foundation helpline and message board, all of which provide opportunities for a reflective outsider (but who has experience of pituitary conditions) to understand and provide support for the physical, behavioural, thoughts (cognitive) and emotional components of living with a long-term condition.

## Counsellors

Talking to a counsellor can provide a place where you can truly understand what is happening to you. A counsellor can help you to hear what you are trying to communicate, by reflecting what you are saying back to yourself. In being reflective, they can help you resolve conflicts and find a way forward in difficult circumstances. A counsellor can be very useful because they are outside your personal situation. They are very good at listening and have no pre-conceptions about you. This last point is very important. Part of the reason our family, friends and work colleagues can miss the point of what you are trying to tell them, is that they have a very particular view of who you are and what you are capable of. In effect, they have you in a box and they are reluctant to let you out of the box. Talking to a counsellor means that there is no box to get in the way.



There are different types of counsellors who work either with groups, partnerships, or one-to-one using a variety of approaches independently or collectively (for example, Cognitive Behavioural Therapy (CBT), Rogerian humanistic approach, Transactional Analysis, Gestalt Therapy, Solution Focussed Therapy). You need to try them out for yourself and if you don't like them you don't have to work with them. Agreeing to see a counsellor does not commit you to a long-term contract with them!

The counsellor should be accredited with the BACP to ensure they are competent to practice. Referral to counselling services can be made through your GP practise, an appropriate professional body (e.g. the BACP) or via the BACP (details in the Resources section).

Not all counsellors can support all people with all conditions; you need to give them enough information so that they can match your needs with their skills and approach to give you an honest assessment of whether they will be able to help you.

# Understanding & managing the emotions associated with change

## Dealing with change

**We vary greatly in how we cope with changes, be they of the short sharp variety or the long slow burn. Preferences in dealing with change will influence the emotion that we associate with the change and affect how well we cope with the situation that we have to deal with.**

- Some of us really like change, the more the better. For some of us moving on to the next thing is really important, and doing things the same old way is boring and can make us restless. Individuals like this are constantly looking for the next exciting thing to do. They do not fear change at all, what they fear is boredom and being stuck in a rut.
- Some of us are ambivalent about change. We are quite happy with the status quo and may belong, at least some of the time, to the “if it ain’t broke, don’t fix it” school. For these individuals they can cope with change if it is necessary, but it is viewed as something of a necessary evil. These individuals know that they can cope with change, they know that it is a sometimes uncomfortable process that will be over. They won’t go looking for change but they can handle it when it happens.
- Some of us really don’t like change. We fear it and we also have concerns as to whether we have what it takes to deal with the change. For these individuals all changes are seen as bad and to be avoided. In the workplace, these individuals will try to keep with the old ways of doing things and sometimes will have to have their old work materials forcibly removed from them before they will start doing things the new way.

They may try to sabotage the new way in the hope that the old way will be brought back again. These individuals may feel overwhelmed by the change and a lot of changes in a short space of time may result in depression or high levels of frustration, anger and anxiety.

- It should be noted that, depending on the change that you are faced with, you might find that your own attitude to change varies. So, for example, you might think that supermarket reorganisations are always a bad thing and resist these changes, but you might remain unbothered by temporary road works. You may really like going to different holiday destinations rather than always going to the same place.

## Dealing with grief & 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 & 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.

# Understanding & managing the emotions associated with change

## 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 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 say feel they are no use and that there is no hope, that life is futile. It is important too, 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 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.



# Understanding & managing the emotions associated with change

## Coping with grief & 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. 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.

## Stress management techniques

The techniques outlined at right, might 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 reduce the build-up of hard skin on your feet and is good for your well-being.

## 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



# Understanding & managing the emotions associated with change

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.



## Learn something

Learning boosts confidence, which improves your well-being, 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.

## 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 it 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 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.

# Understanding & managing the emotions associated with change

## **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”, for example, 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.

## **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.

## **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.

## **Colour**

Looking at colour stimulates the brain, and warm colours such as 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, for example, 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.

## **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 (for example, 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.

# Understanding & managing the emotions associated with change

## 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.
- 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.
- Listen to some nice music.
- Massage your hands and feet.
- Do something creative.
- Spend some time on your hobby.



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## Distraction from Isolation

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

- Listen to the radio.
- Meet up with a friend to watch a film or DVD.
- 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.")
- 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 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.



## 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 above. 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 write the results down on your paper. You keep going until you've got it all out of your head. What

# Understanding & managing the emotions associated with change



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 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 laying awake at night with your head buzzing. Switching your

# Understanding & managing the emotions associated with change

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.



## Skills to help you manage 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.

# Understanding & managing the emotions associated with change

## **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 your life tends to leave you more vulnerable to emotional upheaval, especially anger and depression.



# Useful resources & references

## **The Pituitary Foundation Well-being Series**

### **Psychological Impact of a Pituitary**

**Condition:** Diagnosis and Treatment

**Your Journey:** Living with and Managing a Pituitary Condition

**Living with Infertility**

## **Useful websites, links & contacts**

**Asian Family Support:** PO Box 13686, London SW20 92H; 020 8539 5566

Send an SAE for a list of local therapists.

**British Association for Counselling and**

**Psychotherapy:** [www.bacp.co.uk](http://www.bacp.co.uk)

0870 4435252

Can provide lists of qualified counsellors and psychotherapists in your area.

**Changing Faces:** [www.changingfaces.co.uk](http://www.changingfaces.co.uk);

email: [info@changingfaces.co.uk](mailto:info@changingfaces.co.uk)

0845 450 0275

A support group for people whose appearance has changed.

**Citizen's Advice Bureau:**

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

**Off the Record Charity:** [www.offtherecord.org.uk](http://www.offtherecord.org.uk). Counselling support for young people

**The Obesity Awareness and Solutions Trust**

**(TOAST):** [www.toast-uk.org.uk](http://www.toast-uk.org.uk)

01279 866 010 Helpline: 0845 0450 225;

**Young Carer's:** [www.youngcarers.net](http://www.youngcarers.net)

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

Healthy eating and depression booklet.

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

Website that gives information on how to remain healthy.

**The Royal College of Psychiatrists:**

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

**The NHS Directory of Complementary & Alternative Practitioners (NHSTA):**

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

**Department of Health:** [www.dh.gov.uk](http://www.dh.gov.uk).

Provide guidelines on exercise and healthy eating.

**Relate:** [www.relate.org.uk](http://www.relate.org.uk). Provide services for couples or families who are struggling.

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

**Infertility Network UK:**

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

**About.com:** <http://infertility.about.com/od/copingwithinfertility/a/copestress.htm>

**Fertility Stories:** <http://www.fertilitystories.com/infertility.htm>

## **Useful books**

**Ten Minute Stress Relief Book.**

Erica Brealey, Cassell & Co (2002)

**Alternative Medicine: The Definitive Guide (Alternative Medicine Guides).**

(Paperback, 2nd edition).

Burton Goldberg, Future Medicine Publishing Inc.

**Women's Encyclopaedia of Natural Medicine:**

**Alternative Therapies and Integrative**

**Medicine for Total Health and Wellness**

(Paperback). Tori Hudson. McGraw-Hill Companies

**Bach Flower Therapy:** The Complete



Approach (Paperback). Mechthild Scheffer.

**A selection of books by Tracy Cox at**

[www.amazon.co.uk](http://www.amazon.co.uk) :

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

## References

**Monitor on Psychology: Battling the Self-blame of Infertility.** Rebecca A Clay (2006)

Volume 37 Number 8.

**On Death & Dying.** Elizabeth Kubler-Ross.

(1990) London: Routledge

**Obstetrics & Gynaecology: Grief, Depression, and Coping in Women Undergoing Infertility Treatment.** MP Lukse & NA Vacc. (1999)

Volume 93 pages 245-251.

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**Living Beauty.** Bobbi Brown. (2007) Headline

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**Chronic Illness and the Life Cycle:**

**A Conceptual Framework.** John S Rolland

(1987) Family Process 26:203-221.



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

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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

**86-88 Colston Street,  
Bristol, BS1 5BB**

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

HelpLine: 0117 370 1320

Administration Line: 0117 370 1333

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Pituitary Foundation

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