



Relationships and
Communication

Relationships and Communication

This booklet looks at how pituitary conditions can impact your relationships with yourself and others, and how you can manage this.

The
● Pituitary
Foundation

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Your relationship with yourself



How can a pituitary condition impact my relationship with myself?

Pituitary conditions can affect you in many ways, including how you feel and how you look. These changes can be hard to adjust to and can leave you feeling differently about yourself.

You may feel sad about the things you have missed out on, or angry at yourself for having less energy than you used to. You may also feel like you have a new identity as a “patient”. All of this can impact your self-confidence and understanding of who you are. If your pituitary condition has caused changes to your body, you may also struggle with negative feelings about this.

Pituitary conditions can impact your ability to work, do hobbies and daily tasks, and do the things you usually enjoy. Not being able to do these things can leave you feeling bad about yourself. This is because we often confuse who we are (our self-esteem) with what we can do. If what you can do changes, how you feel about yourself may also change.

If you feel bad about yourself, you may also start to think that other people feel bad about you too. These feelings can be difficult to deal with, but there are things you can do to help. The Pituitary Foundation is also here to help and support you throughout your pituitary journey.

How to build a better relationship with yourself

Just like your relationships with others, a good relationship with yourself takes work. It's important to try to build a good relationship with yourself though, as this will help you to accept your diagnosis and the changes it brings. Some things you can do to help with this include:



Treat yourself how you would treat your loved ones.

If you say something mean to yourself, ask yourself "Would I say this to a loved one?"



Remember that your thoughts are not facts.

If you think something bad about yourself, you can ask "Where is the concrete evidence that supports this judgment I have of myself?"



Take time to think about how you feel.

Ask yourself "How am I feeling right now?", or "What am I most worried about here?"



Remember that your thoughts and feelings are as important as other people's.



Remember that being frustrated about your body's limits is normal, but it will not change your situation.

Treating yourself with kindness, on the other hand, may improve your self-confidence, and in turn, your happiness.



Give yourself what you need.

Do you need rest? Do you need time alone? Do you need to talk to others? Spend time thinking about what you need and how to get this.

Pituitary conditions and body image

Pituitary conditions may also change the way your body looks or feels. This can be upsetting.

How you feel about yourself is called your self-esteem. When you are not happy with how your body looks, this can lower your self-esteem. If this happens, you may find it hard to be happy about other parts of yourself too.

All of this can impact your identity and sense of who you are. However, your identity is made up of many things. This includes what you like, what you think, and what you say.

It is important for you to remember that what you look like is only part of who you are and how other people see you.



Impact on your relationships with others



Communicating with friends and family

Finding it difficult to talk to friends and family

Your pituitary condition may cause you to feel very tired. If you feel tired often, you may not feel like you have the energy to spend time with friends and family.

If you are not happy with changes to how you look caused by your pituitary condition, you may also avoid people.

Avoiding the people you love can cause problems. If you do not talk to other people, you may feel more stressed about your condition and you may feel worse.

If you find it difficult to talk to people about your pituitary condition, it can be helpful to find one person that you feel comfortable enough to talk with. This could be a family member, a good friend, someone you work with, a teacher, counsellor, or a religious leader.

After you talk to one person about your pituitary condition, you may find it easier to talk to other people.

Try to talk to friends and family about how your pituitary condition affects your daily life. This can allow you to work together to find ways to stay close in a way that you are comfortable with.

The Pituitary Foundation can also help when it comes to talking about your condition. Our support groups and helplines offer a way to meet and talk to other people living with pituitary conditions. This can help you feel less alone and help you to understand your condition better.



Understanding your friend's and family's concerns

If your pituitary diagnosis happened very suddenly, it may have been a big shock for you and your friends and family. You may also have needed emergency surgery, which can add to this.

If your diagnosis took a long time, you may have felt unwell for months or years. During this time, you may not have been able to do things you could do before. This can be upsetting for you. It may also have been worrying for those closest to you.

People close to you may not understand what a pituitary condition is, and how it can affect your life. They may have a lot of fears about your health but might not know how to talk to you about it.

When they do not talk about their fears with you, this can cause them to panic, which can be stressful for you both. It can be helpful to explain what your condition means for your daily life and what you need and want from them.

Talking to a partner about your pituitary condition

A pituitary condition can affect both you and your partner. How much your relationship is affected may depend on different factors.

These factors can include:

- how long you have been in a relationship
- the symptoms and treatment you have because of your pituitary condition
- if you live together

You may also find that you have had to change plans you had for your life because of your pituitary condition. Having to change these plans can be painful. Your condition may also cause changes in life goals you share, such as with your partner or family. This process can be hard. You both may struggle with how your pituitary condition can affect your shared life.

Your partner may feel sad about any plans they had that may be more difficult to achieve now. This does not mean that they no longer love you, or care about you.

This only means that you both need to work together to learn what you can and cannot do. Doing this can take time and patience. It is important for you both to remember that you are doing your best to handle a hard situation.

It is also important for you both to be open and honest about your feelings. By talking about what you need from each other, this can help you both support each other and stay close.



It is important to find support if you are struggling with these feelings.

Getting support with work

If you have a pituitary condition, your ability to work may be affected. When your work in your household or job is affected, you may feel a sense of worthlessness, or a lack of purpose.

It is important to find support if you are struggling with these feelings.

There are places where you can get specific advice and support about work, such as the **Citizen's Advice Bureau**. Many libraries and community spaces run coffee mornings or meet ups, where you can turn up and talk to other people. Many libraries also offer support to help you find services online that can help you too. You can also receive support from The Pituitary Foundation.



Returning to work

Many people can continue to work with a pituitary condition, but you may need extra support to help you. You may need to think about how to deal with your treatment and symptoms at work.

You may also need to think about who you want or need to tell in your workplace about your condition. If you have adrenal insufficiency, it is important for those around you to know the signs of adrenal crisis and what to do if you have one. Talking about this with people at work can help keep you safe if you become ill.

It is important to have an honest conversation with your boss about your condition. This will make it easier for both you and your boss to manage expectations of what you can and cannot do.

Where to find more support

If you find it hard to talk to your boss or others at work, there is support available.

Your local council may be able to appoint you with a professional advocate. This is someone who spends some time with you finding out what it is exactly that you need from your workplace. If you are a member of a union, union representatives can also act as advocates. To find out more about this, please see our website.



We have lots of information on our website to help you with talking to people at work, returning to work after sick leave, and making changes at work to better suit your health.

Tips for talking to your healthcare team

It is normal for you to worry about appointments for your pituitary condition. You may have a lot of questions about your condition and symptoms. If your appointments are very short, you may worry that you will not be able to ask all your questions. You may also worry about any tests that you have to have during your appointments.

On the next page are some tips to get the most out of your healthcare appointments.

Make a list of questions to take with you. This can help make sure you do not forget what you wanted to ask.



Tips for your next appointment

- ① **Ask your healthcare team to explain any medical language they use that you do not understand.**
This can help you feel more confident about your care plan.
- ① **Keep a diary of all your symptoms and any side effects of your treatment.** You can then show this during your appointment. This will help your healthcare team know how to support you.
- ① **For short appointments, try and list your questions in order of importance.** This gives your doctor enough time to answer your most important questions.
- ① **It may be better to ask some of your questions at another appointment.** This is because healthcare professionals all focus on different areas. Before your appointment, you can ask The Pituitary Foundation's Endocrine Nurse Helpline who you should ask your questions to.
- ① **If you find medical appointments difficult, you can bring an advocate with you.** An advocate is someone who can support you during a medical appointment. They can also speak to healthcare professionals on your behalf. You can ask anyone to be an advocate for you. This may be a partner, friend, family member, or someone else.
- ① **Your local council may also be able to provide you with a free professional health advocate.**



It is important to have good communication with your healthcare team. This can help make sure that you are looked after well and get the right treatment.

If you are not happy with your care, you can also ask to see another healthcare professional instead. This is called getting a **'second opinion'**, and means you will be referred to a different healthcare professional. It is not a legal right, but your healthcare team should respect this request.

You can also ask the **Patient Advice and Liaison Service (PALS)** for support. PALS can give you medical advice and help find solutions to your complaints. PALS is a free service, and you should find a PALS office in every hospital.



Rebuilding your relationship with yourself



It is important to remember that your body is not to blame for your pituitary condition. Blaming yourself or your body can cause feelings of stress or anger, which may worsen your symptoms. It is important to try to reduce these feelings, if you can.

Things you can do to help improve your relationship with your body:

Dancing

If you are not struggling with fatigue, dancing can help you to appreciate what your body can do and help you to feel more connected to your body. It also makes endorphins (feel good hormones) that can improve your mood, which can help boost your self-esteem.



Gentle movement exercises (yoga, Tai-Chi, Pilates)

If you are struggling with fatigue, more gentle exercises such as yoga, Tai-Chi, and Pilates can help you be more mindful of your body and its movements. They can also help to lower stress and make you feel more relaxed.



Self-care

Take time to look after yourself. This can mean different things for everyone. Self-care for you may mean having a relaxing bath, reading a book you like or taking care of your skin and hair. Self-care is a way to show yourself that you are important and deserve to feel good. This can help you feel more loved and cared for.



Practical tips to feeling better about yourself

Doing things for yourself

Try to think of things you like to do by yourself. For example, do you have a favourite show or film that you make time to watch? This may seem small, but doing things because you enjoy them can help to boost your self-esteem.

Similarly, try to think of small tasks you can do for yourself that you appreciate. For example, are you the only one that can make a cup of tea or coffee the way you like it? Taking the time to do small tasks like this can also help reduce any anger you have for yourself.

Asking for what you need

If your pituitary condition has caused you to have low self-esteem, you may find it hard to ask for what you want. Asking for what you want can help to improve your confidence. It can also help improve your relationship with yourself.

Start by making simple requests. This could be something small, such as asking for time to yourself to do things you enjoy.

Over time, these small requests can help you to improve your self-esteem. It can also make it easier for you to ask for what you need.

Talking kindly to yourself

If your pituitary condition has affected your confidence, you may find it hard to be kind to yourself. This can lead to you talking about yourself using hurtful words. You may also find it hard to think of anything you like about yourself.

When you continue to talk about yourself this way, this can be very harmful to your mental health. Negative self-talk can also make you more stressed. This stress may in turn impact your health. It is therefore important to learn how to be kind to yourself.

Try to take notice of when you say or think something unkind about yourself. Then, replace that thought with a more positive one.

For example, after you think something hurtful about yourself such as:

“ I am so lazy, I haven't done anything today. ”

replace this hurtful thought with a kind one, such as:

“ I tried my best to do what I could today, even though I was tired. ”

Even if you do not believe this kind thought, replacing your thoughts like this can help you feel better. It may seem difficult to replace your hurtful thoughts at first, but over time this will get easier.

Try to talk to yourself, and about yourself to others, as if you like yourself, even if you do not. This can help you to improve your confidence and self-esteem over time.

It can also be helpful to try to talk to yourself the same way you would talk to someone you love. When you think something hurtful about yourself, ask yourself “Would I say this to someone that I love?” This can help you be more mindful about speaking kindly to yourself.

Power Minute

The Power Minute is an exercise to help you remember to listen to what your body needs during the day. It involves you spending one minute each hour asking yourself the following questions:

1 How am I feeling?

2 What do I need?

Asking yourself “How am I feeling?” can help you to notice if your body needs anything. You may find that you are hungry, thirsty, or your head hurts. This question can also help you to take notice of how you are feeling emotionally. You may find that you are bored, stressed, or tired.

Asking yourself “What do I need?” can help you think of small things you can do to help improve how you are feeling. This could be getting something to eat or drink, taking a small break, or going outside.

By spending a minute each hour thinking of what you want and need, this can help you feel more calm and less stressed.

Thought stopping

Thought stopping is an exercise where you say “stop” when you have bad thoughts about yourself. It can also help to stop you being too anxious about your pituitary condition.

You can either say “stop” in your head or say it out loud.

It can be helpful to clap your hands or click your fingers when you say stop. You can also instead imagine a large sign with “STOP” written on it. By clapping your hands or clicking your fingers, this may help stop your bad thoughts for longer.

Tips for communicating well with others

Plan what you want to say

Before you discuss important topics, try to think about what you are wanting to say first.

Think about what it is that you want to gain from talking to the other person. Do you want them to understand how you are feeling about something? Do you want to understand how they feel?

When you start a conversation, it is important to be clear about what your goal is. It is also important to make sure your goals are realistic.

Some topics do not have an easy answer that works for everyone, and you may need to discuss them again in the future.



“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.”

Useful things to remember

- **If possible, try walking together whilst you both are talking.** This can help you both stay calm and can make the conversation feel less stressful.
- **Remember that it can take time for someone else to understand what you are saying.** The other person may need time to think about what you’ve said and come back to you with any questions they have.
- **Have important conversations at times that work well for both of you.** Try to avoid talking about important things when one or both of you are busy, unwell, hungry, or thirsty. This can help make sure that you can both give your full attention to the conversation you want to discuss.

How to be assertive

Being assertive means to talk with confidence, while also being respectful. Learning how to be assertive can help make it easier for other people to understand what you want. It may also make it easier for others to help you.

Tips for being assertive:

- **When you ask a question, focus on what you want instead of what you do not want, as this can lead to confusion.** For example, if you are out with friends and need to go home to rest, instead of saying:

“ I do not want to stay out. ”

Say:

“ I am very tired and so I want to go home. ”

- **Check if the other person understands what you are saying.**
You can do this by asking them kindly to repeat back what you have said. Once they have repeated what you have said, you can then explain any areas they did not understand.
- **Try not to shout or swear when having tricky conversations.**
This might feel hard but it helps to make the conversation less stressful for both of you. If the other person is shouting or swearing, end the conversation. Let them know you can keep talking when they have calmed down. If you both remain calm, this can help you solve the issue together.

Tips on how to say “no”:

When you have a pituitary condition, stress can make your symptoms worse. If you say “yes” every time someone asks you to do something, this can make you more stressed.

Below are some tips to learn how to say no.

- **Remember that you cannot make everyone happy.**
You can only try to do your best in any situation.
- **Remember that saying “no” is not mean or selfish.**
It shows people that you respect yourself and your time.
- **If you are unable to do a task someone asks you to because you are busy, let them know.**
You can also ask if there is anything they can do to make the task easier for you to complete.
- **Be mindful of the words you use when saying no.**
Try not to say “sorry” too much when saying no. Instead, thank the other person for their understanding.



Counsellors

A counsellor is a professional that can help you to find solutions to your own problems. They can help you to find ways to cope with your pituitary condition diagnosis and treatment. They can also help you deal with the difficult feelings that come with a diagnosis, or living with a pituitary condition.

Talking to friends, family, or people you work with about your problems can be helpful. However, because they know you, it can be hard for them to give you advice that is fair and unbiased.

Counsellors are professionals, which means they do not have a personal relationship with you. This means they can give you advice that is fair and unbiased.

Anything you tell a counsellor is confidential. This means they cannot share anything you have told them with anyone. This can make it easier for you to be honest and talk about sensitive topics with your counsellor.

There are different types of counsellors that all use different approaches. You may have to try a few different approaches to find one that works best for you.

When you first meet with a counsellor, try to give them enough information about what you need help with. This can help them work out if the need to refer you to another counsellor that can better support your needs.

If you want to speak to a counsellor, you can ask your GP to refer you. You can also choose to find a counsellor privately.

When choosing a counsellor, be sure to go with someone who is registered with a professional body. This way, you can be sure they know what they are doing and follow good standards in their work. The largest professional body in the UK is the **British Association for Counselling and Psychotherapy (BACP)**.

The Pituitary Foundation also offers a number of online counselling services to support people who are affected by pituitary conditions. These services are run by counsellors who are trained to help people with rare diseases. You can find out more about this on our website, or by giving us a call.

Useful resources

Asian Family Counselling Service

www.asianfamilycounselling.org

Email: admin@asianfamily.co.uk

Phone: 0203 582 0212

British Association for Counselling and Psychotherapy

www.bacp.co.uk

Phone: 0145 583 3300

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

Changing Faces

www.changingfaces.org.uk

Email: info@changingfaces.org.uk

Phone: 0300 012 0275

A support group for people whose appearance has changed.

Citizens Advice Bureau

www.citizensadvice.org.uk

Off the Record Charity

www.talkofftherecord.org

Email: info@talkofftherecord.org

Phone: 0800 980 7475

Counselling support for young people

Carers Trust

www.carers.org

Email: info@carers.org

Phone: 0300 772 9600

Offers support to young and young adult carers

MIND

www.mind.org.uk

Phone: 0300 102 1234

Have lots of information about a wide range of mental health conditions on their information and support pages.

More information

We have a full range of booklets to support people with their pituitary conditions, as well as information across our website. You can find this at www.pituitary.org.uk.

If you would like more support then we have a range of services that may be suitable:



Scan to see our website

Endocrine Nurse Helpline

Our specialist endocrine nurses can provide medical guidance.



Information and Support Helpline

Our volunteer- and staff-run helpline allows you to speak to others with pituitary conditions, and ask practical questions about living with a pituitary condition.



Telephone Buddy

This service provides one to one support with someone with a similar pituitary journey as you. For example someone with the same condition, or a parent of someone with a condition.



Support Groups

We have a number of volunteer-led support groups across the UK, which host meetings with endocrinologists and provide peer support for patients.



Events

We host online and in-person events with endocrinologists on specific conditions/topics. These give people the opportunity to hear from professionals and ask questions.



Psychological Support

You can find out more about our psychological support services on our website.



About The Pituitary Foundation

We're a dedicated team offering practical, emotional and peer support to everyone living with or impacted by a pituitary condition, to feel empowered and live with a greater sense of wellbeing.

For over 30 years, we've been amplifying voices and striving towards positive developments for the pituitary community. We work alongside healthcare professionals, clinical research teams and specialist organisations to raise the profile of pituitary conditions, finding better solutions for everyone affected by these life changing illnesses now and in the future.

Become a member and support our work

Becoming a member is an excellent way to show your support for our work at The Pituitary Foundation.

As a member, you'll enjoy a range of benefits including free copies of Pituitary Life magazine – full of great articles from endocrinologists and inspiring stories from people living with pituitary conditions. You'll also be able to have a say on how the charity is run, and get early access to our fantastic events.

A yearly donation of £25 allows us to continue our work now and in the future.

You can become a member at: www.pituitary.org.uk/membership

All information in this guide is general. If you have any concern about your treatment or any side effects please read the Patient Information booklet enclosed with your medication, or consult your GP or endocrinologist.

Our publications are supported financially by several pharmaceutical companies, in line with ABPI guidelines, including Ipsen, Merck, Sandoz and Sparrow Pharmaceuticals.

This booklet was produced in collaboration with medical experts and patients with lived experience of pituitary conditions. All information has been verified as accurate by clinicians from our Medical Committee. This booklet holds the PIF TICK quality mark for health information.

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