Helpline: 0808 800 2200
Text: 07786 209 501
www.epilepsyscotland.org.uk

Epilepsy Scotland,
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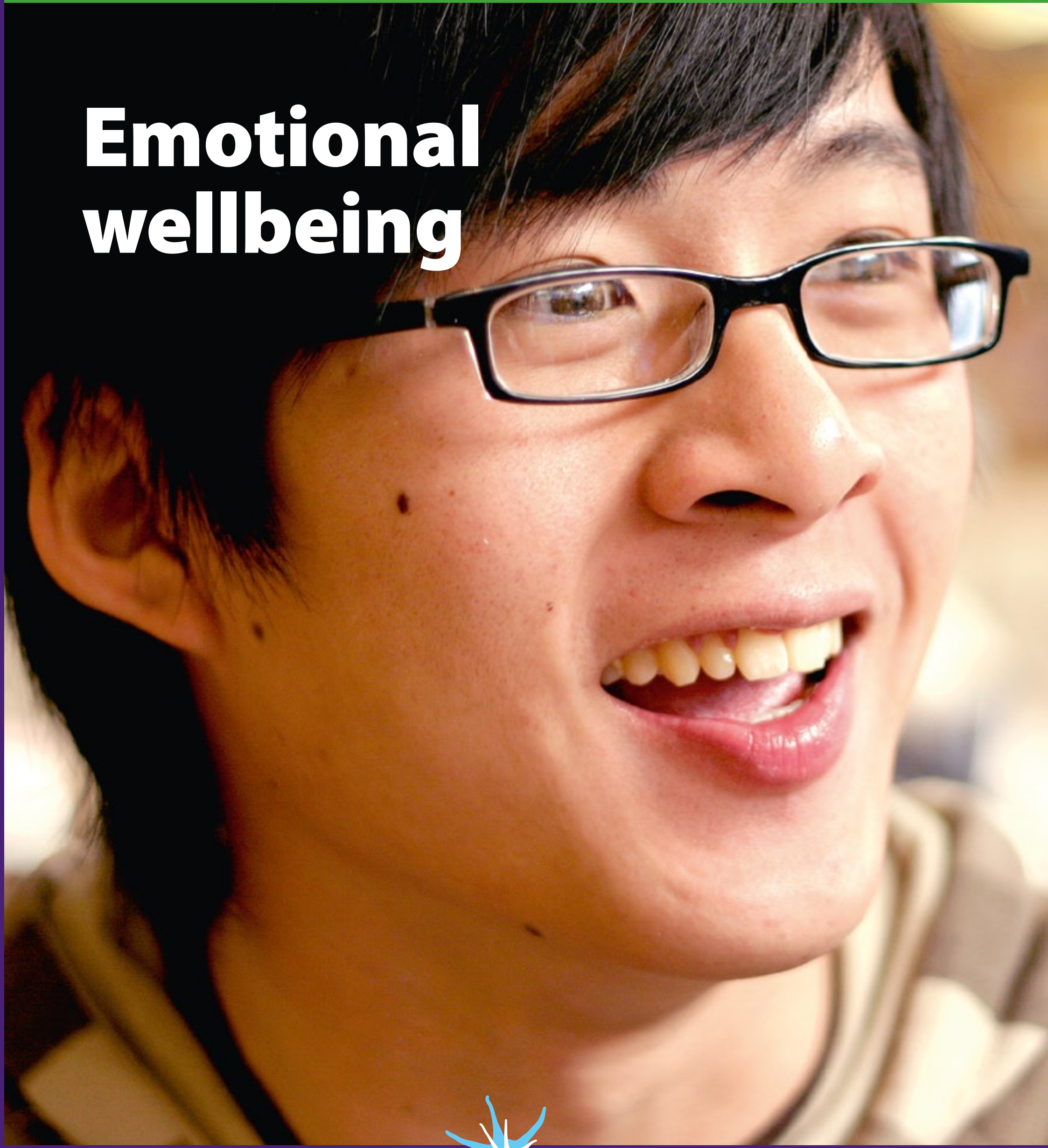
Emotional wellbeing



epilepsy scotland
Scotland's voice for epilepsy

Contents

> **"After I was diagnosed, I felt isolated from my friends and colleagues and I was worried about talking to my family and worrying them. I kept my feelings to myself until one day it became too much. I decided to call the Samaritans who convinced me to talk to my family. I eventually managed to turn my life around."**
>
> Paul Scott, Edinburgh

How this guide can help you

We have written this guide to help you understand how your epilepsy may affect your emotional wellbeing. The majority of people with epilepsy have very good seizure control and are able to live life to the full. However, a number of people feel their epilepsy is holding them back and struggle to cope with it on a daily basis. We hope that reading this guide will give you some tips on how to cope better. It will also tell you where to get help from if you need it.

If you are struggling right now and need to talk to someone, phone our confidential helpline on **0808 800 2200** (10am to 4.30pm Monday to Friday, and 10am to 6pm on Thursday).

Other helplines you can phone are:

Samaritans 0845 790 9090
(anytime)

Breathing Space 0800 838 587
(6pm to 2am every day).

What is epilepsy?

Epilepsy is one of the most common neurological (brain) conditions. Generally, a person with epilepsy has repeated seizures. These are temporary disruptions of the brain's electrical activity. Seizures are usually treated with anti-epileptic drugs. The medication will reduce or, in many cases, control seizures. In fact, up to 70% of people with epilepsy can have their seizures completely controlled by medication.

We have a lot more information on epilepsy, the different types of seizures, diagnosis, treatment, safety and lifestyle. Our helpline staff can talk to you in complete confidence about anything that concerns you. You can also download our many leaflets from our website **www.epilepsyscotland.org.uk** or phone us for a free copy.

It's normal to feel down or out of sorts

When you are told you have epilepsy it's completely normal to feel anxious, sad or angry. Coming to terms with a diagnosis of a long term condition is not easy. Often people struggle with this. Over time, however, many find it becomes easier to carry on with their lives as normally as possible. There are many things you can do yourself to make you feel better.

Once you have begun to feel more positive, you may find that your seizures will also reduce. The more you look after both your mind and body, the better you will cope.

It takes time and patience to accept your condition and how it may affect your life and work. Often just talking to someone about the way you feel will help you move forward. It might also help to speak to someone who has been through a similar experience.

The link between emotional wellbeing and seizures

It's important to address how you feel. Being stressed, anxious or depressed are all negative feelings. These may stop you from carrying on with your life as normal. They can also have a direct impact on your epilepsy and how well your seizures are controlled.

When you are feeling low, you may sometimes forget to take your medication. Some days you may not feel like taking your medication at all.

Sometimes, people try and cope with these feelings by drinking alcohol or taking drugs. All of this can make your seizures worse. It can also make you more depressed.

It is well known that stress and/or anxiety may trigger seizures. This is another reason why you should not ignore how you feel. Changing the way you feel can make a big difference to your seizures.

Reasons for feeling low

If you have been feeling low for a while, the best thing you can do is speak to your doctor, hospital consultant or epilepsy specialist nurse. They will help you understand what is making you feel this way. Then you can get the help you need.

There can be many reasons why you feel out of sorts. Here are some of the more common ones:

You may be upset because you feel everything about you has changed since your diagnosis. We've already mentioned this but it's worth stressing again that it's perfectly normal to feel upset or angry for a while. The more you know about your epilepsy the easier it can be to put things into perspective. Talk to someone you trust about how you feel. Or phone our helpline for more support.

You may be upset because your friends and family now treat you differently. Remember, they will need some time to adjust too. You may find they become over-protective of you. This can affect the way you feel about yourself. They mean well. Once they know more about epilepsy and how it affects you, they will become more relaxed about it.

You may struggle with how other people view you. Sadly, there is still some stigma attached to epilepsy even though this is slowly changing for the better. Accept that you cannot change what others may think. Remember, you may be the first person with epilepsy they have met and they don't know much about this condition. Talk to those whose opinion matters to you. Explain how epilepsy affects you, what you can and cannot do. This will usually change the way people view you.

You may struggle to accept the way your life has changed. This is usually the case if your seizures are not well controlled. Living with frequent and unpredictable seizures can be difficult. Having these seizures may make you feel you have lost control of your own body. Some people start avoiding going to public places, such as the cinema, or won't use public transport because they are afraid of having a seizure.

If you have frequent seizures, you will have to make some changes to your life to keep you safe. But you do not have to cut yourself off from your friends and family. Any loss of independence can be hard to accept. However, talking to someone can give you many ideas on how to strike a balance between keeping as safe as possible and allowing yourself to get some or all of your independence back.

Feeling low can be a side effect of your anti-epileptic drugs. Side effects are usually mild. Once your body gets used to the drugs, these tend to disappear. Common side effects are drowsiness, nausea, weight gain or loss. Mood swings and more permanent changes in your mood can be part of it. If you feel more irritable or your mood has changed in any other way since you've started your drug treatment, talk to your doctor or epilepsy specialist nurse.

Keep a diary about how you feel. You can score between 0 and 10 (0 for worst, 10 for best) on how you feel in the morning, afternoon and evening. Write down anything that's changed since you've started your drugs and take this with you to your next appointment. This will help your consultant, doctor or epilepsy specialist nurse decide whether your mood swings are side effects of your drugs. If this is the case, you may be given a reduced dosage or a different type of drug. **Never reduce your dosage yourself: this could be dangerous and could make your seizures worse.** Sometimes, your doctor or consultant will prescribe other medication such as anti-depressants to help you cope with the way you feel.

Your low moods could be linked to the cause of your seizures. Your seizures may be caused by scarring to one part of your brain. If this scarring is in an area of the brain which also deals with your emotions it can be the cause for the way you feel. One such area is the temporal lobe. Low mood, anxiety and depression are therefore more common for people with temporal lobe epilepsy. Your doctor or consultant will check to see if other medication, such as anti-depressants, could help.

Your low moods could be part of your seizures. Many people find they feel very strong emotions before and after a seizure. This can be anything from feeling very low to feeling excitement or even euphoria. Some of these emotions can occur up to 72 hours before a seizure and up to three days after a seizure. Your consultant or doctor will want to try and reduce the number of seizures you have as much as possible by adjusting your anti-epileptic drugs. Once your seizures are better controlled, you may find these strong emotions disappear.

There could be a link to your family history. Sometimes, others in your family may have experienced depression. However, just because someone in your family has a history of depression, this does not mean you will be affected. Remember that depression is a very common condition which affects more than half of all people at some time in their life. Family history is just another factor worth bearing in mind. Make sure your doctor knows about it as it will help with finding the most effective treatment for you.

When should you get help?

Everyone is different. Some people cope better than others with a diagnosis of epilepsy. They soon begin to feel better without needing support. Others, however, need help with the way they feel. They may continue to feel anxious, sad, angry or depressed. They may find that they are becoming increasingly irritable with those around them. They may also begin to experience feelings of fear or panic. Sometimes they may have a physical pain that cannot be explained by another medical condition.

You may recognise some of these feelings in yourself. This may affect the way you think and also the way you behave. You may find it is beginning to have a more serious impact on your ability to work and interact with people, including your own family.

Give yourself time to adjust. If you find you cannot shake off these feelings after a few weeks, and they are stopping you from getting on with your life, get help.

If you find some or most of the following applies to you, make an appointment to see your doctor:

- You feel sad most of the time.
- You begin to lose interest in the things you used to enjoy, such as a hobby, sport or leisure activity.
- You no longer want to go out with friends and mostly prefer to be left alone.
- You lose interest in your sex life.
- You feel bad or guilty, for no good reason.
- Your appetite has changed. Suddenly you don't want to eat or find you want to eat all the time.
- You find it difficult to get to sleep at night or frequently wake up during the night.
- You feel tired all the time even though you sleep for many hours at night and during the day.
- Friends notice that you no longer pay much attention to how you look.

What to do if you are feeling suicidal

Sometimes people who struggle to come to terms with epilepsy think about suicide. They find it difficult to imagine that things will get better. If you have these feelings talk to someone. This could be a member of your family or a good friend. Some people prefer to speak to their doctor or phone a helpline. You will be listened to and will not be judged. It can help to talk to someone about the reasons why you want to end your life.

If you are feeling suicidal right now, please pick up the phone and speak to someone. It's important that you do.

Samaritans – 0845 790 9090
(any time)

Breathing Space – 0800 838 587
(6pm to 2am every day)

SANEline - 0845 767 8000
(6pm to 11pm every day)

It may be difficult to imagine feeling better but speaking to someone will help.

Where to go if you need help

Your doctor is usually your first point of contact. If you are feeling low, they can look at your anti-epileptic drugs to see if mood changes are a possible side effect. Your doctor will also check whether your low mood is caused by another medication. They may prescribe anti-depressants if they feel this is the right treatment for you. Your doctor can also refer you to a counsellor, psychologist, psychiatrist or community mental health nurse for more support. If your epilepsy medication needs to be reviewed, your doctor will refer you back to your consultant.

You can also talk to your epilepsy specialist nurse. You can ask for advice on medication and possible side effects, as well as how to keep as safe as possible with seizures. You can talk about anything that worries you such as the impact epilepsy may have on your relationship. The specialist nurse will understand how epilepsy can affect your life and how it can make you feel. They may be able to suggest ways to help you accept and deal with this condition better.

Our free and confidential helpline receives many calls from people who struggle to come to terms with their epilepsy. We are here to listen and give you some emotional support. We know it's not always easy to describe how you are feeling. If you cannot find one word, use lots. What does it feel like inside your head? What does it make you feel like doing? We can suggest different ways to help you get on with your life. Our helpline number is **0808 800 2200**.

There are many other organisations and helplines you can phone for emotional support. We have listed some of them in the previous chapter. If you don't know who to phone, talk to us. We can refer you to someone that can best help you.

Changing the way you think and feel

Once you identify the things that may influence the way you feel about yourself, you can start to address these. Many of them are probably practical things. For example, if you are upset about restrictions to your life because of your seizures, talk to people who can help you put things into perspective. There may be things you can do to adjust to the changes. This can be an adjustment to your job, or a leisure activity. Don't give up. Don't listen to well-meaning people who tell you that you can no longer do certain things without good reason.

Remember, you are more than your epilepsy and you don't have to be defined by it. If you act confidently, people will react in a more positive way towards you.

How you think about your life and other people can affect your emotions, feelings and behaviour. Therefore, changing the way you think can often change the way you feel and behave. A counsellor can help you work through this in more detail.

Try some simple steps towards changing the way you think, feel and act. Practising just some of these steps on a regular basis can make a big difference:

- **Stop negative thoughts** before they turn into destructive statements. Some people find that saying 'no' aloud helps to stop these thoughts. Replace them with positive thoughts. Over time, this will become a habit and you will start to feel better.

- **If you feel overwhelmed by a situation and this makes you anxious or depressed, break it down into small manageable chunks.** What was the situation that made you feel so anxious? What did you think at the time? How did this make you feel? How did you react? Could you have thought differently at the time? Would this have changed the way you felt? Realising that you can choose your own thoughts can be powerful.

- **Focus on the good.** Ask a friend to help you list all that's good and bad in your life. When you are down it's easy to see only the bad things. A friend can remind you of all the positive things in your life. Once you have a list of all the good things, remind yourself of this several times a day. If you do this for a while, you will automatically focus on the positive.

- **Imagine a friend in the same situation as you are. Then imagine giving advice to this friend.** What would you say to him/her? Try to be as objective, honest and direct as possible. This will allow you to step back and look at your own situation in a slightly different way. Then follow your own advice.

- **Take responsibility for your actions.** Accept that you are responsible for every decision you make, and for every action you take. Realising this can be very empowering. You don't have to be passive but can play an active role in what happens to you.

- **Learn how to deal with criticism.** Nobody is perfect, we all make mistakes. You will miss the point of helpful criticism if you immediately take it personally. Criticism when it's justified can be an opportunity for you to learn. Be open to this kind of criticism, and react calmly.

- **Learn how to deal with anger in a healthy way.** Being angry is a normal emotion. How you express this though can make a big difference. There are many different techniques you can learn on how to manage your anger better. Recognise when you are angry. Try to keep calm and think about the situation first. Check out the facts – are they correct? Do you really have to deal with this? If not, walk away from the situation. Uncontrolled anger can be destructive to both yourself and those around you.

More ways to help yourself

Hopefully, by now you will recognise that the way you feel about your epilepsy is perfectly normal. There is help if you need it, but there are also many more things you can do to take control of your life again.

It's important to remember that stress or anxiety can be a common trigger for seizures in many people. So, if you learn to control this aspect of your life, you may remove a contributing factor to your seizures. You may find after a while that you have fewer seizures.

You need to find what works best for you. Here are some tips others have found useful:

- **Know as much as possible about your epilepsy.** The more you know the less scary it is.
- Be aware of how you approach your epilepsy. Stop it from being the focus of your life. **It's part of you but there is a lot more to you than epilepsy.**
- Find out if you have any **seizure triggers.** Avoiding them may prevent some seizures.
- **Take responsibility for your own health.** Eating a healthy balanced diet, taking regular exercise and getting plenty of sleep can have a positive impact on how you feel. It can also help reduce seizures.
- **Be confident.** Let others know what you want or don't want. Learn to express yourself with confidence. Learn to stand up for yourself. Being confident also means learning to feel good about yourself.
- **Reward yourself.** Whenever you've achieved something, treat yourself to something you enjoy. This can help you focus more on the things you do well rather than those you don't.
- **Keep a diary of your moods,** in the same way you keep a diary of your seizures. Also write down what you do to counter those moods and if this is successful. This will help you learn to recognise what works for you.
- **Learn how to use breathing exercises** to let go of tension. When you are stressed, your breathing becomes shallow. If it goes on over a long period of time, this can affect the amount of oxygen which is circulated around your body. This in turn can affect your health and energy levels. When you feel stressed, take some slow and deep breaths. Make time and do this several times a day.
- **Take time to relax.** Many of us are constantly on the go, trying to do too many things at the same time. This can put you out of touch with how you feel. Allocating an amount of time to relax every day is important. Simply going for a walk can change the way you feel. Some people enjoy meditation, yoga or tai chi as a way of relaxing and winding down. Find what works for you, and take regular time out for yourself. This will make your life less stressful and will improve your health and wellbeing.
- Explore how **complementary therapies** can help you to relax. Check with your doctor or epilepsy specialist nurse to make sure the therapy you choose is safe for you.
- **Do things you enjoy.** Take up a hobby or leisure activity. Try gardening, join a walking group, go dancing, play golf... there's something for you to get involved in. If you feel isolated because of your epilepsy, choose an activity where you meet other people. Your doctor or epilepsy specialist nurse can advise you if it is safe.
- **Help other people.** Feeling needed is important. Contact your local volunteer centre to see how you can get involved with helping others. Remember that everyone has something to contribute.

Problems with your memory?

We all forget things, such as the name of a person or where we've left our keys. This can be very frustrating. If you have epilepsy, you may find that this happens to you a lot. This forgetfulness is quite common, and can be caused by a number of things.

People with epilepsy tend to remember facts from their long term memory but often struggle with their short term memory. Many people find that they cannot remember much just before a seizure. However, not everyone with epilepsy has the same memory difficulties.

Sometimes, difficulties with your memory can be side effects of anti-epileptic drugs. Common side effects of these drugs can be drowsiness or poor concentration. This in turn can affect your short term memory. However, once the drugs improve your seizure control, your memory will probably get better again.

If you are already experiencing feelings of anger, sadness or anxiety because of your epilepsy, this can make you distracted. You will find it difficult to focus on information. In turn this will affect your memory. Therefore feeling more positive may actually improve your memory.

Don't underestimate the impact forgetfulness can have on your self-esteem, confidence and mood. The sooner you tackle the problem, the better. Simple measures can make a big difference such as:

Focus on one thing at a time – pay attention to what you do. This will help you remember it later on.

Avoid overloading your memory – if you try to remember too many things at once, you are more likely to forget things.

Write down information – make lists of things to do, keep a diary or calendar of events.

Stay active and look after yourself – this reduces stress and keeps you healthy. Feeling unwell or tired can affect your memory.

Use memory aids such as digital voice recorders, post-it-notes or mobile phone alarms – all of these can help you remember important information or appointments.

Our 'Epilepsy and memory' factsheet can give you more information on this. Phone our helpline for a free copy or download it from our website.

If you are affected by severe memory problems, your doctor may be able to refer you to a memory clinic. A psychologist will carry out a neuropsychological assessment. This means they will look at how well your memory works. The test will show the psychologist how well you remember pictures, stories and numbers. After the assessment they will be able to advise you on what could work best for you.

First aid for someone in distress

If you read this booklet because you have concerns about someone's mental or emotional wellbeing, you may find the following four simple steps useful. This will help you understand the person's distress and keep the person safe until professional help is available:

1. Assess risk of suicide or self-harm:

- Talk to the person and find out how they are feeling and what is making them feel this way.
- Identify if that person is at risk by asking them directly if they have suicidal thoughts.
- If yes, allow the person to talk about why they want to end their life. Then try to explore their reasons to live.
- Explore and assess if there is an immediate risk of suicide.
- Find out if they have attempted suicide in the past.
- Do they have any support? Anyone who has previously tried to end their life by suicide and has no support is more at risk.
- Try to disable the person's suicide plan by, for example, taking away any pills the person intends to take.
- Agree a plan of action that keeps the person safe until they get professional help. This could be agreeing with them that they will phone their doctor, or, if appropriate, offer to do this for them.

2. Listen non-judgementally:

Once you have established that there is no risk of suicide, take some time to listen to the person. Don't be critical, don't express your own frustration, don't offer advice such as "pull yourself together". Avoid any confrontation unless this is necessary to prevent someone from harming themselves or others.

3. Give reassurance and information:

Mental health problems affect many people. Stress that people can and do recover from them. Reassure the person that this is not a sign of weakness. Help them to feel more positive by telling them that effective help is available from their doctor and/or a counsellor.

4. Encourage the person to get appropriate professional help:

Ask them to speak to their doctor if they haven't already done so. If appropriate, offer to phone or to go with them. Alternatively, give them the phone number of a helpline such as the Samaritans or Breathing Space. If they don't seek help, don't be afraid of taking charge of the situation. Call their doctor yourself.

Finally

If you experience any other feelings, emotions or sensations not mentioned in this guide, speak to your doctor. This could be seeing things or hearing voices (hallucinations) or having unusual thoughts (delusions). All of this can be part of having seizures, but it's important to tell your doctor about this.

We hope this guide has given you a better understanding of the many things that can affect your emotional wellbeing. Remember, negative feelings and emotions are a normal part of life and epilepsy, but if they don't go away, talk to your doctor. Epilepsy affects your life but doesn't have to control it.

Further information

There is more information on:

- A guide to epilepsy – what you need to know
- A woman's guide to epilepsy
- Epilepsy – a guide for teachers
- A parent's guide to epilepsy
- Epilepsy in later life
- Epilepsy and memory
- An employer's guide to epilepsy
- Men and epilepsy
- Epilepsy and driving
- Diagnosing epilepsy
- Epilepsy and employment
- First aid for seizures
- Epilepsy and leisure
- Photosensitive epilepsy
- Epilepsy and treatment
- Seizures explained
- Staying safe with epilepsy
- Caring for people with epilepsy and learning difficulties
- Sudden unexpected death in epilepsy (SUDEP)
- Brian learns about epilepsy (for pre-school/early primary school children whose parent has epilepsy)
- Farah and Ted visit the hospital (for pre-school/early primary school children going through a diagnosis of epilepsy)

We also have a selection of guides designed for people with mild to moderate learning disabilities.

If you have questions after reading this leaflet, please call our helpline. Our trained staff are available during office hours and until 6pm on Thursdays.

If you would like this leaflet in a different format, large print or language, please call **0808 800 2200.**