

# The Bigger Picture

epilepsy  
society

## Epilepsy and mood

Epilepsy affects everyone differently. This booklet is about epilepsy and mood. It looks at how you may feel about diagnosis and living with epilepsy, and about dealing with common mood problems.

How you feel may be different from the stories shown here. Your view of epilepsy may also change over time. This booklet includes real quotes from people with epilepsy about their feelings and what they have found helpful.



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# diagnosis

Any diagnosis can be a shock, even if you are expecting it. You may feel numb, angry, confused or frightened. Or you may feel relieved – what's been happening to you has a name and a treatment. Everyone has their own way of reacting to a new situation.

## Recognising the impact

Strong feelings such as anger, fear or distress can sometimes be overwhelming, but these are normal emotions, and there may be good reasons for feeling the way you do. You may also feel a sense of loss, that epilepsy is taking something away from you. Recognising what the diagnosis means to you may help you feel more in control of your situation from the start. It may help to talk to someone or to write down how you feel. If you want someone to talk to, Epilepsy Society has a confidential helpline (see back cover for details).

## Adjusting to change

A diagnosis of epilepsy can be hard to accept. It may change some things in your life but not necessarily for ever. Losing your driving licence and taking medication are two of the big issues you may be facing. It can take time to adjust. It may help to remind yourself that you are still the same person you were before the diagnosis and that support is available if you want it.

**“Being diagnosed with epilepsy was the best thing that has happened to me in the last five years. I now feel ‘normal’. My first two months I was in denial but once I accepted it I felt a sense of relief. My family also said I was the person they used to know.”**

## Looking for answers

Epilepsy can happen to anyone, at any age. Doctors may be able to find a cause but this is not always possible. Our brains are incredibly complex and changes take place in the brain throughout our lives. Research looks into why seizures happen for some people and not for others.

Your neurologist, GP or nurse may be able to tell you more about your epilepsy.

You can also get information about epilepsy from us when you are ready for it.



**Contact us for a copy of our free *just diagnosed* pack.**

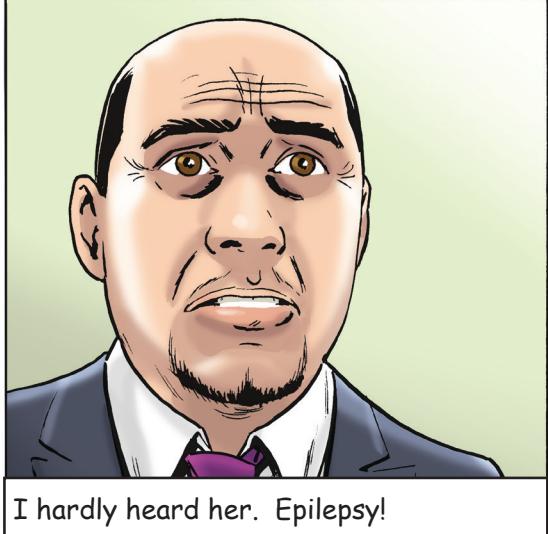
## Dealing with other people

The way family or friends react to your diagnosis may be just what you need, or you may find some reactions hurtful or unhelpful. People around you may also feel shocked, frightened, worried, angry or helpless about your diagnosis. They may not know very much about epilepsy. They may also need time to adjust and work out how they feel. What you need from them may also change over time. Family and friends can best support you if you are able to tell them clearly what you find helpful.

## Where do I start?



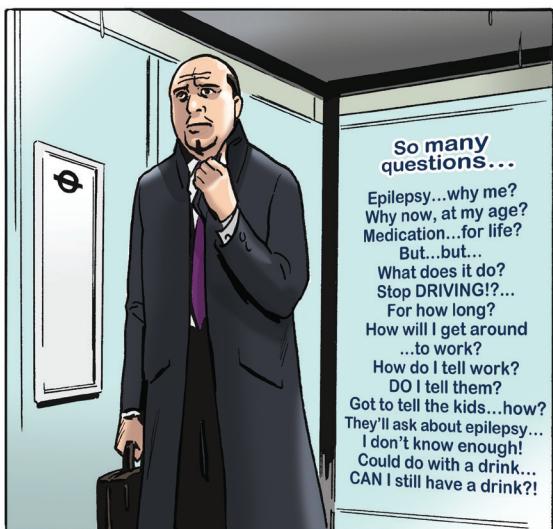
"It is epilepsy... You must stop driving... Medication options are... So we'll see you again in six months. Any questions?"



I hardly heard her. Epilepsy!



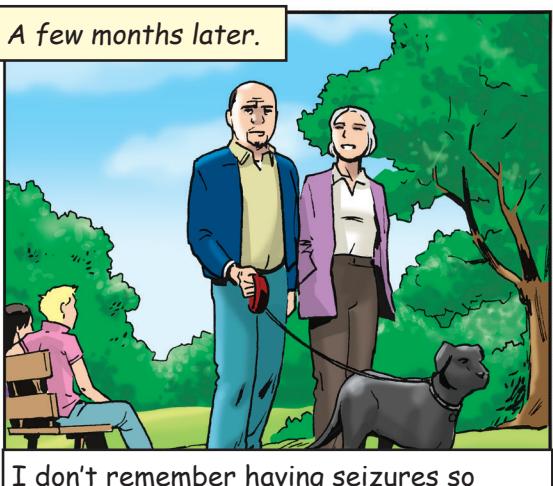
Leaflets, websites, helplines... What do I need to know? **Where do I start?**



So many questions...  
Epilepsy...why me?  
Why now, at my age?  
Medication...for life?  
But...but...  
What does it do?  
Stop DRIVING!...  
For how long?  
How will I get around  
...to work?  
How do I tell work?  
DO I tell them?  
Got to tell the kids...how?  
They'll ask about epilepsy...  
I don't know enough!  
Could do with a drink...  
CAN I still have a drink?!



How dare they stop me driving!  
It's... it's unbelievable!!



A few months later.

I don't remember having seizures so  
how do I know I've really got epilepsy?  
I don't want to think about it anyway...

# anxiety

**"When I feel anxious I find going for a walk or doing something helps. The worst thing I find is sitting doing nothing."**

Everyone feels anxious at times. When you are frightened or feel threatened, your heart beats faster, your muscles tense and your body prepares you to 'fight' the threat, or to run away from it – 'flight'. So anxiety is useful when it alerts you to danger or when it helps you concentrate on something that makes you nervous.

Anxiety becomes a problem when you feel anxious most of the time and it affects basic things such as eating, sleeping, or being able to leave the house. If you are anxious you may feel restless and unable to relax, or have no energy and be easily tired. You may panic in certain situations. You may sleep badly or wake up too early in the morning. Your memory or concentration may be poor. You may feel easily irritated.

Anxiety can also show in physical ways. Your appetite or weight may go up or down. You may sweat, have a dry mouth, or palpitations (racing or uneven heartbeat). You may have regular headaches, or chest or joint pains. You may feel breathless, sick or have diarrhoea. Your hands may feel cold and clammy, or you may feel tingling in your hands or feet.

You can have any of these symptoms for other reasons but if some of them have been happening regularly, and for over six months, anxiety may be the cause.

## Anxiety is common

Anxiety as a medical problem affects around 1 in 4 people in the UK. Anxiety can start at any time of life, and can come and go, depending on what is happening in your life. Sometimes anxiety also happens when people are depressed. Some people with epilepsy have a higher risk of anxiety (see pages 8 – 9).

Anxiety may be triggered by a particular memory, such as having a seizure, and the fear that it may happen again. How you have been treated in the past, for instance being bullied or ignored, may make you worry about how people treat you now. Or you may feel anxious without a specific reason. Anxiety can grow very quickly, and you can find yourself worrying about things you can't control, such as other people's problems, or worrying about how much you are worrying. Realising that anxiety is a problem is the first step in dealing with it.

### Helping yourself – some ideas

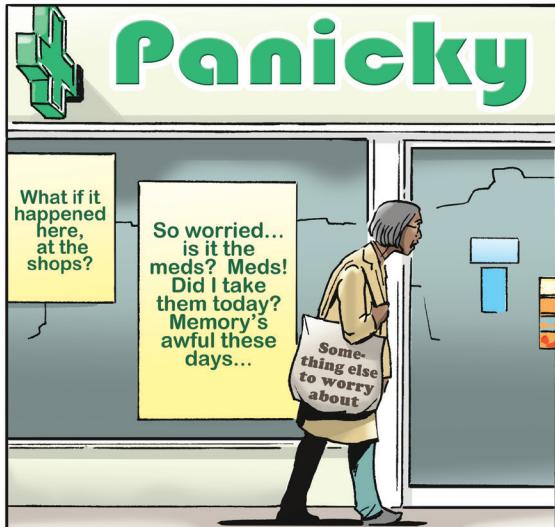
Finding ways to *manage* your anxiety is more useful than trying to stop feeling anxious. These ideas may work best if you do them regularly.

**Focus** on something enjoyable that distracts you: music, a picture, an activity.  
**Plan** small achievable tasks for each day. How does it feel to get things done?  
**Talk** to people. Any social contact can help you feel more confident and valued.

## Is it just me?



Oh my heart's pounding, I feel dizzy.  
This has happened before. Am I going to  
have a fit? Must get off the bus - **now!**



Can't face going out today.  
Maybe tomorrow. Or next week...  
I feel safer here on my own. Or do I?



"No! Don't come in! Just.. just leave them there thank you. Yes, yes. Goodbye."



It's such a relief to talk, it's out in the open. I don't want this **fear** to take over.

# depression

**“Having epilepsy does not mean you have to expect and cope with depression. You have as much right to help and support as anyone else.”**

We all feel low and depressed sometimes, without it being a medical problem. Like anxiety, depression is a problem when the unhappy feelings do not go away and it affects daily life: eating, sleeping, or being able to get out of bed.

Depression is not just about feeling sad or down. It is about losing interest and enjoyment in the things you used to enjoy.

If you are depressed you may feel worthless, hopeless, tearful, tired, restless or anxious. You may lose interest in sex, or not care about your appearance. You may not be able to make decisions, remember or concentrate. You may sleep badly or wake too early. Your appetite or weight may go up or down. You may think that life is not worth living, or think about suicide or death in general.

## Depression is common

1 in 5 people in the UK have some form of depression at some point in their lives. Sometimes depression is triggered by an upsetting or life-changing event, such as a bereavement, unemployment, family problems, debt, an accident or an illness. Some people are more likely to become depressed than others because of a family history of depression. Frequent stress (too much pressure) may make depression more likely.

Depression is more likely in someone with epilepsy (see pages 8 – 9) but this does not necessarily mean that one condition has caused the other. Nor does it mean that depression is something you just have to put up with.

**“Keep yourself safe, and positive as best as you can.  
It helps to have a hobby as well, something therapeutic.”**

## Helping yourself – some ideas

**Exercise** stimulates brain chemicals that may improve your mood and it is a good way of getting out and meeting people. Feeling fitter can also help you feel more positive about yourself. If you are tired or depressed you may not feel like being active, but exercise can actually boost energy levels. You are more likely to stick to exercise when you enjoy it and when you notice that it helps you.

**Regular well-balanced meals** help increase your energy levels and boost your immune system, which may help you feel positive and reduce the risk of seizures. Cutting down caffeine and sugar may help avoid highs and lows in your energy levels, and in your mood. We have more information on how exercise and nutrition can be an important part of living well with epilepsy.

**Note the times** when you feel especially low. What helped you cope last time?

**I'm fine thanks**



"Shall we go shopping? Or you could call Tara. You haven't seen her for ages. Did you have lunch? I'll make you something."



"No, s'OK. I'm fine thanks."



Is she still recovering? That seizure... so **scary**. She used to talk to me. She should get out more. Am I nagging her?



Must sleep. Can't sleep.  
Just feel... nothing.



Tara wants me to go back to dance class. But I'm so tired, and I won't be any good anyway. I'm useless. Is it my fault I can't cope? Is it my meds? Is it my epilepsy?



I'd had enough. Mum stopped trying to make it better for me, and just listened. Next time my doctor asks "how are you feeling?" I'm going to tell him the truth.

# epilepsy and mood – what are the links?

For some people, there is no link between their epilepsy and mood problems, they just happen to have both conditions. However, *potential* links are to do with:

- how epilepsy affects your life; and
- your brain, your genes and your family history.

If some of these links are true for you, focusing on one or two may be easier than trying to deal with several at once. What affects you the most?

## Fear of seizures

is understandable. Seizures can be frightening, unpredictable and risky. Learning about what happens in your seizures, or talking about your fear, may help to reduce your fear.

## Safety

is important, but so is being able to live as fully as possible. Learning about your epilepsy may help you get a balance between keeping safe and being independent.

Life, mood  
and epilepsy  
What affects  
you?

## Employment or education

may be disrupted by epilepsy. We can provide epilepsy awareness training for schools, colleges and employers.

**Losing your driving licence**  
can be hard practically and psychologically. However, some people find that travel alternatives lead to getting fitter or meeting new people.

## Other people

**Family and friends** may not know how you feel or what you need from them. If you can tell them clearly how you feel they can better support you.

**It may help to talk to other people affected by epilepsy.** Details of epilepsy support groups are available from our helpline.

**Other people with long-term conditions** may share common experiences. Self Management UK offers free courses on living well with various conditions. This includes tackling mood problems and isolation. Visit [selfmanagementuk.org](http://selfmanagementuk.org) or call 0800 988 5560 (if dialling from a mobile use 03333 445 840) for more information.

**People around you may also need support.** Our helpline is open to *anyone*. Self Management UK also run courses to support carers (see above for contact details).

**Before a seizure**  
you may feel irritable, anxious, depressed or aggressive. This may last for a few hours or days, and your mood gets better after the seizure.

**During a seizure**  
Up to 1 in 3 people with focal seizures may feel fear as part of their seizures.

**After a seizure**  
you may feel anxious or depressed for days or weeks, if the parts of the brain that affect mood are recovering from the seizure. Confusion or memory loss after a seizure can also be worrying or depressing.

**Medication**  
can have both positive and negative effects on mood (see below). Finding the right dose for you will help avoid side effects.

The brain,  
genes, and  
epilepsy  
What affects  
you?

**Family history**  
Being anxious or depressed may be part of your genetic makeup (the characteristics that are passed to you from your parents). Or being anxious can sometimes be learned, as part of how you are brought up.

**Structural changes or damage**  
to some parts of the brain may affect mood. For some people these can also cause epilepsy. Many people with epilepsy do not have areas of damage to their brain.

## Mood problems as a side effect of medication

Possible side effects of anti-epileptic drugs (AEDs) include mood changes, irritability, agitation or depression. However, AEDs can also improve mood for some people. The risk of you having a side effect may be lower than you think.

If a side effect is listed as *common*, this means that at the most, 1 in 10 people will get it and 9 in 10 people will not. The lists of side effects that come with AEDs may make you expect to have side effects, increasing your anxiety or low mood.

You could keep a diary of your mood along with a record of any medication changes, so you can see if there are any links. This may help discussions with your doctor or nurse, especially when you are new to taking medication. Our seizure diary has a section for comments about your medication and any side effects.

 **Free seizure diaries are available by calling our helpline.**

**Some feelings should not be ignored, especially if you are having thoughts about suicide, or death generally.** Telling *anyone* how you feel is the first step to feeling less alone. Telling your doctor or nurse how you feel means they can help.

# breaking the links – when mood affects epilepsy

Anxiety and low mood may affect your epilepsy and how it is managed. You may be able to help break some of these links.

## The problem

### Stress



### May lead to

feeling that you can't cope  
anxiety or depression  
higher risk of seizures

### Help break the link

#### Reducing stress

Exercise and keeping active  
may help to lower stress.  
Activities and therapies that  
relax you may help to  
reduce the risk of seizures.

### Lack of sleep or sleeping at irregular times



tiredness and low mood  
hard to concentrate  
may miss medication  
higher risk of seizures

#### Regulating sleep

Keeping active and getting up  
at the same time each day  
may help you get more sleep  
in a regular pattern.  
If poor sleep is a big problem  
for you, your GP may be able  
to recommend further help.

### Concentration or memory problems



hard to take in information  
may miss medication  
higher risk of seizures

#### Using memory aids

Lists, alarms, sticky notes or  
drug wallets can help you  
remember and focus on one  
thing at a time.

### Low self-esteem



hard to socialise  
lower self-confidence  
hard to talk to doctors  
about managing epilepsy  
higher risk of seizures

#### Groups or helping others

Joining a group where you  
have a shared interest  
may help lift your mood  
and boost your confidence  
and self-esteem. Helping a  
friend, a community activity,  
or voluntary work can be  
valuable for you and for  
other people.

See our information on *exercise, complementary therapies and memory*.

## asking for help

Sometimes helping yourself feel better is not enough on its own and you may need extra help. Your GP can suggest other treatment options. It can be hard to ask for help and you may not like the idea of seeing a doctor about mood problems. But looking after your mental health is positive, and getting treatment can make a big difference.

Seeing your GP may be easiest when it feels like you are working together. You can help your GP by telling them about the different feelings you have. It may help to write down what you want from the appointment before you go. Your GP can help by listening, by looking at your medical history and by asking you what you think might help you.

If you feel your mood is linked to your epilepsy or to side effects of your AEDs, you can ask your GP to review your epilepsy or refer you to a neurologist. Your GP may refer you to a local exercise programme or make suggestions about your diet. They may recommend a ‘talking’ therapy or medication such as an antidepressant, or a combination of different treatments. Any treatment is more likely to work if it is a treatment that *you want*.

### ‘Talking’ therapies

These may help reduce anxiety or depression and make life more manageable. Talking through your feelings about epilepsy in confidence may be helpful. Different talking therapies include counselling, psychotherapy and group therapy.

**“After many years of attempting to hide the psychological effects of my epilepsy, I chose to seek support in the form of cognitive behavioural therapy. This has allowed me an understanding of the link between epilepsy and depression, and to accept that it’s OK to feel sad.”**

### Medication

If coping with anxiety or depression is very difficult or impossible, your GP may offer you antidepressants or other medication, sometimes along with a talking therapy. Your GP or specialist may check that you are on the right AEDs first. AEDs can have both positive and negative effects on mood and will affect people differently. If you are offered medication for anxiety or depression, your doctor can check which is the best drug for you, and one that is least likely to affect your AEDs or your seizure control. Reporting any side effects will help your GP to see which treatment suits you.

### Where family and friends can help

You may not recognise that you are anxious or low. Family or friends may notice changes in your mood before you do. Comments made by others may be hard to hear but they may be worried about you. Helpful approaches include the following:

- Ask you how you feel, then listen without interrupting when you want to talk.
- Keep any comments about you *factual*, rather than give *opinions* on what they think you should do.

## What happens next?



Accepting the epilepsy is the key thing. I've had to adjust a lot - not driving is still awful. But I'm still the same person and that's the starting point. I'm still me.



My GP and I looked at my epilepsy notes together. Now I know the difference between my fits and anxiety. I also use 'to do' lists - it helps me focus, not worry.



I still get depressed but it helps to write down how I feel. I can see now it's worse after seizures. My doctor says we can adjust my meds if I want to. I feel like I have some choices again.

Everyone is different.

What would **you** do?

Epilepsy Society is grateful to those who have helped with this booklet:  
Warren Pleece, Dr Pam Thompson, Professor Mike Kerr and the many people with epilepsy who generously shared their experiences.

**confidential helpline 01494 601 400**

Monday and Tuesday 9am to 4pm, Wednesday 9am to 7.30pm.  
National call rate. Information and emotional support.

**epilepsysociety.org.uk**

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