Epilepsy and wellbeing

How are you feeling?

A guide to looking after your wellbeing

epilepsy.org.uk
Epilepsy Helpline: 0808 800 5050
Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

**Our work...**

- We provide information to anyone with an interest in epilepsy
- We improve the understanding of epilepsy in schools and raise educational standards
- We work to give people with epilepsy a fair chance of finding and keeping a job
- We raise standards of care through contact with doctors, nurses, social workers, government and other organisations
- We promote equality of access to quality care

Epilepsy Action has local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

**Your support**

We hope you find this booklet helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this.

- Visit epilepsy.org.uk/donate
- Text ACT NOW to 70700 (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- Send a cheque payable to Epilepsy Action

Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.
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About wellbeing and epilepsy

"Wellbeing is about feeling good and functioning well."

Health experts believe that our minds and body are connected. We all need to look after both to ensure we have a good state of wellbeing.

Healthy body + healthy mind = good wellbeing

When you have epilepsy, looking after your wellbeing can help you to have as few seizures as possible. It can also improve how you feel about having seizures. As a result, you will feel better and function better in your daily life.
Looking after your body – looking after your mind

“People with long-term conditions who take more control of their health have a much better quality of life.”
NHS Choices

The NHS offers advice to everyone about how to look after their body and mind.

- Eat a well balanced diet
- Limit your alcohol
- Aim to get active
- Have a good sleep routine

If you follow this advice, your physical health will benefit. What’s more, so will your mental health. This is because having a healthier body reduces your risk of stress and depression.

When you have epilepsy, you have more risk of developing stress and depression than other people. So, following this advice to improve your physical and mental health can be especially helpful for you.

Following the NHS advice may also help you to reduce the number of seizures that you have. Find out why, next.
**Eat a well balanced diet** – some people with epilepsy say that if they skip meals, they are more likely to have a seizure.

**Have a good sleep routine** – for some people with epilepsy, sleep is especially important. Disturbed sleep patterns, or not having enough good quality sleep, can make seizures more likely.

Epilepsy Action has more information about epilepsy and sleep.

**Limit how much alcohol you drink** – drinking small amounts of alcohol doesn’t usually increase the risk of having seizures. But if you have a history of alcohol abuse, even drinking small amounts could increase the number of seizures you have.

Drinking more than modest amounts of alcohol in 24 hours may increase the risk of having seizures.

Drinking alcohol can also make some epilepsy medicines work less well than they should. And it can make the side-effects of your epilepsy medicine worse. You might find that drinking alcohol when you are taking epilepsy medicine makes you feel drunk quicker than other people.

If you think you are drinking too much, and would like to do something about it, talk to your GP. They can offer you advice and support.

If you are ‘alcohol dependent’, it means you drink heavily. If you want to cut down your drinking, it is especially important that you do this gradually. This is because there is a real risk of having seizures if you stop drinking suddenly after a long session of heavy drinking. Talk to your GP, who will give you advice and support. They may refer you to someone who can help you to safely reduce the amount of alcohol you drink.

Epilepsy Action has more information about epilepsy and alcohol.
Taking control of your seizures

Getting the best possible control of your seizures will improve how well you feel and how you function in your daily life. So, as well as looking after your general health, there are some more things you can do.

Take your epilepsy medicine

Recognise and avoid your seizure triggers

Get the best treatment for your epilepsy
Take your epilepsy medicine

Missing a dose of your epilepsy medicine could cause you to have a seizure. Here are some helpful tips about taking your medicine.

If you have a smartphone, download the Epilepsy Action app. Set it to remind you when to take your epilepsy medicine.

If you don’t have a smartphone, use an alarm clock, alarm on your mobile phone or a pill reminder to help you remember when to take your epilepsy medicine. The Disabled Living Foundation can give you details of suppliers of pill reminders (details at the end of this book).

Make sure that you never run out of your epilepsy medicines.

Ask your epilepsy specialist or epilepsy nurse in advance what you should do if you ever forget to take your epilepsy medicines.

Never stop taking your epilepsy medicines, or make changes to them, without talking to your doctor first.

Recognise and avoid your seizure triggers

Some things make seizures more likely for some people with epilepsy. These are often called ‘triggers’. Here are some common triggers.

- Forgetting to take epilepsy medicines
- Not getting enough sleep
- Feeling stressed
- Drinking too much alcohol
Some people with epilepsy also say they have more seizures if they miss meals.

Keeping a diary of your seizures can help you to identify things that may trigger your seizures. Make a note of what you were doing or how you were feeling before each seizure, to see if you can find any patterns.

Avoiding your triggers will lower the risk that you’ll have a seizure.

Epilepsy Action has more information about keeping a seizure diary.

Get the best treatment for your epilepsy

Attend all your medical appointments to do with your epilepsy. Talk to your doctor about any changes in your epilepsy, or anything else that you are concerned about.

If your seizures continue, ask to be referred to an epilepsy specialist for a review of your epilepsy. They might suggest changes to your epilepsy medicines, or other possible treatments, such as surgery.

Keep a diary of your seizures. This can help doctors when they are considering the best treatment for you. It can also help you to see if there is a pattern to your seizures, or anything that triggers your seizures.

If your epilepsy is very difficult to control, ask your specialist if they can refer you to a specialist epilepsy centre for treatment. Contact Epilepsy Action for more information about this.
Some health issues to watch out for

Feeling anxious, depressed or stressed can affect anyone. You have a higher risk of being affected when you have epilepsy. How long it lasts for and how you deal with it can have a real impact on your overall wellbeing.

Here’s some information about signs to look out for and how you can manage them.
Anxiety and depression

About anxiety
Anxiety affects everybody at some time or other. It’s the feeling of fear that we get when faced with threatening or difficult situations. Anxiety can help us to avoid danger. It makes us more alert and gives us energy to deal with problems. However, if the anxiety is too strong or is there all the time, then it can become a problem.

Some symptoms of feeling anxious

- Feeling fearful and tense
- A fast heart rate
- Palpitations
- Shaking
- Sweating
- A dry mouth
- Chest pains
- Headaches
- Fast breathing
- Problems with memory
- Problems with concentration
- Feeling sick

Signs that anxiety is becoming a problem

- Your anxiety is out of proportion to the stressful situation
- You continue feeling anxious when a stressful situation has gone, or the stress is minor
- You feel anxious for no apparent reason, when there is no stressful situation
About depression

Everybody feels down from time to time and this is quite normal. If you have been feeling low for a long time, and this is affecting your daily life, you may be experiencing depression.

Depression affects people in different ways and can cause a wide variety of symptoms. At its mildest, you may feel persistently low in spirit. At its most severe, depression can make you feel suicidal and that life is no longer worth living.

Some signs that you may have depression

- Having difficulty sleeping, or sleeping more than usual
- Feeling tired, restless or agitated
- Avoiding other people
- Having suicidal thoughts
- Losing interest in things you used to enjoy
- Having physical aches and pains that have no obvious cause
- Feeling unhappy most of the time
- Losing confidence
- Losing your appetite
- Finding it hard to concentrate or make decisions
- Losing interest in sex
- Having memory problems

Epilepsy Action has more information about depression.
Links between epilepsy, anxiety and depression

When you have epilepsy, here are some reasons why you could be more at risk of anxiety or depression than other people:

- Coming to terms with a new diagnosis can be very difficult
- Sometimes the physical changes in your brain immediately after a seizure can cause anxiety
- Your seizures might cause injuries that make you feel anxious or depressed
- If there is something in your brain that is causing your seizures (for example, tumours or infections in the temporal lobes), this could also cause anxiety or depression
- Your epilepsy medicine might cause anxiety or depression as a side-effect
- Your epilepsy medicine might cause other side-effects, which also cause you to feel anxious or depressed
- You might find it difficult to adjust to the changes in your life, such as losing your driving licence
- You might feel that family and friends treat you differently
Managing anxiety and depression

Just because you have epilepsy, you shouldn’t expect to have anxiety or depression. But if anxiety is becoming a problem in your day-to-day life, or you think you might be depressed, it’s important to get help from your GP. The sooner you seek help, the better.

The kind of treatment your GP will suggest will depend on how the anxiety or depression is affecting you. Some people take anti-depressant tablets. Other people have therapy that involves talking about how they are feeling (see page 22). Some people have both treatments.
If you have severe depression, your GP might refer you to a mental health team. This can include psychologists, psychiatrists, specialist nurses and occupational therapists. These teams often provide intensive specialist talking treatments as well as prescribing medicine.

Here are some things you can do yourself to manage anxiety and depression.

Talk to a family member or a friend you trust about how you are feeling. Just doing this can help you to feel some relief.

Join Epilepsy Action’s on-line community, forum4e (forum4e.org). You can share how you are feeling with other people with epilepsy and recognise that you are not alone.

Learn about mindfulness – becoming aware of your present experience, your thoughts and feelings, without judging or trying to change them (for more information, see page 23).

If you are feeling very depressed or suicidal, speak to your doctor urgently. You can also call the Samaritans at any time. There is always a trained person available who will listen to you and explore your problems.
Tel: 08457 90 90 90
Website: samaritans.org
Stress is a natural part of life. It can be described as the way you feel when you are under pressure. Stress helps us cope with the challenges of daily life. This could be pressure from your job, a relationship or any number of things. A small amount of stress can help us to deal with things going on around us. However, too much stress, or stress which goes on for too long, can have harmful effects on us, both physically and emotionally.

Some common signs of stress

**Physical signs**
- Having difficulty sleeping or waking early and being unable to get back to sleep
- Having indigestion, constipation or diarrhoea
- Nail biting
- Having nervous twitches
- Feeling tired
- Breathlessness or palpitations
- Tense muscles

**Emotional signs**
- Feeling easily irritated or angry
- Feeling very sensitive to criticism, or taking things very personally
- Drinking increased amounts of alcohol or smoking more
- Lacking concentration
- Feeling very emotional
- Feeling restless and unable to settle
When you have epilepsy, there are reasons why you’re more at risk of stress than other people. Living with epilepsy can be frustrating and it can sometimes restrict you from doing things you want to. For example, losing your driving licence can be stressful. And seizures themselves can be stressful events.

Many people with epilepsy say that if they are feeling stressed, they’re more likely to have a seizure. Sometimes, feeling stressed can lead to other behaviour, such as changed sleeping or eating habits, or drinking more alcohol. It might also make you feel anxious or depressed. All of these can also increase your risk of having a seizure.

Just because you have epilepsy, you shouldn’t expect to feel more stressed than other people. But if you are feeling stressed, it’s important that you know when to seek help, and where to go for it. There are lots of things that can help you.
Managing stress

Here are some tips for reducing your stress levels:

- Make time for relaxation and the things you enjoy
- Do some exercise – even a short visit to the shops can help
- Aim to get enough sleep
- Learn about mindfulness – becoming aware of your present experience, your thoughts and feelings, without judging or trying to change them (for more information, see page 23)
- Share your feelings and ask for support (from family, friends, your GP or a counsellor)
- Ask your GP if you can have any talking therapy (see page 22)

Epilepsy Action has more information about stress and epilepsy.
Memory problems

Everybody experiences problems with their memory from time to time. They can happen when we are under stress, trying to concentrate on a number of things at once, feeling unwell or feeling tired. Also, as we get older, lapses in memory can become more common.

Finding it hard to remember things seems to be a common problem when you have epilepsy. Your memory can sometimes be affected by seizures, some epilepsy medicines and by any damage to the brain that has caused the epilepsy.

Memory problems can have a big impact on your everyday life. They can affect work or education, or your ability to cope with everyday living. They can also have an impact on relationships. These problems can affect your wellbeing, by making you feel embarrassed, stressed, anxious or depressed.

Managing memory problems

If you are having problems with your memory here are some things you can do to help yourself.

Follow a set routine
Make things easier for yourself, and your memory, by following a set daily routine. If you know what to expect each day, your memory doesn’t have to work as hard.

Adapt your surroundings
Make changes to your surroundings, and put simple systems in place, so that you don’t need to rely on your memory as much. Here are some ways you can do this.
• Always put items such as keys and glasses in the same place
• Label cupboards to remind you what goes in them
Use memory aids
There are lots of different things you can use to record things that you have learnt, or things that you have done. This can make it easier for you to remember them in the future. Here are examples, but you may be able to think of many more:

- Smart phones and tablets
- Diaries and calendars
- Tape recorders and Dictaphones
- Notebooks
- Photos and videos

There are also aids to help you remember things you need to do in the future:

- Diaries and calendars
- Alarm clocks and timers
- Pill reminder boxes
- Mobile phones with alarms
- Wall charts and wipe clean memo boards
Look after your general wellbeing
Memory problems are often worse when we are feeling stressed, unwell or tired. So taking care of yourself, and aiming to get enough sleep, may help your memory to perform better.

Talk to your GP
If you are feeling anxious or depressed, speak to your GP. Many people find that their memory problems improve when their anxiety and depression is treated.

If your memory problems continue, talk to your epilepsy specialist. They can consider if the problems are connected to your epilepsy, the cause of your epilepsy or your epilepsy medicine. They can then look for ways to help you.

Epilepsy Action has more information about epilepsy and memory.
Therapies to help your mental and emotional health

If you are experiencing anxiety, depression or stress, your doctor may suggest that you try a psychological therapy. These are sometimes called ‘talking treatments’, ‘counselling’, or ‘psychotherapy’. They offer an opportunity to explore problems that are affecting your mental or emotional health with a trained professional. They also help you to find ways of dealing with the problems.

Here are two different types of psychological therapy.

**Counselling** – a type of talking therapy that allows you to talk about your problems and feelings in a confidential environment. A trained counsellor listens to you and can help you deal with your negative thoughts and feelings.

Counselling can take place face-to-face, individually or in a group, over the phone or by email.
Your GP may offer you some counselling through the NHS. Alternatively, you can pay privately to see a counsellor. Your GP will be able to recommend suitable counsellors to you.

**Cognitive Behavioural Therapy (CBT)** – a therapy that can help you to manage your problems by changing the way you think and behave.

CBT focuses on the problems you are having at this moment in time, rather than issues from your past. It makes you think about how your actions affect how you think and feel at this moment. This can help you to manage your problems in a more positive way.

CBT is usually provided by a CBT therapist, but psychiatric nurses and social workers may also be able to do this. CBT is also available through online courses. Your GP may be able to arrange for you to do a CBT course through the NHS, or you can pay privately to do one.

Contact Epilepsy Action for more information about CBT courses.

**Mindfulness**

Mindfulness is a way you can change the way you think and feel about your experiences, especially stressful experiences. It involves clearing your mind and paying attention to the present moment, using techniques like meditation, breathing and yoga. Mindfulness training helps us become more aware of our thoughts and feelings. It can positively change the way we see ourselves and our lives.

*continued overleaf*
Mindfulness meditation has been shown to affect how the brain works and even its structure. People undertaking mindfulness training have shown increased activity in the area of the brain that regulates our emotions. This can improve our attention, how much we achieve and how satisfied we are.

Many doctors believe that mindfulness would be helpful for people with mental health problems, including depression, anxiety and stress. There is lots of research that supports this belief.

Mindfulness training can take place in classes with other people. There are also online courses available. You can pay for these yourself, or your GP may arrange for the NHS to pay for you. Your GP can give you more information about mindfulness training.
In 2008, the UK government’s Foresight Project did some research about wellbeing. They wanted to find out how everybody can improve their wellbeing, based on scientific evidence.

The New Economics Foundation found a way to explain the results of the research. They produced a set of five simple actions which can improve wellbeing. The UK government hopes to encourage everybody to build these into their everyday lives.

Connect…

With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.

Be active…

Go for a walk or run. Step outside. Cycle. Play a game. Garden. Dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness.

Take notice…

Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling.
Keep learning…

Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.

Give…

Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.

Find out more about Five ways to wellbeing:
New Economics Foundation
website: neweconomics.org/projects/five-ways-well-being
Find out more

If you would like to find out more about the topics we have covered in this booklet, here are some useful organisations.

**Anxiety UK**
Anxiety UK works to relieve and support those living with anxiety disorders by providing information, support and understanding through an extensive range of services, including therapy.
Tel: 08444 775 774
Website: anxietyuk.org.uk

**Change4Life**
An NHS campaign which gives advice and support to help you eat well, move more and live longer.
Website: nhs.uk/Change4Life

**Depression Alliance**
Depression Alliance provides information and support services for people with depression.
Tel: 0845 123 23 20 (leave your name and address to receive an information pack)
Website: depressionalliance.org

**Depression UK**
Depression UK is a national self-help organisation that helps people cope with their depression.
Website: depressionuk.org

**Disabled Living Foundation**
Disabled Living Foundation helps disabled people find equipment that enables them to lead independent lives.
Tel: 0845 130 9177
Website: dlf.org.uk

**Drinkaware**
Drinkaware provides information about the effects of alcohol on health and wellbeing.
Tel: 020 7766 9900
Website: drinkaware.co.uk
Epilepsy Action Learning
Epilepsy Action Learning has a range of online learning resources to help you understand more about epilepsy and wellbeing.
Website: learn.epilepsy.org.uk

International Stress Management Association (ISMA)
ISMA exists to promote sound knowledge and best practice in the prevention and reduction of stress.
Tel: 0845 680 70 83
Website: isma.org.uk

Mental Health Foundation
Mental Health Foundation helps people to survive, recover from and prevent mental health problems, including anxiety, depression and stress. Also has information about mindfulness.
Website: mentalhealth.org.uk

Mind, the mental health charity
Mind provides advice and support to empower anyone experiencing a mental health problem, including anxiety, depression and stress.
Tel: 0300 123 3393
Website: mind.org.uk
Mind Full
Mind Full is a service for 11–17 year olds. It provides support, information and advice about mental health and emotional wellbeing.
Website: mindfull.org

NHS Choices
The NHS Choices website provides advice and information about healthy living for everyone.
Website: nhs.uk/livewell

Rethink mental illness
Rethink mental illness challenge attitudes and help people living with conditions like schizophrenia, bipolar disorder, personality disorders and more to recover a better quality of life.
Tel: 0300 500 0927
Website: rethink.org

Samaritans
If something’s troubling you, the Samaritans will talk things through with you. They are available 24 hours a day, 365 days a year.
Tel: 08457 90 90 90
Website: samaritans.org

Stress Management Society
The Stress Management Society is dedicated to helping people tackle stress.
Tel: 0203 142 8650
Website: stress.org.uk

WebEase (Epilepsy Awareness, Support and Education)
Webease is an interactive on-line self-management program for people with epilepsy. It guides you to think about what is important to you in managing your epilepsy. Modules covered include taking your medicine, managing stress and getting a good night’s sleep.
Website: webease.org
About this publication

This booklet is written by Epilepsy Action’s advice and information team, with guidance and input from people living with epilepsy, and medical experts. If you would like to know where our information is from, or there is anything you would like to say about this booklet, please contact us.

Epilepsy Action makes every effort to ensure the accuracy of information in its publications, but cannot be held liable for any actions taken based on this information.

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Our thanks

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Learn to manage your epilepsy online!

The Epilepsy Action Learning website contains a collection of online resources to teach you, your friends and colleagues all about epilepsy. Ranging from personal stories to seizure first aid, these resources aim to help you in living with your epilepsy.

On Epilepsy Action Learning, you can:
• Learn more about how you can improve your wellbeing
• Learn how to help someone who is having a seizure
• Watch short videos of people describing their lives with epilepsy
• Be confident that all the information is covered by the Information Standard

Find out about these resources, and many more, at learn.epilepsy.org.uk

“Modules are clear, concise and easy to follow… The programme is simple and easy to work through.”
Further information

If you have any questions about epilepsy, please contact the Epilepsy Helpline.

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Information is available in the following formats: booklets, fact sheets, posters, books and DVDs.

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue.

Epilepsy Action’s support services

Local meetings: a number of local branches offer support across England, Northern Ireland and Wales.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. For people aged 16 years or over. Join at forum4e.com

Epilepsy awareness: Epilepsy Action has a number of trained volunteers who deliver epilepsy awareness sessions to any organisation that would like to learn more about epilepsy. The volunteers are able to offer a comprehensive introduction to epilepsy to a range of audiences.

If you would like more information about any of these services, please contact Epilepsy Action. Contact details are at the back of this booklet.
Epilepsy and wellbeing

We would like to know if this booklet has been helpful to you.

As a result of reading the information, please let us know if you agree with any of the following statements. Tick any boxes that apply to you.

☐ I feel more informed about issues surrounding epilepsy.

☐ I feel more confident about talking to my GP/epilepsy specialist/epilepsy nurse.

☐ I feel more confident about talking about my epilepsy with other people.

☐ I have talked to my employer/colleague/teacher/family and they have improved how well they support me.

☐ I have used other Epilepsy Action services, such as the website, the Epilepsy Helpline, support groups or online community (forum4e).

☐ I have used other support services mentioned in the booklet, and found them helpful.

Please tell us how you think we can improve this information

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Please return the completed form to:
Epilepsy Services, Epilepsy Action, FREEPOST LS0995, Leeds LS19 7YY

If you would prefer to tell us over the telephone, please contact the Epilepsy Helpline, freephone 0808 800 5050.

Thank you!
How to contact the Epilepsy Helpline

Telephone the Epilepsy Helpline freephone 0808 800 5050
Monday to Thursday 9.00 am to 4.30 pm Friday 9.00 am to 4.00 pm
Our helpline staff are Text Relay trained

Write to us free of charge at
FREEPOST LS0995, Leeds LS19 7YY
Email us at helpline@epilepsy.org.uk or visit our website:
epilepsy.org.uk  Text your enquiry to 0753 741 0044
Send a Tweet to @epilepsyadvice

About the Epilepsy Helpline

The helpline is able to offer advice and information in 150 languages.

We provide confidential advice and information to anyone living with epilepsy but we will not tell them what to do. We can give general medical information but cannot offer a medical diagnosis or suggest treatment. We can give general information on legal and welfare benefit issues specifically related to epilepsy. We cannot, however, take up people’s cases on their behalf.

Our staff are trained advisers with an extensive knowledge of epilepsy related issues. Where we cannot help directly, we will do our best to provide contact details of another service or organisation better able to help with the query. In doing this, Epilepsy Action is not making a recommendation.

We welcome comments, both positive and negative, about our services.

To ensure the quality of our services we may monitor calls to the helpline.
Environmental statement

All Epilepsy Action booklets are printed on environmentally friendly, low-chlorine bleached paper. All paper used to make this booklet is from well-managed forests.