Epilepsy and wellbeing

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About wellbeing and epilepsy

Wellbeing is about feeling good and functioning well\(^1\). 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 are likely to feel better and function better in your daily life.

In this booklet we look at some ways to look after your wellbeing. We also look at some common health issues that can affect you when you have epilepsy, and give some tips for dealing with them.

Looking after your body - looking after your mind

You might feel that your mind and body are separate, but looking after your physical health can have a big impact on your mental wellbeing.\(^2\)

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

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If you follow this advice, your physical and mental health will benefit. What’s more, following the advice may also help you to have fewer seizures. Here’s why.

**Eat a well-balanced diet** – some people with epilepsy say that if they skip meals, they are more likely to have a seizure. ³

**Get active** – exercise can help you to feel less stressed. ⁴ Many people with epilepsy find that if they feel stressed they are more likely to have a seizure. ⁵

**Limit how much alcohol you drink** – drinking small or modest amounts doesn’t usually increase the risk of having seizures. ⁶ But moderate to heavy drinking over a short space of time can make you more likely to have a seizure. ⁷ Excessive drinking can also make some epilepsy medicines work less well. ⁸

**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. ⁹

### 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.

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⁴ Stress | Mental Health Foundation. Available at: [https://www.mentalhealth.org.uk/a-to-z/s/stress](https://www.mentalhealth.org.uk/a-to-z/s/stress) [Accessed September 16, 2016].


Take your epilepsy medicine

Taking your medicine as prescribed is one of the most important things you can do to keep your seizures under control. Missing a dose can increase your risk of having a seizure. \(^{10}\)

Here are some helpful tips for taking your medicine.

- Make sure you never run out of your epilepsy medicine
- Ask your epilepsy specialist or epilepsy nurse in advance what you should do if you ever forget to take your epilepsy medicine
- Never stop taking your epilepsy medicine, or make changes to it, without talking to your doctor first

Studies have shown that many people with epilepsy do not take their medicine regularly. And many people do not realise they are missing doses. \(^{11}\)

If you find it hard to remember to take your medicine, or are not sure if you are missing doses, you could:

- Count out how many pills you need for two weeks and put them in a box. Put a reminder in your diary or calendar for two weeks’ time. When it gets to that date check if there are any pills left in the box to see if you’ve missed any doses
- Set a reminder on your phone to take your medicine. If you have a smartphone, you could download a medicine reminder app
- Ask your pharmacist if they sell pill organisers (sometimes called a dosette box). These keep your medicines organised and may help you to take the right ones at the right time
- Get a pill box with an alarm that alerts you when it’s time to take your medicine. The Disabled Living Foundation has details of suppliers. See page 15 for contact details

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• Write an instruction to yourself about where you will take your medicine, when you will take it and what you will be doing at the time. For example: I will take my morning tablets in the bathroom, at 7am when I brush my teeth. Research has shown that writing this sort of instruction and reading it back to yourself at least three times can help to lay down an ‘automatic’ reminder in your memory.12

**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.

<table>
<thead>
<tr>
<th>Missing doses of epilepsy medicine13</th>
<th>Not getting enough sleep14</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling stressed15</td>
<td>Drinking too much alcohol16</td>
</tr>
</tbody>
</table>

Some people with epilepsy also say they have more seizures if they miss meals.17

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.

**Get the best treatment for your epilepsy**

UK guidelines say you should have a review of your epilepsy treatment at least once a year. This could be with your GP or with an epilepsy specialist. If you normally see your GP about your epilepsy, but your seizures are not fully controlled, you could ask them to refer you to a specialist.

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If your seizures are very difficult to control, your specialist may refer you to a specialist epilepsy centre. Guidelines recommend you are referred to a specialist centre if you are still having seizures after trying two medicines or more, or after two years. A specialist centre will look again at your diagnosis and epilepsy medicines, to make sure you are getting the best treatment.

**Self-esteem**

Self-esteem is how you feel and what you believe about yourself. It’s about how you view your own worth as a person.

People with good self-esteem tend to have positive beliefs and feelings about themselves. They tend to be better at dealing with life’s ups and downs.\(^{18}\)

People with poor self-esteem tend to have negative beliefs and feelings about themselves.\(^{19}\) Low self-esteem can have a big impact on mental wellbeing and make it harder to deal with life’s challenges.

**Epilepsy and self-esteem**

Living with a long-term health condition such as epilepsy can have an impact on self-esteem.

For example, you might have:

- Lost independence and had to rely on others
- Changed how you think about yourself
- Felt less able to do your job, be a parent, or be a carer
- Had to stop doing your job or activities that you enjoy
- Been told by others that you can’t do things because of your epilepsy
- Experienced negative reactions from others

**Improving self-esteem\(^{20}\)**

There are some things that you can do to try and improve your self-esteem and feel better about yourself.

**Recognise your negative thoughts and beliefs**

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If you can recognise which thoughts and beliefs are affecting your self-esteem, you can try and challenge them.

**Do things that you enjoy and are good at**

Think about what you enjoy doing, and what you are good at. This could be at work, when caring for others, while volunteering or doing a hobby.

**Be kind to yourself**

Instead of criticising yourself, try being kinder to yourself. Think about what you would say to someone else in your situation, and say it to yourself. Focus on your own skills and strengths, rather than comparing yourself to other people.

**Learn to be assertive**

Being assertive is about expressing your needs and knowing your own physical and emotional limits. It’s about learning when to say no. It’s also about respecting other people’s limits.

**Give yourself a challenge**

From time to time, everyone feels nervous about doing certain things, or feels like they can’t do something. However, if you set yourself a challenging goal and work towards it, this can have a huge impact on your self-esteem and confidence. Breaking this down into small steps can make it less daunting.

**Fatigue and tiredness**

We all feel tired from time to time, but if you feel tired most of the time you might have fatigue. Fatigue is a feeling of overwhelming tiredness, weakness or exhaustion that can be mental, physical or both.

When you have epilepsy, you are more likely to be affected by fatigue than other people.\(^{21}\) Having disrupted sleep, because of seizures or the effect of epilepsy medicines, makes fatigue more likely.\(^ {22}\) You are also at more risk of being affected by fatigue if you are depressed.\(^ {23}\)

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Managing fatigue and tiredness

If you think you have fatigue, talk to your doctor. They can help you to find out what may be causing your fatigue, and suggest ways to help.

The NHS also gives advice to help everyone with tiredness and fatigue:

**Eat regularly:** Eating regular meals, with healthy snacks in between can help to keep your energy levels up.

**Get active:** Regular physical activity can help you feel less tired over time. If you're not used to exercising, start with small amounts of gentle exercise and build up slowly.

**Lose weight:** If you're overweight, gradually losing weight can help you have much more energy.

**Ask your GP about talking therapies:** there's evidence that talking therapies can help some people with fatigue. See page 12 for more information about talking therapies.

**Cut down on caffeine and alcohol:** Drinking too many drinks containing caffeine (such as coffee, tea, cola and energy drinks) can make it harder to get a good night’s sleep. And drinking alcohol before bed can make you sleep less deeply, so you'll feel more tired in the morning.

**Have a good sleep routine:** Try to follow a relaxing bedtime routine and go to bed and get up at the same time each day.

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.

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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

Using memory aids can help you to remember things you have learned and done, and remind you to do things in the future. Here are some examples of memory aids, but you may be able to think of many more:

- Smartphones and tablets
- Diaries and calendars
- Tape recorders and Dictaphones
- Notebooks
- Photos and videos
- Alarm clocks and timers
- Pill reminder boxes
- 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 doctor

Your GP can help you find out what might be causing your memory problems. Sometimes memory problems can be a symptom of depression. In fact some people with depression are more aware of their memory problems than their low mood. If you and your GP feel you might be depressed, then treating the depression can often help your memory.

If your memory problems continue, talk to your epilepsy specialist at your next appointment. If you don’t see an epilepsy specialist you can ask your GP to refer you. The
specialist 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.

Some emotional health issues to watch out for

Feeling anxious, depressed or stressed can affect anyone. But you have a higher risk of being affected when you have epilepsy. How long these feelings affect you for and how you deal with them can have a huge impact on your overall wellbeing.

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 anxiety

<table>
<thead>
<tr>
<th>Feeling ‘on edge’</th>
<th>Increased heart rate</th>
<th>Feeling irritable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shaking</td>
<td>Sweating more than usual</td>
<td>Dry mouth</td>
</tr>
<tr>
<td>Muscle aches</td>
<td>Headaches</td>
<td>Shortness of breath</td>
</tr>
<tr>
<td>Stomach aches</td>
<td>Difficulty concentrating</td>
<td>Feeling sick</td>
</tr>
</tbody>
</table>

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
- You feel anxious even when there is no stressful situation

Depression

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

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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**

<table>
<thead>
<tr>
<th>Having difficulty sleeping, or sleeping more than usual</th>
<th>Losing interest in things you used to enjoy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling down, upset or tearful</td>
<td>Finding it difficult to think clearly</td>
</tr>
<tr>
<td>Finding it hard to concentrate</td>
<td>Losing interest in sex</td>
</tr>
<tr>
<td>Feeling tired all the time</td>
<td>Having physical aches and pains that have no obvious cause</td>
</tr>
<tr>
<td>Losing your appetite, or eating too much</td>
<td>Having suicidal thoughts</td>
</tr>
<tr>
<td>Losing confidence</td>
<td>Having memory problems</td>
</tr>
</tbody>
</table>

**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
- If there is something in your brain which is causing your epilepsy, this could also cause anxiety or depression (for example, tumours or infections in a part of the brain called the temporal lobes)
- Your epilepsy medicine might cause anxiety or depression
- 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**

29 Symptoms | Mind, the mental health charity - help for mental health problems. Available at: [http://www.mind.org.uk/information-support/types-of-mental-health-problems/depression/symptoms/#.V9_BlcVSLHc](http://www.mind.org.uk/information-support/types-of-mental-health-problems/depression/symptoms/#.V9_BlcVSLHc) [Accessed September 19, 2016].


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 12). 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 prescribe 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.
- 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: 116 123 Website: samaritans.org

**Stress**

Stress is a natural part of life. It can be described as the way you feel when you are under pressure. A small amount of stress can help us to deal with challenges of daily life. 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**

<table>
<thead>
<tr>
<th>Feeling easily irritated or angry</th>
<th>Finding it difficult to get to sleep or stay asleep</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating too much or too little</td>
<td>Having indigestion, constipation or diarrhoea</td>
</tr>
<tr>
<td>Drinking increased amounts of alcohol or smoking more</td>
<td>Biting your nails</td>
</tr>
<tr>
<td>Feeling unable to enjoy yourself</td>
<td>Finding it difficult to concentrate</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Feeling like you can’t switch off</td>
<td>Feeling tearful</td>
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</table>

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 changing sleeping habits, drinking too much alcohol or forgetting to take epilepsy medicine. All of these can also increase your risk of having a seizure.

**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
- Share your feelings and ask for support (from family, friends, your doctor or a counsellor)
- Ask your family doctor if you can have any talking therapy

**Therapies to help your mental and emotional health**

If you are experiencing anxiety, depression or stress, your GP may suggest that you try a psychological therapy. These are sometimes called talking therapies. 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.

Not all psychological therapies are suitable for everyone, so talk to your GP about which one might work best for you. Here are some examples of psychological therapies, but many others are also available.

**Counselling**

Counselling 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. The Counselling Directory has details of counsellors in the UK. See page 15 for details.

**Cognitive Behavioural Therapy (CBT)**

CBT can help you to manage your problems by changing the way you think and behave. It helps you to understand the links between your thoughts, feelings and behaviour. This can help you to manage your problems in a more positive way.

CBT is usually provided by a trained 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.

**Mindfulness-based therapies**

Mindfulness is about paying attention to the present moment. It involves being aware of your thoughts, feelings and bodily sensations, and calmly accepting them. Mindfulness-based therapies include Mindfulness-Based Stress Reduction (MBSR) and Mindfulness-based Cognitive Therapy (MBCT). They can include techniques such as meditation, breathing and yoga.

Research suggests mindfulness-based therapy may be helpful for people with depression. However, there have been some reports of people having negative effects from practising mindfulness. A good mindfulness teacher should be able to advise you on any potential risks, and help you decide if it’s right for you.

Mindfulness-based therapy can take place in classes with other people. There are also online courses available. Your GP may be able to arrange for you to do a mindfulness course through the NHS, or you can pay privately to do one. The UK Network for Mindfulness-Based Teacher Training Organisations publishes a list of trained mindfulness-based teachers. See page 15 for details.

**Self-referral**

In some areas of England you can refer yourself for talking therapy without seeing your GP. This is offered through an NHS programme called Improving Access to Psychological Therapies (IAPT). To find your nearest IAPT service visit nhs.uk and search for IAPT.

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Five ways to wellbeing for everybody

In 2008, the UK government’s Foresight Project did some research about wellbeing. The New Economics Foundation (NEF) found a way to explain the results of the research. They produced a set of five actions which can improve wellbeing.

<table>
<thead>
<tr>
<th>Connect</th>
<th>Be active</th>
<th>Take notice</th>
<th>Keep learning</th>
<th>Give</th>
</tr>
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</table>

NEF also suggested some ways people can build these actions into their everyday lives. They might give you some ideas of new things you could try. Doing all these things would be too much for a lot of people. But even if you just try one of these suggestions, it could help you to improve your wellbeing.

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 a 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**
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

**Counselling Directory**
The Counselling Directory website allows you to search for counsellors in your area. Also provides information about different types of counselling.
http://www.counselling-directory.org.uk/

**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: 0300 999 0004
Website: dlf.org.uk

**Drinkaware**
The Drinkaware website provides information about how alcohol can affect your health, and how to get support if you think you may be drinking too much. Includes a tool to help you work out how many units you drink.
Website: drinkaware.co.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 and an online mindfulness course.
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

**NHS**  
The NHS website provides advice and information about healthy living for everyone.  
Website: nhs.uk/live-well

**Rethink mental illness**  
Rethink provide practical information and advice for people affected by a mental illness on issues such as different types of therapy, medicines and benefits.  
Tel: 0300 500 0927  
Website: rethink.org

**Royal College of Psychiatrists**  
This website has an advice section where you will find evidence-based information on various mental health problems, treatments and other topics.  
Website: rcpsych.ac.uk

**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: 116 123  
Website: samaritans.org

**Stress Management Society**  
The Stress Management Society is dedicated to helping people recognise and reduce stress.  
Tel: 0203 142 8650  
Website: stress.org.uk

**UK Network for Mindfulness-based Teacher Training Organisations**  
Publishes a list of trained mindfulness-based teachers.  
Website: mindfulness-network.org
About this information
This information 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 the information, please contact us at epilepsy.org.uk/feedback

To find out why you can trust Epilepsy Action’s information, please contact us or visit epilepsy.org.uk/trust

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Your support
We hope you have found this information 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:

- Call the Epilepsy Action fundraising team on 0113 210 8851
- Donate online at epilepsy.org.uk/donate
- Send a cheque payable to Epilepsy Action to the address below

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.

Epilepsy Helpline
Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk, tweet @epilepsyadvice

Contact details
Epilepsy Action, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK, +44 (0)113 210 8800. A registered charity in England and Wales (No. 234343) and a company limited by guarantee (Registered in England No. 797997).

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