

# Employer toolkit

Supporting employees with epilepsy in the workplace

## Supporting employees – With references

### Key points

- Epilepsy affects everyone differently
- Creating a seizure action plan with your employee will help everyone know what to do if your employee has a seizure at work
- There are practical things that employers can do to help with memory problems and to avoid seizure triggers

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## Find out about your employee's epilepsy

By finding out about your employee's epilepsy and what support they need, you can help them to stay in work and retain their knowledge and skills.

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**Talk to your employee about their seizures. Even if they are seizure free now, you need to know what to expect if that changes.**

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Not everyone who has epilepsy will have seizures during the working day – some people might only have them when they're asleep. Others might have them when they first wake up before they need to be at work. And some people will be seizure-free.

If you don't know much about epilepsy take a look at 'About epilepsy' (Link to page) to find out how it can affect people.

Once you know an employee has epilepsy, you'll need to ask them questions about how their epilepsy affects them, such as:

- Are you still having seizures?
- How often do they happen?
- What type of seizures do you have?
- Do you get a warning a seizure is going to happen?
- What happens during a seizure?
- How long do they last?
- How do you feel afterwards?
- Do you usually need any help or first aid?

The answers to these questions will help with deciding, with the person, what type of support, if any, they need.

## Seizure action plans

Epilepsy is different for everyone. To understand how epilepsy affects an employee, it's a good idea to work with them to complete an individual seizure action plan.

1. Ask your employee to complete the 'My epilepsy' template and talk to you about their epilepsy so you understand how it affects them
2. Complete a seizure action plan with them
3. Familiarise yourself with the appropriate first aid for their seizures (see our [first aid information](#))

[My epilepsy template](#)

[Seizure action plan template](#)

[Example completed seizure action plan – Security worker](#)

If your employee usually recovers quickly after a seizure, they might be able to get straight back to work. Or they might just need a quiet place to rest, before going back to work. Their seizure action plan should say where they can rest.

If they normally take longer to recover from a seizure, they might need to go home. Their seizure action plan should include options for how they will get home, and who will travel with them, if necessary. This should be in line with company policies and procedures for anyone who becomes unwell at work.

## Case study: Erin

“Aside from educating themselves on the facts, I’d say the most important thing employers can do is to get to know your employee and their individual needs. Seizures can be frightening but less so if you know what to do.”

## Supporting employees

Watch a video of Grace from the Epilepsy Action Helpline talking about how you can support employees at work.

[Watch the video](#)

## Health and safety risk assessment

A health and safety risk assessment is needed for anyone who might have a seizure at work.

Complete a risk assessment with your employee. Start by using the same risk assessment that would be used for any employee. You can talk about whether your employee’s epilepsy increases the risks for their job or not. There may not be any additional risk.

[See our risk assessment template](#)

## Epilepsy is different for everyone

There are different types of seizures which affect people differently. There could be other factors that affect what support people with epilepsy might need at work, for example, coping with the side-effects of epilepsy medicine. People who have had a seizure but don’t yet know if it’s epilepsy may need different support to people who have lived with epilepsy for a long time.

## Having a first seizure and getting a diagnosis

It can be a shock to have a seizure – for the person it affects, and for those around them. It’s difficult to know when a first seizure is a ‘one-off’, or the first of many.

A one-off seizure doesn’t always mean someone has epilepsy.<sup>1</sup> Around 1 in 10 people globally may experience a one-off seizure in their lifetime.<sup>2</sup> Epilepsy is only diagnosed if a person has had more than one seizure or a doctor thinks there’s a high chance that they could have more.<sup>3</sup>

It might take time to get a diagnosis. If someone is well enough to be at work, there’s no need for them to stay off work until they get a diagnosis. However, they may need some time off for diagnostic tests. A fit note isn’t needed for time off unless the employee is off work for more than 7 calendar days.

## **Case study: Antony**

“When I started having seizures, I knew nothing about epilepsy. I explained to work what was happening, and this was before I got a diagnosis. They were as understanding as they could be but bearing in mind none of us knew anything about epilepsy. We both needed to learn about it and what it meant. I thought everyone needed to know so that they knew how to help me.”

## **Case study: Staci**

“Having my first seizure was a real shock. The immediate thing was not being able to drive anymore. I didn’t realise that epilepsy can have such a big impact on people’s lives and I had no idea what an employer would need to know.”

## **Newly diagnosed**

Being newly diagnosed with epilepsy can be a very unsettling time. It can take people a while to adjust to getting a diagnosis and find the right treatment. Some people have to try different epilepsy medicines to find one that controls their seizures. They may be having more seizures until they find the right treatment. They may also be getting used to the side-effects of epilepsy medicines, such as tiredness, poor concentration or memory issues.

People will also be learning about epilepsy themselves, so may not have all the answers to questions their employer might have.

## **Case study: Doug**

When I was diagnosed with epilepsy, my manager arranged for Epilepsy Action to do some awareness training for my colleagues. I took part so that my colleagues could ask me questions about how epilepsy affected me. I think it helped get rid of some of the misconceptions they had about epilepsy. And also that it’s not as scary as they thought it might be. They also did a seizure action plan to find out how I wanted them to respond if I have a seizure.

I’ve had one seizure at work since the training and they dealt with it brilliantly. One colleague said afterwards that it definitely helped to know before hand what might happen and what to do.

## **Case study: Maria**

“When you are first diagnosed doctors try you on different medications and they’re obviously going to have side-effects. For me one medicine made me a bit aggressive, and another turned me into a zombie. I remember one time when I was switching from one medicine to another. In a meeting I was feeling a bit out of it. A teammate asked if I was ok as apparently, I was sat there swaying. I can laugh about it because I

had a good team around me who knew what was going on and understood it. That day they made sure I went home for my own safety.

“I’m so grateful to have that support around me. Imagine if you didn’t and people thought you were actually stoned at work or something.”

## Long-term epilepsy

Some people will have had epilepsy since childhood, which may well be controlled with their epilepsy medicines. This is not ‘cured’ epilepsy, it’s just that the seizures are controlled with the medicine.

Bear in mind that people with seizure control may still need to avoid any potential triggers for their seizures. They may also still experience side effects of epilepsy medicine, such as tiredness or memory issues. If they are seizure-free they are still protected by the equality laws.

## Epilepsy that changes over time

Epilepsy can change over time – for better, or worse. Seizures can be controlled in around 6 out of 10 people with epilepsy.<sup>4</sup> But sometimes a breakthrough seizure can happen unexpectedly. This might be because the person is unwell with something else or needs their epilepsy medicine re-assessed.

If the employee’s epilepsy changes you will need to review their health and safety risk assessment and consider if any new reasonable adjustments are needed. You will also need to review their seizure action plan. People can become seizure-free and no longer need the same level of care or reasonable adjustments.

# Practical ways to support employees

## Helping with memory problems

- Memory problems are common for people with epilepsy.<sup>5</sup> But there are things you can do to help. Strategies for coping with memory problems are individual, so discuss these with your employee
- Create a work environment where the employee can focus and avoid distractions
- Allow extra time for learning new tasks
- Give information/instructions in different ways: verbally and in writing
- Highlight important information with colour or highlights
- Repeat instructions and demonstrate tasks several times if needed
- Encourage the use of checklists, notes and voice recorders
- Provide software for employees to create reminders for tasks and appointments, such as email and calendar applications
- Check their understanding - encourage them to repeat information back to you

## Avoiding seizure triggers

Some people with epilepsy have things that trigger their seizures. Possible triggers include:

- Tiredness
- Irregular sleep patterns
- Stress
- Flashing or flickering lights (this only affects 3% of people with epilepsy)
- Missing meals
- Not taking epilepsy medicines as prescribed

Find out if your employee has any seizure triggers. If there are triggers, discuss how they can be avoided or minimised. Make a plan for how you can work together to help avoid any triggers at work.

## Photosensitive epilepsy

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**Although flashing lights are often associated with epilepsy, in fact only 3% of people with epilepsy have seizures triggered by flashing lights.<sup>6</sup>**

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Seizures triggered by flashing lights are known as photosensitive epilepsy. Computer screens are unlikely to be a seizure trigger. However, if there are flashing or flickering images, or some types of pattern on the screen, these could be.

## Managing stress

Some people with epilepsy find that during periods of stress they are more likely to have seizures. This can be particularly likely if the stress happens over a long period of time<sup>7</sup>.

If work-related stress is a trigger for your employee, work with them to identify the issues and agree realistic and workable ways to tackle them.

You could also encourage them to enrol on our self-management course, [Epilepsy and you](#). It contains helpful strategies for managing stress.

## Reasonable adjustments

Under the equality laws employers have a legal duty to make reasonable adjustments for employees with epilepsy. Many reasonable adjustments involve little or no cost. If there are costs involved, funding might be available from Access to Work.

Sometimes a small, inexpensive, adjustment can make a big difference for someone with epilepsy.

For more information see the section about [reasonable adjustments](#).

## References

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## [employers.epilepsy.org.uk](http://employers.epilepsy.org.uk)

Epilepsy Action, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK, +44 (0)113 210 8800  
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