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A BRIEFING FOR SCOTTISH MINISTERS

**80,886 people.**  
**2+ deaths per week.**  
**One condition.**

*Source: Public Health Scotland, General Practice disease prevalence data visualisation, 8 July 2025.*

# The truth about epilepsy.

The most common serious neurological condition in Scotland, and the case for a National Epilepsy Action Plan.

## Reveal the truth.

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**The unredacted briefing.**

Every word visible. Every fact named. Read it in full.

**epilepsy.scot**

Freephone Helpline 0808 800 2200  
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# It's time to reveal the truth about...



# epilepsy

Epilepsy is the most common serious neurological condition in Scotland. 80,000+ people live with it. More than two die from epilepsy-related causes every week. It's time for a **National Epilepsy Action Plan**.

**80,000+**

people live with epilepsy in Scotland.

Source: Public Health Scotland, General Practice disease prevalence data visualisation, 8 July 2025.

**2+**

epilepsy-related deaths per week.

**0**

action plans for epilepsy, yet.

## READ · SHARE · ACT

Read the full briefing online at:

**[epilepsy.scot](https://epilepsy.scot)**

Scan a QR, or type the URL into your browser to read, listen, pledge, and download the toolkit.

**ON THE MOVE?**  
3-min audio overview.



**READ THE BRIEFING**  
Read, pledge, share.



AT A GLANCE

Read time: ~5 minutes

# Why this briefing matters.

Epilepsy is the most common serious neurological condition in Scotland, yet there is no national action plan guiding how it is diagnosed, treated or supported. This briefing sets out the case for change.



Source: Public Health Scotland, General Practice disease prevalence data visualisation, 8 July 2025.

## What's inside

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Dear Angela Constance MSP, Cabinet Secretary for Health and Care, and Maree Todd MSP, Minister for Public Health.

# It's time to reveal the truth.

Congratulations on your election to the Scottish Parliament and on your appointment to the Scottish Government's health portfolio. The early days of this new Parliament are a fitting moment to begin a conversation that has been overdue for years.

Epilepsy is the most common serious neurological condition in Scotland, affecting more than 80,000 people. More than two people die from epilepsy-related causes every week. People living in more deprived communities are more likely to develop epilepsy and to experience poorer outcomes, including earlier mortality. This makes epilepsy a public-health issue, and a social-justice issue closely linked to poverty and inequality.

Through my 18 years as Chief Executive of Epilepsy Scotland, I have seen both the progress that can be made and the consequences when epilepsy is not prioritised. Too many individuals still face delays in diagnosis, inconsistent access to specialist care, and avoidable risks to their health and lives. These challenges are not new — they have persisted for years without the level of coordinated action needed to resolve them.

The Scottish Government's own Long Term Conditions Framework consultation paper recognises that '*conditions that are major contributors to the burden of disease, but which happen not to have a strategy, receive less resource than conditions which have a framework or action plan*' (paragraph 24). Epilepsy is exactly that condition. There is no current national action plan or framework for epilepsy in Scotland.

80% of consultation respondents supported a balanced approach combining cross-cutting framework work with condition-specific action plans. Epilepsy — major burden, no current action plan, ready clinical infrastructure — is the textbook case for the condition-specific half of that balance.

Scotland already has world-leading paediatric Managed Clinical Networks, the Scottish Epilepsy Register, and the Psychology Adding Value Epilepsy Screening (PAVES) programme. The Government's own consultation paper cites epilepsy as a *Safe* healthcare quality success — '*100% of women with epilepsy in NHS Greater Glasgow and Clyde offered specialist appointment*' thanks to the Scottish Epilepsy Register. The model works.

Epilepsy Scotland is calling for a National Epilepsy Action Plan, commissioned as one of the first condition-specific workstreams under the Long Term Conditions Framework. Done well, this would set the template for how condition-specific protections can be built into the framework's cross-cutting approach — a concern raised by many in the consultation, and one that an epilepsy action plan, with its existing clinical infrastructure, is well-placed to answer.

I would welcome the chance to meet you both, brief your officials, and discuss what a National Epilepsy Action Plan can deliver. Epilepsy Scotland stands ready to work with you to achieve that.

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**Lesslie Young OBE**

Chief Executive, Epilepsy Scotland

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EPILEPSY IN SCOTLAND

# The numbers behind the condition.

The figures below are drawn from Public Health Scotland's most recent practice-level data, supplemented by published evidence on epilepsy outcomes. They show a growing population in need of consistent, high-quality care.



**1 in 70**  
people in Scotland have epilepsy.

**2+**  
epilepsy-related deaths per week in Scotland.

**~70%**  
of people could be seizure-free with the right medication and care.  
Source: ILAE

## A postcode lottery in prevalence

*Prevalence = the share of the population diagnosed with epilepsy.*

Diagnosed prevalence varies across Scotland's NHS Boards (2025).



Source: Public Health Scotland, General practice, disease prevalence data visualisation, published 08 July 2025. Figures rounded.

## OUR VISION FOR THE ACTION PLAN

# Six pillars for a fairer, safer system.

Epilepsy Scotland's proposed National Epilepsy Action Plan is built around six interconnected pillars. Together, they would deliver consistent, evidence-led care, and the policy infrastructure to keep improving it.

*These six pillars map directly to the Long Term Conditions Framework's emerging themes, they are not a parallel ask. They are how epilepsy fits within the framework.*

## 01 Minimum standards of care

Timely diagnosis, regular clinical review, clear referral pathways, and access to specialist expertise, including epilepsy specialist nurses, for every person in Scotland.

### SUCCESS

*Every person with a first suspected seizure should receive timely specialist assessment, with national standards set through the action plan and reported publicly by NHS Board.*

## 02 Paediatric care that builds on Scotland's strengths

High-quality, coordinated support from the moment of diagnosis, extending the world-leading paediatric Managed Clinical Networks and pathways already in place.

### SUCCESS

*Current gold-standard paediatric care protected, and the same coordinated approach extended to adult care.*

## 03 National training standards

Recognised training across health, education and community settings, including the safe administration of emergency medication such as midazolam.

### SUCCESS

*Nationally recognised standards for consistent care and training across Scotland.*

## 04 A boost for Scottish life sciences

Support for Scotland's neurolongevity, brain-health and mental-health technology sector to drive research, digital innovation, earlier intervention and better use of data to improve epilepsy outcomes.

### SUCCESS

*Scotland-led innovation in epilepsy diagnosis, care and prevention.*

## 05 Better data, better decisions

Improved data on epilepsy outcomes, including epilepsy-related deaths, to strengthen service planning, prevention and accountability.

### SUCCESS

*Annual public reporting of epilepsy outcomes by NHS Board.*

## 06 Public awareness & first aid

Greater understanding of epilepsy, seizures and seizure first aid across public services and communities, reducing stigma and improving safety.

### SUCCESS

*Reduced stigma and fewer avoidable 999 call-outs.*

## ABOUT EPILEPSY SCOTLAND

# More about us.

Founded in 1954, Epilepsy Scotland is the national charity for the more than 80,000 people living with epilepsy across Scotland. We exist to ensure their voices are heard, by services, by employers, by communities, and by government.

### OUR MISSION

To work with people living with epilepsy to ensure that their voices are heard.

### OUR VISION

People living with epilepsy, free from stigma and discrimination, with access to high-quality care and support, valued and included in society.

## What we do

### Free Helpline & Check-In

Our freephone helpline (0808 800 2200) supports anyone affected by epilepsy. Our Check-In service provides regular calls for people going through difficult periods.

### Wellbeing Support

1:1 sessions, peer groups, counselling, relaxation classes, helping people manage anxiety, stress and isolation linked to epilepsy.

### Youth Service (8-24)

Youth groups, residentials, school workshops and 1:1 support helping young people thrive with epilepsy.

### Welfare Rights

Specialist benefits advice, application support, appeals and tribunal representation.

### Training & Awareness

Epilepsy awareness training for care providers, teachers and employers, including safe administration of emergency medication.

### Influencing

Working with government, parliament, the NHS and the public to drive better policy and reduce stigma.

## UNDERSTANDING EPILEPSY

# What epilepsy is, and what it isn't.

Epilepsy is a neurological condition characterised by a tendency to have recurrent seizures. There are over 40 different seizure types and many different causes, including genetics, stroke, brain injury and infection. For many people the cause is never identified.

## Quick facts

- Epilepsy can develop at any age, but is most commonly diagnosed in childhood or after the age of 60.
- Around 1 in 70 people in Scotland live with epilepsy.
- Most seizures last a few seconds to a couple of minutes and stop without the need for emergency treatment.
- Epilepsy is associated with higher rates of mental health difficulties, unemployment and premature death.

## Common myths

**Myth: You should put something in someone's mouth during a seizure.**

Never. It can cause serious injury. Cushion their head, time the seizure, and stay with them.

**Myth: Everyone with epilepsy has flashing-light triggers.**

Photosensitive epilepsy affects only around 3% of people with the condition.

**Myth: Epilepsy is rare.**

It's the most common serious neurological condition in Scotland.

**Myth: People with epilepsy can't lead full lives.**

With the right management, most people work, study, drive and live independently.

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## VOICES FROM THOSE WE SUPPORT

# Behind every figure, a person.

Each year Epilepsy Scotland's services reach thousands of people across Scotland. The voices below are drawn from those we have supported through our Helpline, Wellbeing Service and Check-In Service, and they show why a national, coordinated approach to epilepsy matters.



*I feel much more supported and knowing that the Helpline exists helps to reduce my anxiety around my epilepsy. The Epilepsy Scotland Helpline staff listened to the problems I was having and facilitated counselling and support for me. Their empathy and support helped me to find some positivity and determination to live a good life despite my epilepsy.*

– Dave, who contacted the Epilepsy Scotland Helpline

*“My mood has improved, and I've noticed a reduction in my seizure activity.”*

A participant in our Adult Wellbeing Service

*“Having the support is wonderful when someone understands the impact epilepsy can have on mental health.”*

A user of our Check-In Service

Quotes published by Epilepsy Scotland (service-user stories and Adult Wellbeing Service report).

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## FUNDRAISING · HOW WE RAISE WHAT WE NEED

# Our partnership with Glasgow 2026 Commonwealth Games, All In.



## GLASGOW 2026 ALL IN EXAMPLE EVENT

### Breaking Barriers

A panel discussion with **Stephanie Inglis, Katie Ford, Annie Brooks** and **Dai Greene** on drive, determination and what it takes to perform at the highest level while living with epilepsy.

*Hosted by Kieron Achara MBE*

## GLASGOW 2026 ALL IN EXAMPLE EVENT

### Let's Get Quizzical

A 1980s and Commonwealth Games-themed quiz party hosted by actor Tom Urie (River City). Big hair, big tunes, big prizes.

*A relaxed evening with the Epilepsy Scotland team*

## Other fundraising.

### INDIVIDUAL FUNDRAISER

#### Caitlin Andrew, running the length of the UK

Caitlin Andrew, 25, from Clydebank, is taking on **827 miles from Land's End to John o' Groats**, running a **marathon every day for 35 days**, from 1 June to 5 July. She is running in memory of her best friend Tyla-Neve Malone, who died from epilepsy aged 19, and aims to become the first Scottish woman to run the length of the country.

### EVENT

#### The Kelpies Experience

A guided aerial experience around Andy Scott's monumental horse-head sculptures in Falkirk. **Saturday 10 October 2026 · £30 booking, £250 minimum fundraising target.**

### TAKE ON A CHALLENGE

#### Marathons & Kiltwalks across Scotland

We support fundraisers running every distance, from local 10ks to the London, Edinburgh and Loch Ness marathons, and we have a team in every Scottish Kiltwalk: Glasgow, Dundee, Aberdeen and Edinburgh.

## SEIZURE FIRST AID

# What to do if someone has a seizure.

You do not need to be a qualified first aider to help someone during and after a seizure. Most seizures will stop on their own and will not require any intervention. The guidance below is for a tonic-clonic seizure, when someone suddenly loses consciousness, falls and starts convulsing (jerking).

## DURING THE SEIZURE

- Time the seizure (the convulsive part).
- Move any objects that could cause injury.
- Put something soft, a jacket or flat cushion, under the person's head.
- Loosen tight clothing around the neck.
- Remove their glasses if they are wearing them.
- Reassure others and stop people crowding around.

## ONCE THE JERKING STOPS

- Wipe away any vomit or saliva to keep their airway clear.
- Tilt their head slightly backwards to maintain the airway.
- Check whether they have injured themselves.
- Turn the person onto their side (recovery position).
- Check nothing has blocked their airway, such as dislodged dentures or inhaled food.
- Stay with them until their breathing and colour have returned to normal.
- Talk gently to help re-orientate them, and stay with them until they are fully recovered.

## WHAT NOT TO DO

**DO NOT** move the person unless they are in danger, for example, on a busy road or at the top of stairs.

**DO NOT** try to stop the convulsing or restrain the person.

**DO NOT** put anything in the person's mouth or between their teeth.

**DO NOT** offer food or drink until they are fully conscious and their breathing has returned to normal.

## Call 999 if...

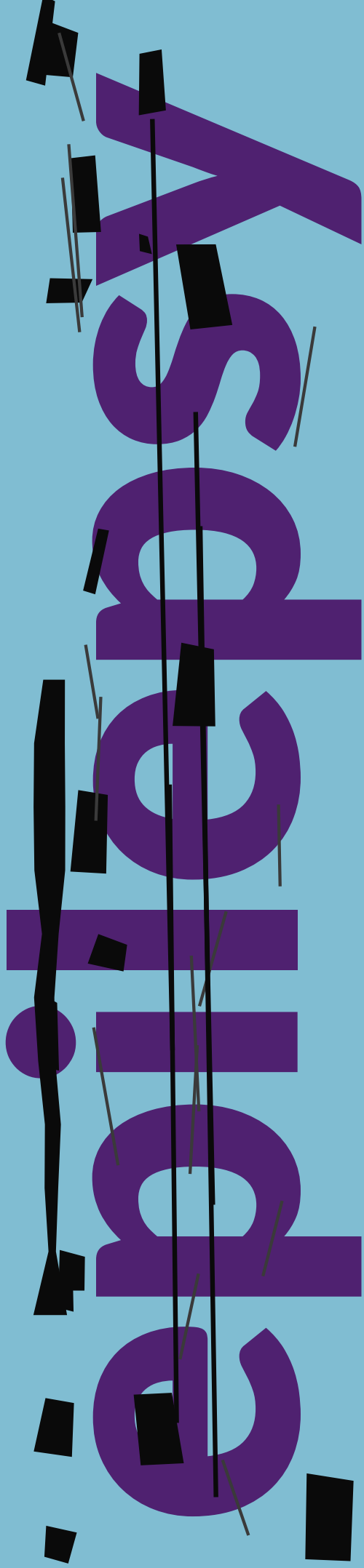
Call an ambulance straight away if any of the following apply:

- it is the person's first seizure, as far as you know
- they are badly injured beyond first aid
- they may have inhaled food, drink or vomit
- the convulsions last five minutes, or longer than is normal for that person
- one seizure follows another with no full recovery in between
- the person is having problems breathing after the seizure has stopped

*Do not hesitate to call an ambulance if you have any concerns.*

Source: Epilepsy Scotland, [epilepsy.scot/about-epilepsy/first-aid](http://epilepsy.scot/about-epilepsy/first-aid). Free training in seizure first aid is available from Epilepsy Scotland.

# Reveal the truth.



## It's time for a National Epilepsy Action Plan.

[epilepsy.scot](http://epilepsy.scot)

*Cut out this page and snap a pic with the poster.*

#RevealTheTruth



# Let's work together.

We'd welcome the chance to meet you, brief your team and discuss how a National Epilepsy Action Plan can deliver better outcomes for the more than 80,000 people in Scotland living with epilepsy.

## GET IN TOUCH

### Office

Epilepsy Scotland  
48 Govan Road  
Glasgow G51 1JL  
0141 427 4911

### Helpline

Freephone, free & confidential  
Mon–Fri, 10:00–16:30

**0808 800 2200**

### Online

epilepsy.scot  
publicaffairs@epilepsyscotland.org.uk

## Scan to set up a meeting with

**Lesslie Young OBE, CEO of Epilepsy Scotland.**

*QR code opens a new email to [lyoung@epilepsyscotland.org.uk](mailto:lyoung@epilepsyscotland.org.uk)*

