EPILEPSY
ACTION

YOUR EPILEPSY

People with epilepsy helped to make this booklet. This is what they'd like to say to you:

"We know that epilepsy can be scary and isolating, but it's also important to remember that you're not alone.

The good news is that this information and support is here for you. Many of us had our epilepsy diagnosis a long time ago and wish we'd had this sort of information back then.

It would have helped us to understand our seizures and we could have used it to educate others. We often found that people would give us the wrong information – or even the wrong medication.

Things have come a long way and people now have every reason to be hopeful.

We've each met some brilliant specialists who have given us good and practical advice. Some of us have been seizure free for years, and don't really feel the impact of epilepsy day-to-day. There may not be a 'quick fix' for your epilepsy, but stick with it because if you follow the medical advice, the chances are life will be relatively normal.

We'd also encourage you to embrace the support Epilepsy Action offers – talking to others who really understand what epilepsy means can make such a big difference. Epilepsy isn't always easy, but by sharing experiences, advice and companionship, you can learn to understand, accept and see life beyond epilepsy.

We hope you find this information helpful."

Chris, Christine, Tony, Anthony, Sally, Fiona, Mark, Martha, Rachel and Ruthanna

Epilepsy says stop. We say go.

We're Epilepsy Action. If you're affected by epilepsy, we're here for you. We want to help you live your best life with epilepsy, and to make you feel like you again. Having seizures or a diagnosis of epilepsy can be a confusing and worrying time. Whatever you are going through, we're with you for every stage of your journey, connecting you with others, and offering you support and information you can trust.

About epilepsy

Our website has a whole section called 'About epilepsy'. You can visit the website at **epilepsy.org.uk/info** or you can scan this QR code to go straight there.

This booklet has been written for people with epilepsy and anyone affected by it whether you're a family member, friend or colleague.

Contents

> “Although it has been hard to accept that my epilepsy may be permanent, I have developed willpower and feel mature, confident and comfortable in who I am.”

Tayyibah, Coventry

What is epilepsy?

It might be a shock to find out you have epilepsy. It can affect anyone at any age and there are lots of different types.

Epilepsy is a condition that affects the brain and causes seizures. It is one of the most common neurological conditions in the world. It affects around 630,000 people in the UK.

This means that around 1 in 100 people in the UK have epilepsy. Around 80 people are diagnosed with epilepsy in the UK every day. That means there’s a big community of people who can help and support you if you need it.

Why do I have epilepsy?

There are lots of different types of epilepsy. For around half of people with epilepsy, doctors don’t know what causes it. Some possible causes include:

- Brain damage, for example damage caused by a stroke, head injury or infection
- Brain tumours
- The way the brain developed in the womb
- A genetic cause

Researchers have found a number of genes linked to particular types of epilepsy. There are many types that doctors think are likely to be genetic, but they don’t yet know which genes are involved. If your epilepsy does have a genetic cause, this doesn’t always mean it can be passed on (inherited) to your children.

We know it can feel lonely and confusing when you’ve recently been diagnosed with epilepsy. We run face-to-face and online talk and support groups so you can meet and talk with other people in a similar situation. epilepsy.org.uk/support

What are seizures?

Electrical activity is happening in our brains all the time, as networks of tiny brain cells send messages to each other.

These messages control all our thoughts, movements, senses and body functions.

A seizure happens when there is a sudden, intense burst of electrical activity in the brain. This causes the messages between cells to get mixed up. The result is an epileptic seizure.

There are many different types of seizures and you might have more than one type.

Types of seizure

When people think of epilepsy, they often think of **tonic-clonic seizures** where a person falls to the floor and their whole body shakes (convulsions).

But there are many other types of seizure. With **focal seizures**, one part of the brain is affected. You might be aware of what is happening during the seizure, or you might be totally unaware until the seizure ends.

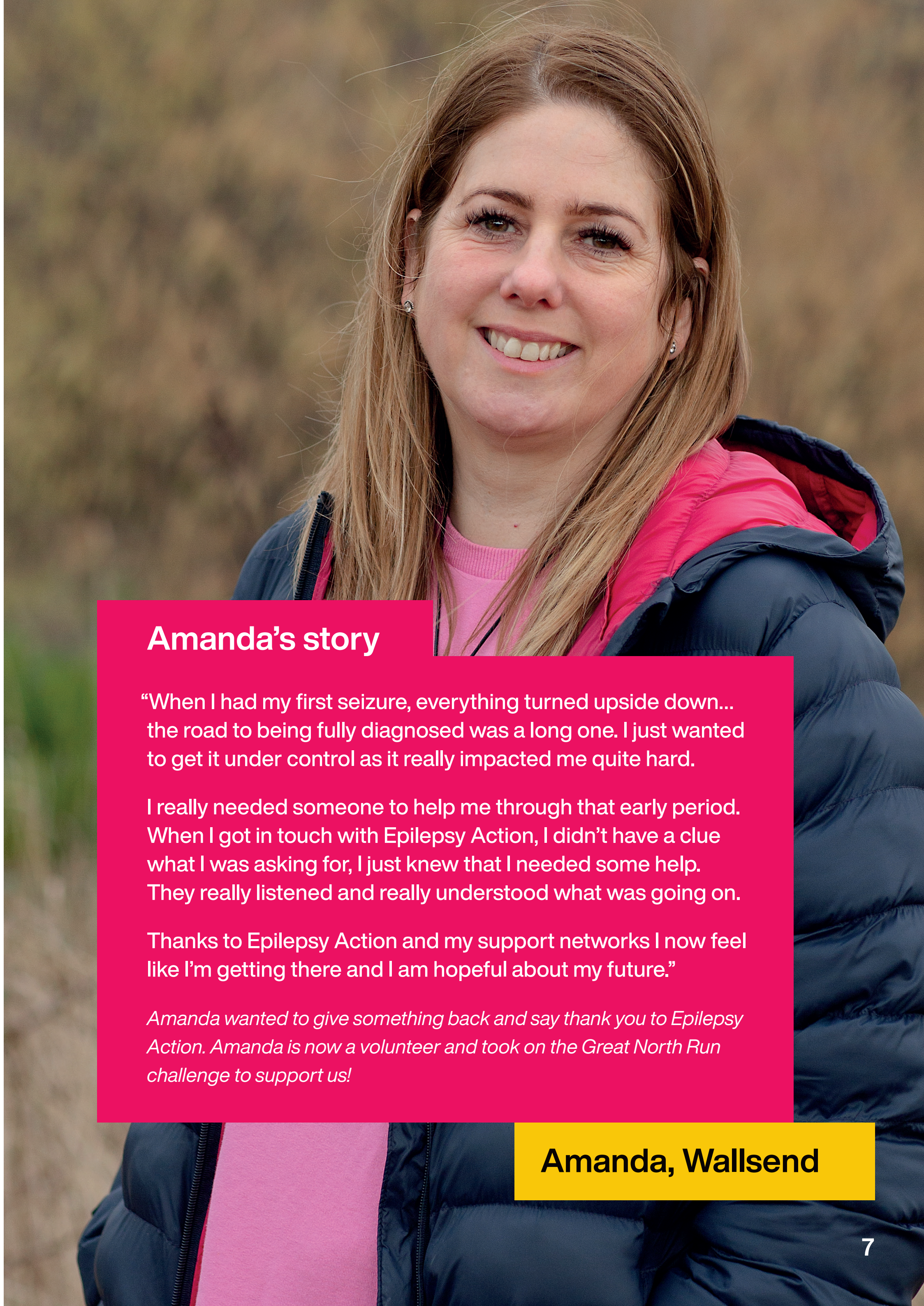
Some types of seizure might cause you to have sudden muscle jerking (**myoclonic seizures**), or your body might become very stiff (**tonic**), or your muscles relax all at once (**atonic**). You might have absence seizures where you appear distant for a moment.

You might feel strange sensations before the seizure happens. This is sometimes called an **aura**, which is actually a type of focal seizure. Or, you might behave in an unusual way before, during or after seizures.

A wide range of symptoms can happen during a seizure. Some people have only one symptom while others experience several. The part of brain the seizure affects has an impact on what happens during a seizure.

Seizure triggers

Some people notice triggers that can make a seizure more likely. Some common triggers are stress, lack of sleep and not taking epilepsy medicines regularly. Find out more about triggers and how to avoid them **epilepsy.org.uk/triggers**



Amanda's story

"When I had my first seizure, everything turned upside down... the road to being fully diagnosed was a long one. I just wanted to get it under control as it really impacted me quite hard.

I really needed someone to help me through that early period. When I got in touch with Epilepsy Action, I didn't have a clue what I was asking for, I just knew that I needed some help. They really listened and really understood what was going on.

Thanks to Epilepsy Action and my support networks I now feel like I'm getting there and I am hopeful about my future."

Amanda wanted to give something back and say thank you to Epilepsy Action. Amanda is now a volunteer and took on the Great North Run challenge to support us!

Amanda, Wallsend

Your diagnosis

New diagnosis

There are a number of conditions that can cause symptoms similar to epilepsy. This means it can sometimes take a while to diagnose. To help your epilepsy specialist make a diagnosis, they will take a full description of your symptoms. They may also arrange for you to have some tests.

If you are diagnosed with epilepsy, you should be told what type of epilepsy you have and the name of your seizures. You should also be given information about your treatment options, and about living with epilepsy. This will include any safety risks you might have and how to reduce them.

You will probably have a lot of different emotions when you are diagnosed with epilepsy. But there are things you can do to help you feel more in control.

We have lots of information on our website about the steps you might go through while being assessed for epilepsy. You should be referred to an epilepsy specialist, usually a neurologist (for adults) or a paediatrician (for children). If it's not mentioned, you could ask if there's an epilepsy clinic or Epilepsy Specialist Nurse in your area.

Epilepsy Action is here to support you and your family. Whatever you're going through, we'll be with you for as long as you need us.

Visit **epilepsy.org.uk/newdiagnosis** to read about:

- What to expect from diagnosis and treatment
- Preparing for your appointments
- Managing your epilepsy
- Support for you

> "After being diagnosed, I became withdrawn. I thought I'd never be able to do the things a normal teenager does.
>
> But, I proved people wrong. I began to do all the things anyone without epilepsy would. Now, I have a job doing something I love and I'm planning my wedding.
>
> I have epilepsy. Epilepsy does not have me."

Megan, Liverpool

> “The support of my family and friends has helped me through the many challenges I’ve faced and has helped me to live a ‘normal’ life.”

Harry, Wrexham

How is epilepsy treated?

For around two thirds of people with epilepsy, their seizures can be controlled with epilepsy medicines. It can take some time to find the right medicine for you, as there are lots of different types available and everyone’s situation is different.

Your specialist should explain which medicines may be suitable for you and tell you about any possible side effects or risks.

Some epilepsy medicines have rules about who they may be prescribed to. You might need to use contraception while you take your medicine. This is because they might cause problems for your baby. We have more information about this at **epilepsy.org.uk/living/starting-a-family/epilepsy-medicines-and-pregnancy**

It’s important to not stop taking your medication without speaking to a medical professional first.

If medicine does not work well for you, your specialist might suggest some other treatment options, like surgery, vagus nerve stimulation or a special medical diet (ketogenic). Scan the QR code or visit our website to find out about these.

We have many different webpages about all of these topics and more:

- Managing side effects
- Taking epilepsy medicines while you are pregnant
- Switching between medicines
- Medical cannabis
- Being referred for surgery
- What to expect if you live in different parts of the UK, including Wales and Northern Ireland
- Complementary treatments

You may have lots of questions about your epilepsy and your treatment options. You could ask your specialist about talking to an epilepsy specialist nurse. They can answer your questions and give you practical advice on things like managing side effects, or reducing your risks.

Treatment

Living with epilepsy

Living

Epilepsy is more than just seizures. On top of your physical symptoms, you may need support with your mental health.

Our website has a section called ‘Living with epilepsy’. Visit this section at **epilepsy.org.uk/living** or scan this QR code to go straight there. Each page is printable.

Risks and daily life

There are some things it is important to know. Depending on the type of epilepsy you have there could be some risks, and if you know about these you can take steps to lower your risk. We have a lot more information about this on our website, but here’s an introduction to some of the topics:

Safety

Safety

Seizures can put you at risk of accidents and injury, so it’s a good idea to think about safety. You’ll often find you can still do things you enjoy, with some simple measures to reduce any risks.

You might want to carry an ID card to help people know what to do if you have a seizure. You can order these or print them from our website at **epilepsy.org.uk/IDcard**

Work

You don’t automatically have to tell your employer about your epilepsy, if you don’t believe it will affect your ability to do your job safely and effectively. But if you do tell them, they must put in place reasonable adjustments that would reduce or remove any disadvantage caused by your condition.

If there’s a chance you’ll have seizures at work, it’s a good idea to draw up a seizure action plan with your employer. Epilepsy Action has employment information and a seizure action plan template that you can fill in together at **epilepsy.org.uk/living/work**

You might want a more detailed summary of your epilepsy and how you manage your seizures by completing a care plan. We have a blank one that you can fill at **epilepsy.org.uk/careplan**

Status epilepticus

Status epilepticus

Status epilepticus is when a seizure lasts a long time or when you have one seizure after another without recovering in between. It is a medical emergency that can happen with any type of seizure.

A tonic-clonic seizure lasting more than five minutes, or going from one seizure into another without recovering in between, needs urgent medical attention.

For some people who are at high risk, emergency medicine is sometimes prescribed to use in case of status epilepticus. You would also need a care plan and someone trained to give the medicine. We have more information about this on our webpage.

Non-convulsive status epilepticus can also be very serious for some people, depending on the cause of the seizure.

Tonic-clonic seizures

If you have tonic-clonic seizures, you might want to share this video with your friends and family. It explains the simple steps to follow to keep you safe during and after a seizure: **epilepsy.org.uk/care**

Memory

A lot of people with epilepsy have problems with their memory. This could be because of seizure activity, side effects of epilepsy medicines, or an after effect of surgery. Our webpage has more details on the causes of memory issues and tips on how to manage this at **epilepsy.org.uk/memory**

Driving

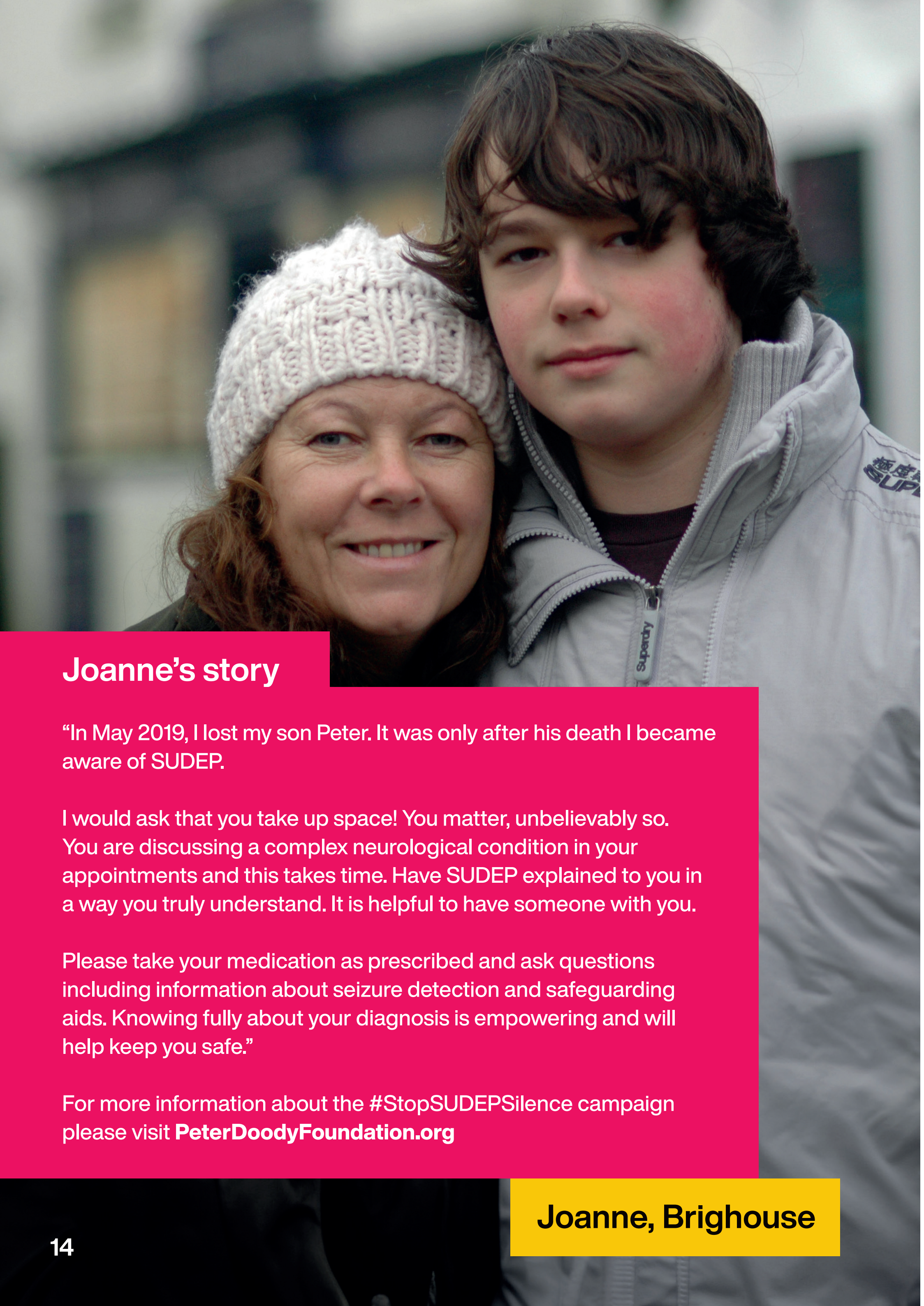
If you have a driving licence, or want to get one, you need to tell the driving agency about your epilepsy. Many people with epilepsy are able to drive, as long as they meet the driving rules for their type of seizures.

You can find out what to do if you’re told to stop driving, the rules for when you can drive again, and how to apply or reapply for your licence at the webpage **epilepsy.org.uk/driving**

Keep a diary

Keep a diary

Seizure diaries can be a really helpful way to understand more about your epilepsy. You can use it to identify what types of seizures you’re having and when, and what might possibly be triggering them, visit **epilepsy.org.uk/living/keeping-a-seizure-diary**



Joanne's story

"In May 2019, I lost my son Peter. It was only after his death I became aware of SUDEP.

I would ask that you take up space! You matter, unbelievably so. You are discussing a complex neurological condition in your appointments and this takes time. Have SUDEP explained to you in a way you truly understand. It is helpful to have someone with you.

Please take your medication as prescribed and ask questions including information about seizure detection and safeguarding aids. Knowing fully about your diagnosis is empowering and will help keep you safe."

For more information about the #StopSUDEPSilence campaign please visit **PeterDoodyFoundation.org**

Joanne, Brighouse

We need to talk about SUDEP

Around 1 in 1000 people with epilepsy die from SUDEP every year.

We know that you may be new to epilepsy and this is an already overwhelming time. We know this can be a hard topic.

But we believe that talking about SUDEP now, with your medical team and loved ones, is important. It can also be life-saving.

We don't know exactly what causes SUDEP, and everybody's individual level of risk is different. It will depend on what type of seizures you have and how well-controlled they are. For many people, the risk is very low.

But we do know that there are some general things which seem to increase the risk of SUDEP for some people. These include:

- Having uncontrolled tonic-clonic seizures
- Night-time seizures
- Missing doses of seizure medication

Some things may increase your chance of having a seizure, which can affect your risk of SUDEP. These could include alcohol and drug misuse, and not getting enough sleep.

SUDEP

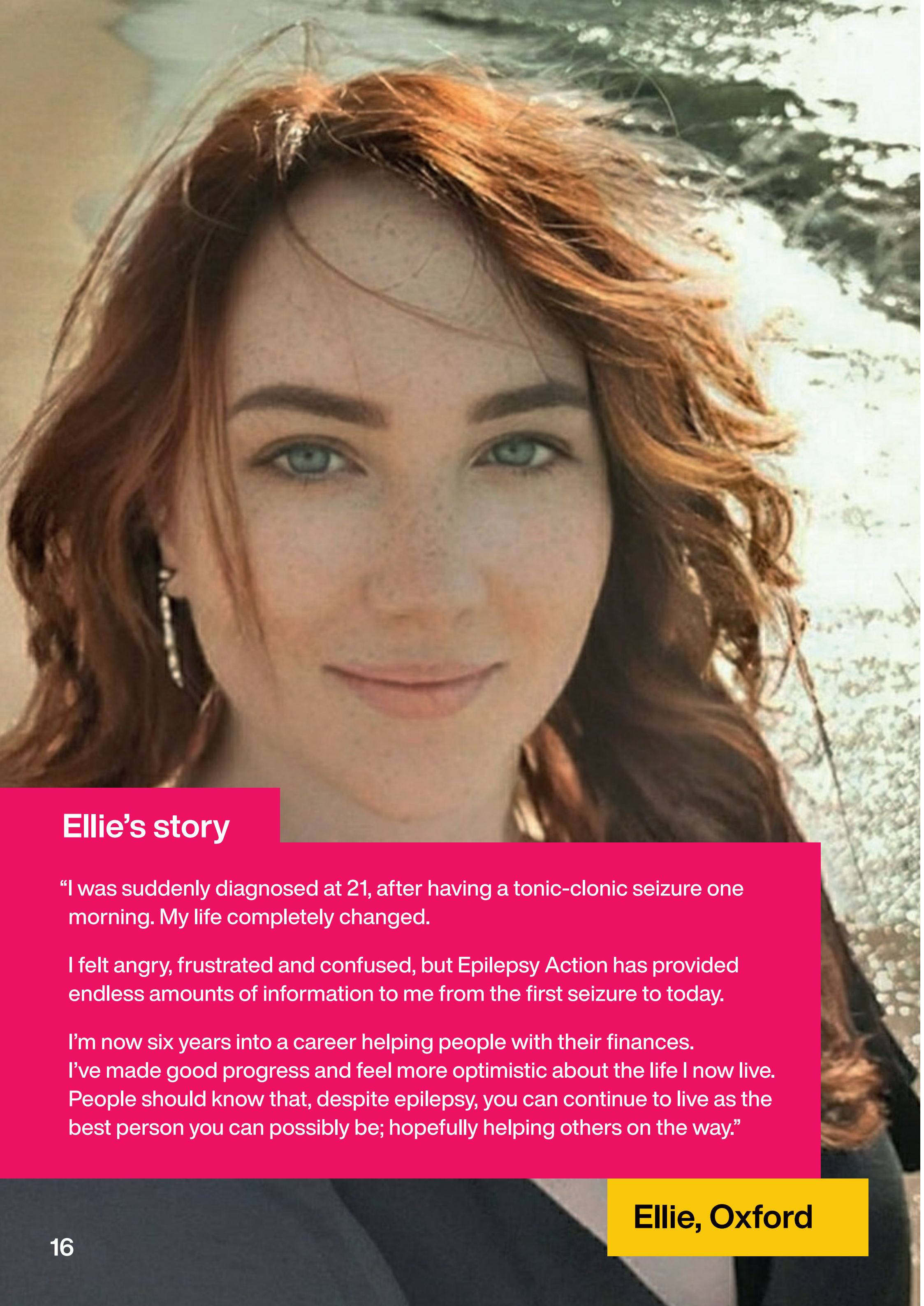
Your risk for SUDEP can change over different stages of your life. This is why it is so important to keep talking about it with your medical team.

Our advice is to:

- Talk about your SUDEP risk regularly with your GP and epilepsy specialist
- Ask about night-time monitors and alarms, and consider using a seizure diary to track and manage your epilepsy
- Stay aware of anything that could affect your own risk for SUDEP
- Reach out to us if you have any questions. You do not have to deal with this on your own

Monitors and alarms

Call our helpline on **0808 800 5050**, or visit **epilepsy.org.uk/info/sudep-sudden-unexpected-death-in-epilepsy** for more information about SUDEP.



Ellie's story

"I was suddenly diagnosed at 21, after having a tonic-clonic seizure one morning. My life completely changed.

I felt angry, frustrated and confused, but Epilepsy Action has provided endless amounts of information to me from the first seizure to today.

I'm now six years into a career helping people with their finances. I've made good progress and feel more optimistic about the life I now live. People should know that, despite epilepsy, you can continue to live as the best person you can possibly be; hopefully helping others on the way."

Ellie, Oxford

How should I feel?

Having a diagnosis of epilepsy can come as a shock, and living with seizures can be hard at times. People respond to this in different ways and there is no 'right' way. If you feel stressed, anxious or depressed, we have more information about how to understand and manage these feelings:

- Low mood, depression and epilepsy
- Anxiety and epilepsy
- Fatigue and tiredness
- Stress and epilepsy

There are lots of ways that you can get support with your mental health. Talking to your medical team about your feelings is a good place to start. They may be able to offer support or treatments. As well as this, building a good support network can really help. We have lots of ways that we can help you begin to build your support network.

Our community

Epilepsy Action's work is informed by a growing community of people with lived experience. Like you, they understand what it means to live with epilepsy. We invite you to join the community, the biggest of its kind in the UK.

Our free magazine

If you'd like to receive a free copy of our member magazine, Epilepsy Today, you can by visiting **epilepsy.org.uk/freemagazine**

Wellbeing

Epilepsy and wellbeing

Wellbeing course

Looking after your wellbeing can help you to have as few seizures as possible. It can also improve how you feel about having seizures. Some things you can do to improve your wellbeing are:

- Eat a well-balanced diet
- Get active
- Limit how much alcohol you drink
- Have a good sleep routine
- Take your epilepsy medicine as prescribed
- Recognise and avoid your seizure triggers

Our wellbeing course

'Epilepsy and your wellbeing' is a free online course for people with epilepsy. It's designed to help you manage your epilepsy and take steps to improve your wellbeing.

It's packed with tips, tools and information to help you feel good and function well.

Find the wellbeing course by scanning the QR code or visiting **epilepsy.org.uk/wellbeing**

You will learn about:

- How wellbeing links to epilepsy
- Ways to manage epilepsy
- Coping with stress
- Physical and mental health
- Next steps for you

Speak to a Samaritan

If you are feeling that life is too much, contact the Samaritans on 116 123 or text 'Shout' to 85258. They are both available any time, day or night.

If you need help straight away, call 999.

Financial help

Depending on individual circumstances, people with epilepsy are entitled to certain benefits. These might include a Disabled Person's Bus Pass and Railcard, a Blue Badge, free prescriptions and Personal Independence Payments or Universal Credit.

Information about benefits is at **epilepsy.org.uk/living/benefits**

> "I found Epilepsy Action in January 2020, but I wish I'd found them sooner. I've learnt so much about epilepsy and about myself, which has been a relief."

Anne, Fermanagh

Support and advice

Helpline

Whether you need advice and information or support and a friendly chat, Epilepsy Action is here for you. We offer a range of **free, confidential services** for anyone affected by epilepsy.

Helpline

Our helpline team is ready to answer any questions you might have on the phone, via live chat or email. Whatever you're going through, we're here to help.

Freephone 0808 800 5050

Email helpline@epilepsy.org.uk

epilepsy.org.uk/helpline

Staff are text relay trained and able to offer advice and information in 150 languages, via an interpreting service.

Live chat

Visit **epilepsy.org.uk** to chat with a member of the helpline team. We usually reply to chat requests within two minutes.

Talk and support

Share your experiences and connect with others affected by epilepsy at one of our regular support groups. Online and in-person groups are available.

Befriending

If you prefer one-to-one support, you might like to try our befriending service. Enjoy a weekly chat with one of our friendly volunteers either online, or on the phone.

Counselling

Available in Wales, we can offer professional counselling support to anyone affected by epilepsy.

Family support

We also offer tailored support for families and carers in South Wales and Northern Ireland, including practical help and opportunities to connect.

Contact our helpline or visit **epilepsy.org.uk/support-for-you** to find out more.

Getting involved

Getting involved can be one way to build your support network and improve your own wellbeing. When the time is right, you might like to explore getting involved so we can be here for more people affected by epilepsy.

Campaign with us

Help us campaign to improve the lives of everyone affected by epilepsy. We work with healthcare professionals, politicians and the public to fight for the services, care and support that people with epilepsy need and deserve.

Share your story

Everyone's epilepsy story is unique. Sharing your story can help others feel less alone.

Take part in research projects

Epilepsy Action is frequently contacted by researchers who want to find people with epilepsy, or their carers, who are willing to take part in their research project. They might invite people to complete a survey or take part in an interview, workshop or focus group.

Volunteer for us

Our volunteers make an enormous contribution to improving the lives of people with epilepsy.

Raise money with us

Do something amazing with Epilepsy Action. Run, cycle or walk, or create your own fundraising event.

Partner with us

Support us through your business. We have funding, research and fundraising opportunities for all types of organisations.

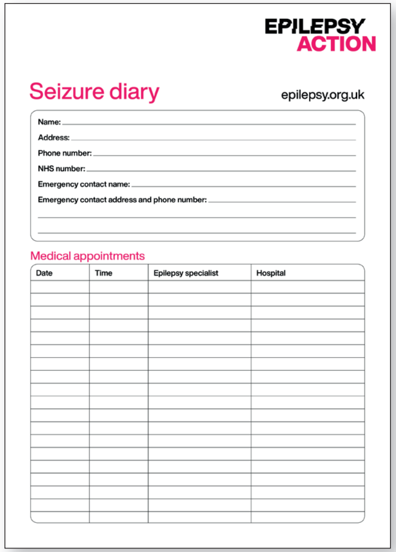
Give a donation

Making a regular donation to Epilepsy Action means that we can continue our work supporting people with epilepsy to live a better life. With your donation we can get people the information they need, when they need it, and provide support to help reduce isolation.

We'd love to hear from you at **epilepsy.org.uk/involved**

Notes and questions I have

It can be difficult to keep track of all the information relating to your epilepsy. Use this page to jot down any important details, or questions you might want to ask someone.



EPILEPSY ACTION

Seizure diary

epilepsy.org.uk

Name:
Address:
Phone number:
NHS number:
Emergency contact name:
Emergency contact address and phone number:

Medical appointments

Date	Time	Epilepsy specialist	Hospital

Visit **epilepsy.org.uk/seizure-diary-download** to download your personal seizure diary.

Seizure diary

EPILEPSY
ACTION

TRUST US.
WE’RE HERE FOR YOU.

Epilepsy Action is here for everyone affected by epilepsy. We’re here to help you at every stage of your journey. We can connect you with others, and offer you support and information that you can trust. We want to help you live your life your way, so you feel like you again.

We want to know what you think about this booklet. If you have any thoughts please share them with us at **epilepsy.org.uk/feedback**

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Trusted
Information
Creator
Patient Information Forum

Registered charity in England and
Wales (No. 234343)

Date: January 2025
Due for review: November 2026
Code: SB01.02