



epilepsy on the mind

A report by Epilepsy Scotland on the impacts of epilepsy on mental health.
Survey conducted in February and March 2023.

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**“Epilepsy and mental health are so closely linked, even the strongest person can be suffering inside.”
- survey responder.**

6-7	Introduction from Lesslie Young, Chief Executive
8-9	Personal story from Nicola, Orkney, who was first diagnosed with epilepsy in May 2017.
10-11	Personal story from Niamh, Edinburgh, who is 17 years old and a member of Epilepsy Scotland's Youth Group.
12-27	The results of the Epilepsy Scotland survey on epilepsy and mental health conducted between February-March 2023.
28-29	The recommendations of the report.

TABLE OF CONTENTS

Lesslie Young has been Chief Executive of Epilepsy Scotland since January 2009.



Foreword

It has been known for some time, it is common for people living with epilepsy to experience mental health issues.

That has been abundantly clear from the many hundreds of phone calls and enquiries Epilepsy Scotland

receives on an annual basis, which are almost entirely related to mental health in some way.

As a charity we do all we can to support those who reach out or are referred to us.



Consultant Paediatric Neurologists have been referring children to our Edinburgh Youth Group for nearly two decades and describe it as a lifeline. They say it benefits the child and the wider family. The work of the Glasgow Youth Group provides similar support with similar outcomes.

The adult services we provide are just as essential. We offer 1 to 1 support services, breathing and relaxation classes, peer support groups, access to professional counselling, as well as a number of other services including support to those who are struggling to navigate the benefits system.

We provide in person support groups in Glasgow and in Aberdeen, with national groups held online in addition to a number of other online services including our popular private Facebook group which connects so many.

The highly skilled helpline call handlers have dealt with complex and difficult to manage calls from people standing on the ledge of a bridge, a railway platform, the verge of a road. These calls can last two hours or more.

In recent years we have expanded our helpline service to include 'check-in calls', a service whereby one of our helpline officers, with counselling qualifications, will call someone once a week for ten weeks to let them talk about their worries and issues related to epilepsy.

We offer so much but we are already at capacity forcing us to create waiting lists to access many of these

vital services.

We want to help more people. We need to help more people. But in order to do that government and local authorities must recognise the specific mental health needs of people living with epilepsy and provide the resources for those needs to be met.

The findings of this report present some shocking statistics, which highlight the immense and unimaginable mental strain so many people living with epilepsy face every day of their lives.

One in three responses say they have depression and almost half have anxiety – if these statistics are reflected across the number of people estimated to be living with epilepsy in Scotland, that would be 20,000 with depression and 27,000 with anxiety.

In addition, 54% of survey responses (31,000 people if reflected across the population) said that their epilepsy had a "significant impact" on their mental health.

There are so many different experiences of epilepsy, but what this survey highlights is so many people living with the condition – whether their seizures are controlled or not – are suffering mentally and need specifically-targeted support.

People living with epilepsy, through this survey, say that having someone to speak to and connecting with others through support groups are key to what they need to support their mental health.

I urge government and stakeholders to work together with us to ensure we provide them with that much needed support people living with epilepsy are asking for.

Lesslie.

Pic: Lesslie Young is pictured at Holyrood with Willie Rennie MSP.



Nicola's story

At the age of 20, Nicola from Kirkwall in the Orkney Islands started experiencing seizures for the first time.

It forced her to take time off work and to speak to her GP before being referred to a neurologist where she was diagnosed with epilepsy.

Receiving a diagnosis felt like “the end of the world” and she was forced to give up her drivers licence which, in a rural community where there was little in the way of public transport links, restricted Nicola's life and meant she had to depend on her partner and family for lifts to work and to see friends.

She said: “I really struggled with losing my driver's licence. I lost all my independence and really had to rely on other people to take me places because we weren't really on a bus route.

“So it was a case of making sure I had a lift from Ross (her partner) or my mum or dad. They were really good with me and were always there, but it's quite a lot of responsibility for them and I hated asking all the time.

“It was really frustrating because I'd get so close to getting my licence back but then I would have another seizure which would put it back again.”

It wasn't just the loss of Nicola's independence that impacted her life following an epilepsy diagnosis, the long period of trying out different anti-seizure medications, some of which caused sickness, felt never-ending.

She said: “When I first got diagnosed I was mentally quite low and I never thought I was going to get through it.

“I was in a rut of trying medications where I was trying something and then trying something else, which would work for a little while and then they would have to change the medication again. It was really frustrating.

“It felt like I was never going to get out of this. It was like I was in a box and I couldn't get out of it. I felt really, really stuck. I remember feeling really sick on a lot of medications and was spewing. It felt pretty rubbish.”

Thankfully, after a few months of trying, Nicola found a medication that worked for her.

“There are so many medications out there and I just kept going until I found the right one. I thought I was

never going to find something but I have now and I take it every day and night and I'm fine. I would say to others going through the same that you can get through it.”

Six years later after her diagnosis, Nicola is recently married to her partner Ross, has two young children, and because her seizures are under control, has been able to get her driving licence back.

She hopes her journey, including the many barriers she has faced and overcome, can inspire others who are living with the condition and that more support can be put in place in Orkney and other rural parts of the country.

She said: “I did feel in Orkney there wasn't much of a support network for people living with epilepsy. I feel it would be good to get something in Orkney to support people living with epilepsy so that they don't feel so isolated and alone.

“When you first get diagnosed, because it's all new, it's quite overwhelming. I remember being really upset and thinking ‘this is the worst thing ever’ because I didn't understand it and I didn't know anyone else who had it.

“But there's loads of information available which you can find to help understand the condition better. Once you get that knowledge it can be ok and it's just something you learn to live with.

“A part of my epilepsy I find tricky is my memory, which was caused due to seizures or the medication. I really struggled with that because somebody would ask you about something and you just can't remember it.

“I can still struggle with it but I've learned some mechanisms for helping with it now like I write things down and keep a diary. Those coping mechanisms have really helped me.

“My employer has been really good with me to make sure that I'm supported and I have somewhere to write things down if I need to.

“I've also realised what my seizure triggers are – which are tiredness and being in stressful situations. So I make sure that I get enough rest and I do what I can to prevent me from being really stressed about something because I don't want to take another seizure.



Nicola lives in Kirkwall on the Orkney Islands and was diagnosed with epilepsy in May 2017.

“I also couldn't be in a room with flashing lights, so when I was younger and wanted to be going out with friends it can feel like the worst thing ever to be missing out. So if I wanted to go out partying I had friends who had to make sure it was somewhere which didn't have flashing lights. My friends that were closest to me realised how difficult it was for me and wanted to support me as much as they could.

“I've been lucky to have so much support from my friends, as well as my wider family and Ross's (Nicola's husband) family, but particularly Ross, my mum and dad, and my sister.

“And I would say the epilepsy nurses in Aberdeen were amazing. They were always on the other end of the phone, as was Epilepsy Scotland – my mum phoned them quite a lot for advice when I needed it.

“I think people living with epilepsy can live a normal life, you just have to keep going and not let it beat you. You have to beat *it*.”

Niamh's story



Niamh is 17-years-old from Edinburgh and is pictured taking part in a firewalking Epilepsy Scotland fundraiser.

There is no easy time to be diagnosed with epilepsy – it is a condition which will impact your life regardless of your age.

However, it is particularly difficult for children and young people to learn they have epilepsy due to the consequences it can have on their studies, potential career prospects, and their social life and self esteem.

Niamh, 17, began experiencing tonic-clonic seizures three years ago. A tonic-clonic seizure is when the person will lose consciousness, may fall to the floor, and the body goes stiff and their limbs start to jerk.

Thankfully due to medication, Niamh has now been able to bring her seizures under control, however not without some side effects.

She said: "I recently hit the one year seizure-free mark which is such a massive milestone for me. However, I still have many side affects which make my everyday life very hard.

"I get extreme migraines which can last for hours on end, and these alone are very hard to live with as I cannot focus on what I'm doing and will 9 times out of 10 have to go to bed to recover.

"I also struggle with bad memory loss meaning that I don't remember everything I'm meant to. My doctor once told me that my brain picks and chooses what it thinks it needs to know and farts away the rest of it - I thought was quite funny!

"This affects my school work and having a conversation with someone as I regularly forget what has been said at the start of a conversation meaning the person I'm speaking to doesn't think I've been listening - I can confirm that that isn't the case. I have other side-affects but these are my main ones."

As highlighted throughout this report, epilepsy is not just seizures, it is a condition with many potential ramifications for someone's quality of life, with particular consequences for mental health.

Niamh continued: "One of the hardest things I live with daily is my anxiety, and loneliness. Since being diagnosed 3 years ago I've really struggled with my mental health, and feeling like the whole world is against me.

"Being diagnosed left me feeling different than all my friends and unable to talk to them about it as I thought they would feel weird and stop talking to me or would start treating me like a freak.

"I wake up every morning and take medication and do the same every night, this is another big challenge for me as it is a constant reminder that I am different and not like some people around me.

"I often feel very alone and isolated from the world which causes me to shut people out and bottle my feelings deep inside. I leave the house each day worrying about what might happen and always come to the worst case scenario.

"I recently opened up to a couple of my closest friends about how I was truly feeling and they couldn't have been more supportive. They asked me questions and really took the time to listen to me and I couldn't be more grateful!

"Since being diagnosed I haven't let it stop me from doing what I do best. I can cook on an open fire, I can go to parties with my friends, I can go on long camps without my mum and dad and I can do all the scouting activities I want.

"I know what I have to do to keep me safe and healthy and am very open to telling people that I have epilepsy. I believe that just because I have a neurological condition doesn't make me any different from someone who doesn't have one and I shouldn't be discriminated because of it either.

"My epilepsy is always on my mind but it doesn't and shouldn't stop me doing what I love. I treat everyday as a new one and feel so blessed that I have such a big support system behind me every step of the way."

Q1: Are you a person with epilepsy or are you answering on behalf of someone with epilepsy?

87%

A person living with epilepsy

13%

Answering on behalf of someone living with epilepsy

Q2: Which age group are you?

0-17yrs	48	7%
18-29	122	17%
30-49	311	43%
50-64	175	24%
65+	62	9%

There were 718 responses to both questions. In total, 627 said they were a person living with epilepsy, while 91 said they were answering on behalf of someone living with epilepsy.

Q3: Which NHS Scotland healthboard do you live in?

G. Glasgow & Clyde	145	20%
Lothian	127	18%
Lanarkshire	86	12%
Grampian	72	10%
Ayrshire & Arran	61	9%
Fife	60	8%
Tayside	45	6%
Forth Valley	35	5%
Highland	32	5%
Borders	13	2%
Dumfries & Galloway	13	2%
Western Isles	10	1%
Shetland	7	1%
Orkney	4	1%

There were 710 responses to this question.

Q4: Do you have any mental health conditions?



1 in 3 said they have depression



Almost half said they have anxiety



1 in 4 said they have both depression and anxiety

There were 718 responses to this question. 330 (46%) listed anxiety in their answer; 242 (34%) listed depression; 182 (25%) listed both anxiety and depression. Among the other answers, 36 (5%) said OCD and 23 (3%) said PTSD.

Q5: Are you living with any other long term health condition and/or a learning disability or learning difficulty?

Yes: 41.5% **No: 58.5%**

Arthritis: 32 (6% overall)

Asthma: 27 (5%)

Dyslexia: 26 (5%)

Autism: 25 (4%)

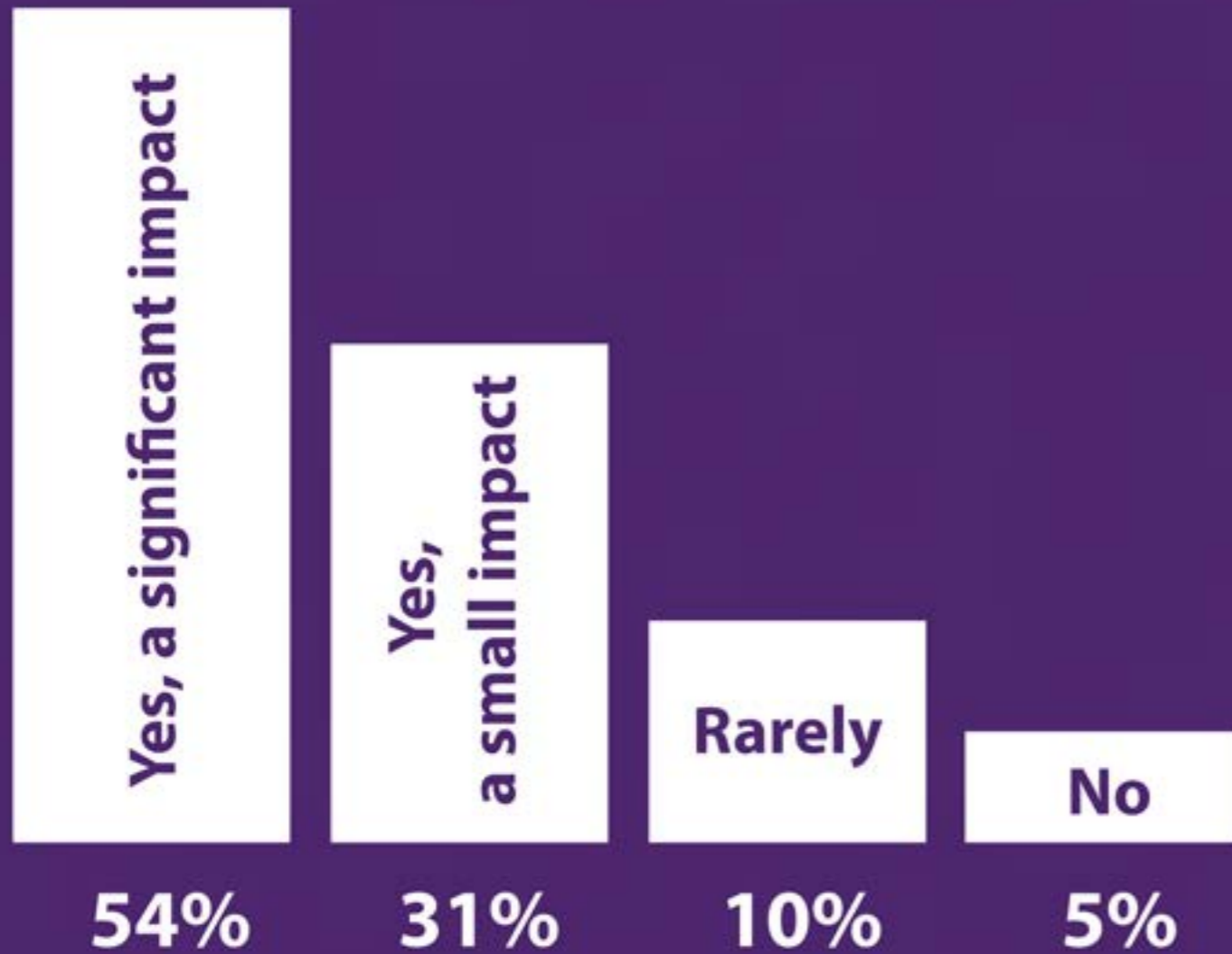
Learning Disability: 18 (3%)

Thyroid issues: 18 (3%)

Diabetes: 16 (3%)

There were 718 responses to this question. Other answers include: Fibromyalgia 16 (3%), ADHD 9 (2%), Brain Tumour 7, ADD 5, MS 5, FND 5, Brain Damage 3.

Q6: Do you think epilepsy impacts your mental health?



There were 711 responses, 381 (54%) chose "Yes, a significant impact", 220 (31%) chose "Yes, a small impact", 72 (10%) chose "Rarely", and 38 (5%) chose "No".

Q7: In what ways do you think your epilepsy affects your mental health?



There were 655 responses. Answers given were grouped into the above themes. Other common answers were: lacking confidence (8.4%), lack of understanding from others/society (7.9%), medication side-effects (7.5%), lacking independence (7.3%), actually having a seizure and after effects (7%).

Q8: How easy do you find talking about your mental health?

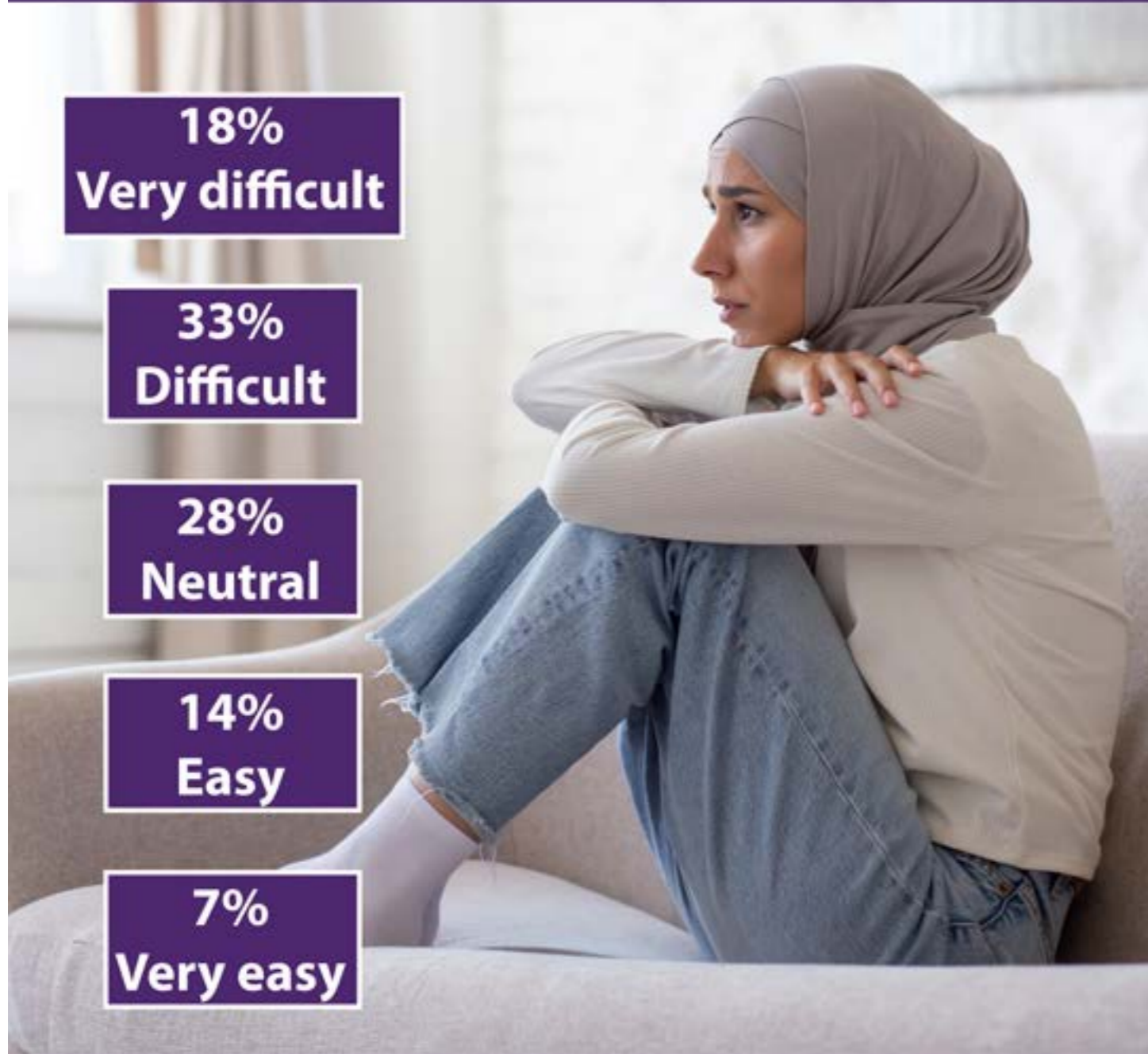
18%
Very difficult

33%
Difficult

28%
Neutral

14%
Easy

7%
Very easy



There were 709 responses. Answers given were: Very Difficult 129 (18%), Difficult 232 (33%), Neutral 197 (28%), Easy 99 (14%), Very Easy 52 (7%).

Q9: If you were struggling with your mental health, where would you seek support?



69% Friends or family
46% General Practitioner (GP)
27% Epilepsy specialist
24% Only a close friend
17% Epilepsy Scotland
9% A mental health charity
5% Another epilepsy charity

There were 701 responses.

Q10: What do you think you need to support your mental health?

14%
Greater public understanding

9.7%
Having someone to speak to

7.7%
Therapy/
counselling

7.52%
Required support
being readily available

7%
Having a good level of
access to epilepsy
professionals

There were 558 responses. Answers were grouped in themes: Greater public understanding 78 (14%), Having someone to speak to 54 (9.7%), therapy/counselling 43 (7.7%), required supporting being readily available when required 42 (7.5%), having a good level of access to epilepsy professionals 39 (7%), support from friends and family 38 (7%), support groups 31 (5.6%), connecting with others who feel the same 28 (5%), someone to speak to who understands epilepsy 26 (4.7%), support from employer 23 (4%), counselling from someone with an understanding of epilepsy 11 (2%).

Q11: What aspects of your life does your epilepsy affect? (Tick all that apply)



Social life: 507 (72% overall)
Employment: 427 (61%)
Physical health: 409 (58%)
Hobbies: 339 (48%)
Relationships with friends: 329 (47%)
Relationship with family: 51 (36%)
Romantic relationships: 235 (33%)
Education: 205 (29%)

There were 704 responses to this question.

Q12: Are you currently in paid employment?

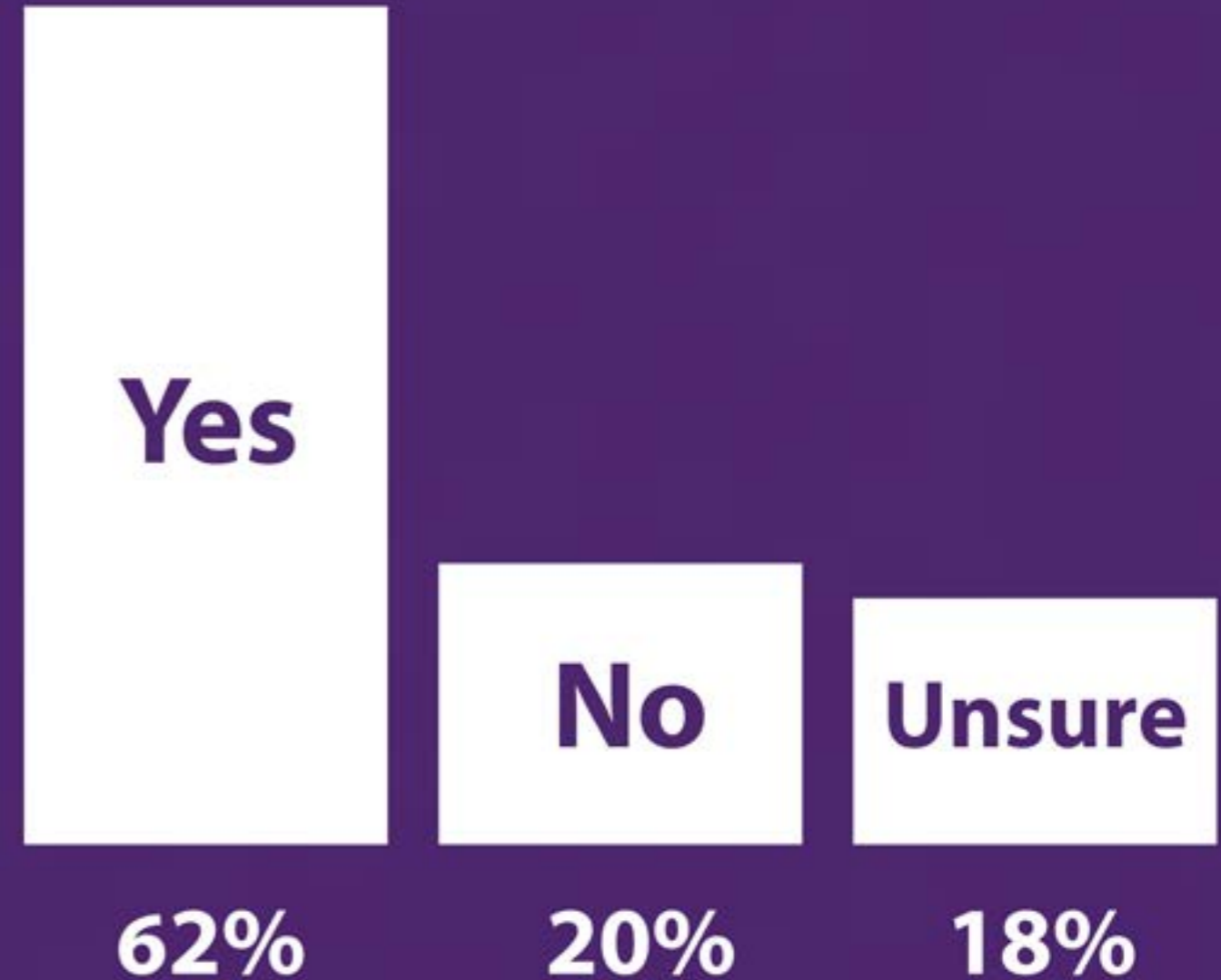


Yes
52%

No
48%

There were 711 responses. Answers above are when only responses which were "yes" or "no" were included. If responses other than "yes" or "no" are included, the full responses would be: Yes 343 (48%), No 310 (44%), stated they were retired 19 (3%), and other was 5%.

Q13 (part 1): Do you think your epilepsy has affected your employment prospects?



There were 657 responses. 407 (62%) chose "Yes", 133 (20%) chose "No", 117 (18%) chose "Unsure".

Q13 (part 2): Do you think your epilepsy has affected your employment prospects?



Most common feedback

- Seizures are too frequent/declared not able to work: 67
- Believes stating they have epilepsy hinders opportunities: 28
- Issues related to memory/concentrating: 25
- Lack of drivers licence/being unable to drive: 19
- Has mental health issues affecting ability to work: 17
- Had to change career path due to epilepsy: 15
- Can't find work which accommodates lateness/time off: 13
- Lack of jobs available for someone with their epilepsy: 12

Q14: What advice would you give to someone with epilepsy struggling with their mental health?

"Talk" (29%)

**ask for/seek/get
"help"** (27%)

**"Friends or
family"** (20%)

"Speak" (19%)

"GP/doctor" (12%)

"Reach out" (4%)

"Epilepsy Scotland" (4%)

There were 614 responses to this question which was not multi-choice and the keywords were lifted from the answers given.

Q15: Do you have any further comments?

"I think there needs to be a better understanding from health professionals in general of the link between epilepsy and mental health. It is far too common to be ignored."

"It is very hard to deal with and cope with the constant fear of seizures."

"It's the unpredictability of epilepsy that makes your mental health worse."

"Epilepsy is such a debilitating condition. It is so much more than having seizures. It affects many aspects of your life."

"I think there needs to be a better understanding from health professionals in general of the link between epilepsy and mental health. It is far too common to be ignored."

"It's not just the individual epilepsy affects, the whole family go through the journey."

"I've lived with epilepsy for over 20 years since being diagnosed at 30. I wish I'd acknowledged and dealt with my feelings around it then."

"Epilepsy and mental health are so closely linked, even the strongest person can be suffering inside."

"Epilepsy also leaves you with heavy regret on the impact it has on those around you that care about you."

Q15: (continued)

"I wish my high school would/could do more to help and support me. Possibly raise awareness. People always react strange when they find out I have epilepsy, just because they don't understand it. Myself and family have reached out to Epilepsy Scotland on a few occasions and they have always been amazing."

"I was given a weekly chat group but it was based in Aberdeenshire and I am in Fife, so this needs to be addressed."

"I can't be medicated for mental health, depression or anxiety because of the epilepsy medication. So I just need to get on with it."

"I lost my brother to epilepsy and I know others who have lost loved ones. The loss of my brother had a serious impact on one of my sister's mental health. She doesn't have epilepsy but I think a bereavement support service for people who have lost a loved one to epilepsy would be helpful."

"Support is lacking from the NHS to help come to terms with this new life changing diagnosis in a person-centred way, in my experience. The prescribed medication is only a small part of the whole story – it's about the ongoing needs of the patient."

"When I was at school I was made to feel ashamed and different to normal children. This has impacted the rest of my life as I feel inferior."

"It's not widely enough known that epilepsy has such a big impact on your mental health. The two go hand in hand as far as I am concerned."

"My workplace is very up on mental health awareness but knew nothing about epilepsy and how it affects mental health"

"I think that when a diagnosis of epilepsy is given, especially when medication is involved, there should be a automatic mental health support in place."



Recommendations; a call to government, local authorities, healthboards, and all stakeholders

1. To increase the number of mental health-trained professionals (including counsellors) available to people living with epilepsy and to increase the level of understanding of epilepsy amongst those working in mental health services.
2. To increase the number of in-person support groups for people living with epilepsy and their families across Scotland.
3. For interested epilepsy charities and mental health charities to work collaboratively to create a strategy to improve the mental health of people living with epilepsy in Scotland.
4. To ask the Scottish Government and local authorities to take steps to increase public awareness of epilepsy to the wider public for improved societal understanding of a complex neurological condition affecting many aspects of a person's life. Any awareness campaigns should also seek to inform people living with epilepsy and their families of information and support available to them.
5. To ask health boards across Scotland to consider steps for routine screening of mental health issues in epilepsy clinics with immediate referral to mental health support where required.

(An example of current routine screening schemes is the PAVES project for children in NHS Lothian. Potential destinations of mental health referrals could include programmes such as Epilepsy Scotland's Wellbeing Service and similar programmes run by other epilepsy or mental health charities.)

