

The Epilepsy Society: Online Safety Bill Committee written evidence

I) Clause 150: inclusion of physical harm

The Government has been unequivocal in its pledge that Part 10, Clause 150 will cover the psychological harm many people with epilepsy face when targeted by online trolling. It is vital, however, that the Bill also includes the physical harm caused by these vicious online attacks. Clause 150, Subsection 4 defines harm as “*psychological harm amounting to at least serious distress.*” There is no doubt that trolling has caused considerable psychological distress to people with epilepsy, and we welcome the recognition of this in the Bill. But it is imperative that physical harm is also covered. Sadly, where people with epilepsy are targeted by trolls who send them flashing images to trigger a seizure, the harm caused is often of a physical nature.

Professor Ley Sander, Medical Director at the Epilepsy Society and Professor of Neurology at UCL:

“The impact of a convulsive seizure cannot be underestimated. Seizures may result in severe facial injuries where a person falls on rough ground, broken bones and concussion. It is not unusual for people to suffer severe burns from falling against a radiator or scalding themselves with a hot drink.”

“While some people recover quite quickly from a seizure, others experience physical fatigue and confusion for several days, even a week. Seizures are not benign events: one thousand people die every year in the UK from epilepsy-related deaths.”

Simply put, we believe epilepsy is the only condition where a person can have a physical response – in this case a seizure – to a digital attack.

Where flashing GIFs and images have been sent to people with photosensitive epilepsy, there is significant evidence of the recipients experiencing seizures. One example is of a 25-year-old man who had been newly diagnosed with epilepsy. His friends directed him to Epilepsy Society’s Twitter account for peer support and well-researched information. Instead, he was confronted with a flashing image causing him a serious convulsive seizure, which included him biting through his own tongue.

We have enclosed some photographic evidence of the physical impact a seizure can cause **(appendix 1)**.

Trolls often deliberately target people with epilepsy who are celebrating “seizure freedom”, a period of time without a seizure. In these cases, trolls typically respond to messages posted by people who are marking months or years without a seizure and directly try to trigger a relapse. There is demonstrable evidence that the intent of many of the online trolls is to cause physical harm. We have enclosed a few graphic examples. **(appendix 2)**.

II) Clause 152: inclusion of the application of physical harm

The Bill does recognise the impact of threats of physical harm but not of physical harm in actuality. In Clause 152, the Threatening Communications Offence clause, it states that a person commits an offence if “*the message conveys a threat of death or serious harm*”, with serious harm defined as “*serious injury amounting to grievous bodily harm.*”

This, therefore, raises the possibility that a threat of harm could result in a conviction but the application of harm – as demonstrated by sending a flashing image to someone who resultingly suffers a seizure – would not.

The Epilepsy Society urge the Government to address not just the threat of physical harm, but its actual application.

III) Clause 154: extraterritorial jurisdiction

The internet has created amazing global opportunities in facets of life as diverse as education, employment, relationships, finance and leisure. It has, however, also severely blurred national and jurisdictional borders.

Many of the trolls who target people with epilepsy are based overseas. The Epilepsy Society is concerned that the Bill's limited geographic scope, covering only England and Wales, will enable this trolling to continue unabated.

The current Bill refers only to crimes committed within England and Wales, or those committed by a habitual resident of England and Wales while temporarily abroad.

While the Epilepsy Society acknowledges the globally unprecedented nature of the Online Safety Bill, we urge the Government to ensure that more is done to tackle the roots of this trolling. With perpetrators operating around the world, this is clearly a global problem which requires a global solution. We would urge the Government to engage with its counterparts outside the UK to ensure that, where the UK leads, the world follows in implementing similar laws to safeguard people with epilepsy from this type of abuse.

IV) Clause 155: regulatory power of Ofcom

We are concerned that the outlined Communications Offences do not include the same regulatory powers for Ofcom as set out elsewhere in the Online Safety Bill.

The Epilepsy Society are seeking clarity from the Committee that Ofcom's regulatory powers will also include oversight of the Communications Offences, specifically the need to hold corporate officers of social media companies financially liable (Clause 155) in order to incentivise them to change their algorithms and stop the transmission of offending material at source.

Background

I) What is #ZachsLaw?

We are calling for the Online Safety Bill to criminalise the sending of flashing images and GIFs to a person with epilepsy with the intention of causing a seizure.

For a number of years, people with epilepsy have been targeted by internet trolls sending malicious flashing images with the deliberate intent to trigger a seizure. These attacks are ongoing and relentless. One of the people targeted, in 2020, was a young boy, then eight years old with epilepsy

called Zach Eagling. Zach has become the figurehead of our campaign which we have called [#ZachsLaw](#).

We were delighted that in July 2021, the [Law Commission](#) backed Zach's Law in their report [Modernising Communications Offences](#) and that, in December 2021, the [Joint Committee on the Draft Online Safety Bill](#) recommended its specific inclusion in the Online Safety Bill.

"We recommend that the intentional sending of flashing images to a person with epilepsy with the intention to cause that person to have a seizure should be made an offence." **(The Law Commission, July 2021. Backed by the Joint Committee on the Draft Online Safety Bill, December 2021 and the DCMS Select Committee, January 2021)**

We have received assurances from the Government that Clause 150 of the Bill will cover the psychological harm experienced by people with epilepsy due to online trolling. We also understand that the Ministry of Justice is currently road testing a stand-alone epilepsy trolling clause.

II) About the Epilepsy Society

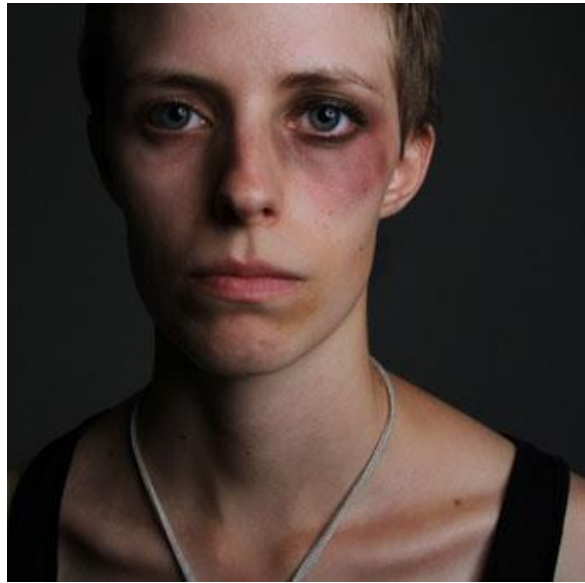
The [Epilepsy Society](#) are the UK's only charity transforming the lives of people with epilepsy through world-leading research, advocacy and care. Our headquarters in Chalfont St Peter, Buckinghamshire is a centre for medical research into the condition, housing the only MRI scanner in the UK dedicated solely to epilepsy. We also operate a globally unique NHS epilepsy assessment facility providing individual assessment, rehabilitation training and ground-breaking research opportunities. Our site additionally provides residential care to around 100 people with severe epilepsy.

Epilepsy Society has been ranked as the leading epilepsy research centre in the world every year since 2012. Our Medical Director, Professor Ley Sander, has been named the world's leading epilepsy expert, again every year since 2012.

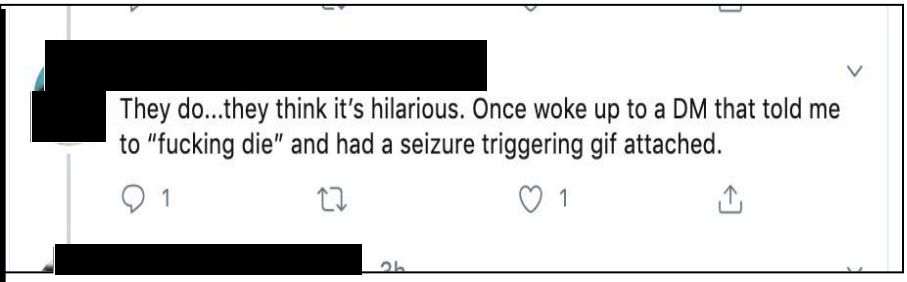
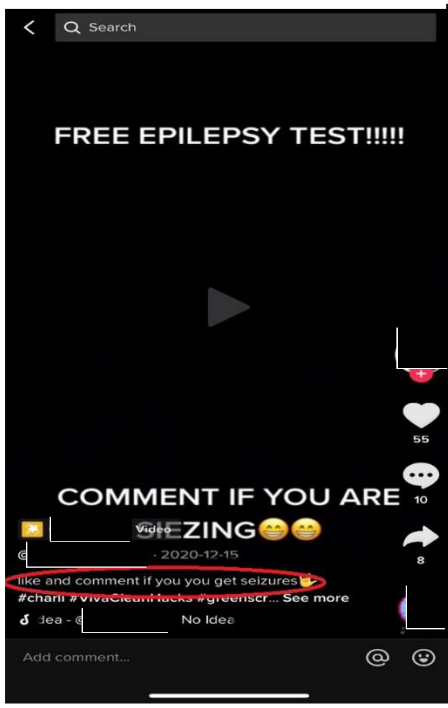
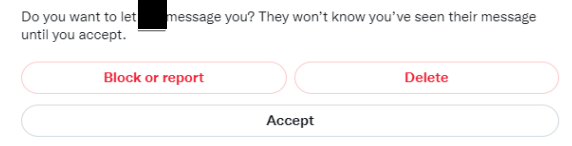
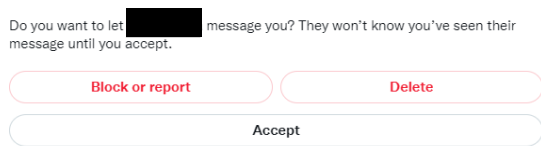
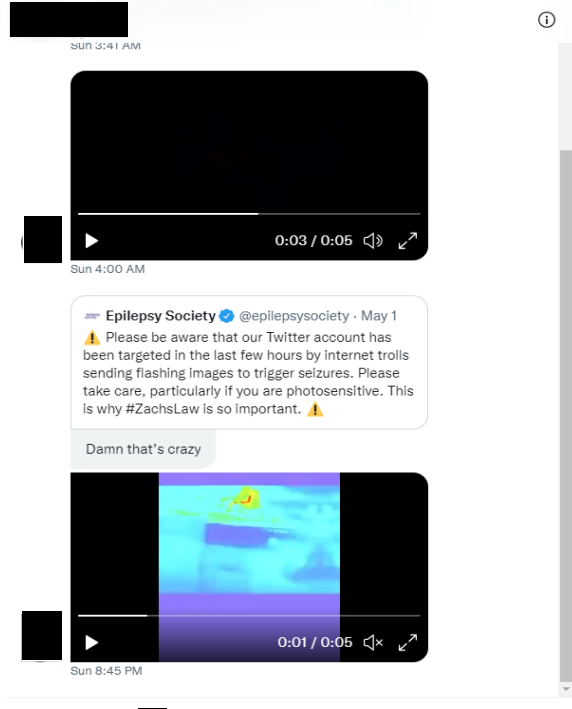
III) About Epilepsy

Epilepsy is not just one condition, but a group of many different 'epilepsies' with one thing in common: a tendency to have seizures that start in the brain. Epilepsy is the most common serious neurological condition and affects more than 600,000 people in the UK, around one person in every hundred. Seizures have many different causes, including a person's genetics, a structural change in the brain or from other underlying conditions. There are over 40 different types of seizure, and not all of them are physical which is why epilepsy can also be an invisible condition.

Appendix 1: Examples of the physical harm caused by epileptic seizures



Appendix 2: Examples of social media messages explicitly seeking to cause physical harm



Tweet

████████████████████ 9h

████████████████████ OMG. I'm 1 month seizure free!! #seizure #seizurefree

3 11

████████████████████ 9h

congrats bestiee



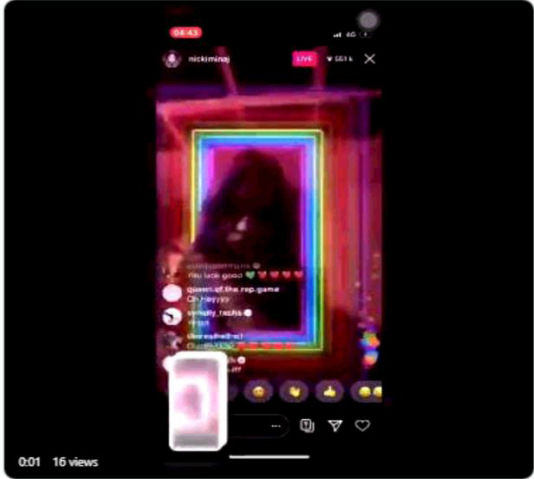
1 1

Tweet

████████████████████

Replying to ██████████████████████

time to break the streak ❤️



0:01 16 views

8:59 am · 17 Jun 2020 · Twitter for iPhone

1 Like

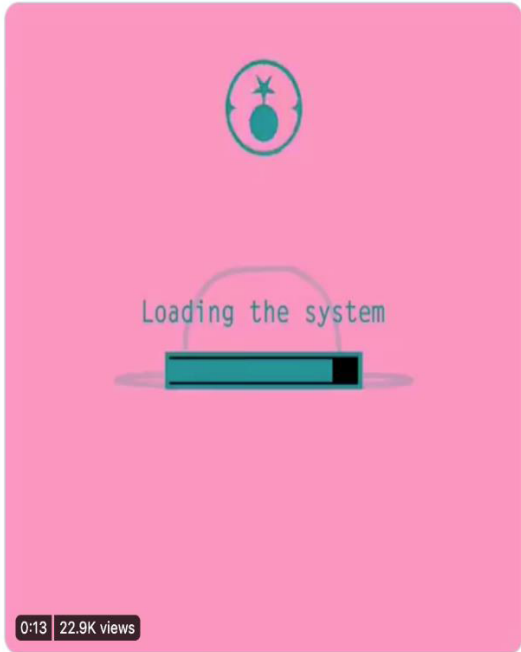
Thread

████████████████████

1124 Tweets

████████████████████

let's spam this to the epelipsy community ❤️



0:13 22.9K views

████████████████████

1 3 7

Show more replies

████████████████████ 11h

Replying to ██████████████████████

sure 🤔

Thread

████████████████████

thread of strobe light gifs to send to epileptix

8:28 am · 17 Jun 2020 · Twitter for Android

5 Retweets 9 Likes

████████████████████ 9h



1 1

████████████████████ 9h



Tweet

3 months seizure free!!! 🥳🥳🥳 #seizure #seizurefree #epilepsy


Translate Tweet

5:40 am · 17 Jun 2020 · Twitter for iPhone

9 Likes

Replied to [redacted] 6h

so happy for you



Replied to [redacted] 5h

Replied to [redacted] 6h

thread of strobe light gifs to send to epileptix

Show this thread

Replied to [redacted] 6h

Replied to [redacted] she is coming

1,124 Tweets


Follow

22h

For the first time ever, it seemed as though I was actually on track to have a whole year without having a #seizure. Last night, however, with my eyes closed, a Simple Focal Seizure seemed to come out of nowhere.

263 days seizure-free 🥳


@epilepsysociety @epilepsyaction



7 1 11

11h

Time to break the streak babe



22.9K views 0:05 / 0:16