



Media Release

National charity launches a petition to improve mental health support for children and young people with epilepsy

Epilepsy is not a mental health condition, yet children and young people with epilepsy are four times more likely to develop mental health problems than their peers.

To help address the situation, national charity Young Epilepsy has now launched a petition [link to petition here](#) to call on healthcare leaders across the UK to ensure that every child with epilepsy is offered mental health screening and support as an integrated part of their paediatric epilepsy care.

The petition is part of the charity's **#OnTopOfEpilepsy** campaign that highlights the link between epilepsy and mental health and will take the lead from young people affected by the condition to advocate for better support.

A recent survey of young people by the charity found that three quarters (77%) said their experience of living with epilepsy has had a significant impact on their mental wellbeing (including their thoughts, feelings and how they're able to cope with everyday life).

Anxiety, depression, a sense of isolation and being overwhelmed by the ways the condition changed their lives are just some of the daily challenges faced by young people with epilepsy. At the same time more than half of them did not find it easy to talk about their feelings with friends and family.

Beth Dobbin, British 200m athlete, and Olympian who was diagnosed at age 14 shared:
"For me the worst part about epilepsy is how it affects your mental health and the worries you have about a seizure striking. I'm seizure free, but it still never goes away. Every day you think about it and worry will a seizure strike today?"

It is so important to offer children mental health screening and support as part of their epilepsy care. To be asked by your consultant or nurse about how it's impacting your mental health, and to have support services available would be a game-changer for dealing with such a life-changing diagnosis."

Mark Devlin, Chief Executive of Young Epilepsy, explained: *"For those of us working in the field of the epilepsy care, we know that on top of the physical challenges of living with their epilepsy, children and young people face extra struggles such as dealing with the side-effects of medication, anxiety about having a seizure, concerns about school or missing out on normal growing-up activities."*

"Every child with epilepsy deserves mental health support as part of their care, but only 15% of paediatric epilepsy clinics offer mental health services. At Young Epilepsy we are determined to bring the much needed change to how mental health care is addressed and we need the support

of everyone who cares about children and young people living with the condition to help us campaign for real change together.”

Children and young people with epilepsy are more at risk of experiencing a mental health problem due to a range of factors. This could include the underlying cause of the epilepsy (such as a brain injury), side effects from anti-seizure medication, as well as the anxiety, stigma and marginalisation often associated with living with this condition.

#OnTopOfEpilepsy campaign is looking at all elements of mental health care and wellbeing support. The charity will take a lead from young people, living with epilepsy and managing their mental health to develop a co-created Mental Health and Wellbeing resource, compiling the best information available, to help young people with epilepsy find the right mental health support for their individual needs.

Other findings from the Young Epilepsy survey include:

- 66% of young people with epilepsy said their mental wellbeing has **affected their physical health.**
- 77% of young people with epilepsy said their mental wellbeing has **affected their time with friends**
- 57% of young people with epilepsy said their mental wellbeing has **affected their learning.**
- 63% of young people with epilepsy said their mental wellbeing has **affected their employment.**
- 50% of young people with epilepsy said their mental wellbeing has **affected their time with family.**

-ENDS-

NOTES TO EDITORS:

About Young Epilepsy:

Epilepsy can be one of the most frightening and isolating conditions a child can experience. The loss of any sense of safety, trapped in an unpredictable world, not knowing when their next seizure will happen. All this takes its toll on a child's mental and physical health, and they miss out on childhood.

Young Epilepsy is dedicated to supporting children and young people with epilepsy. We're here for them. It is our job to listen and work with them so they can fulfil their potential. We coordinate research that improves diagnosis and treatments. We campaign for children's rights. We provide innovative tools, information, and practical support for living everyday life.

Together we create possible.

We offer a digital information service [The Channel](#), offering advice and guidance to both young people and their families and our online peer support forum, [The Hub](#)



About epilepsy:

112,000 children and young people in the UK are living with epilepsy. Epilepsy is one of the most common long-term conditions that affects children.

Epilepsy is a neurological condition that disrupts the normal electrical activity our brains use to communicate with the rest of the body. This disruption causes seizures.

There are over 40 different types of seizure and every young person's epilepsy is unique to them. In order to be diagnosed with epilepsy, a young person must have had at least two seizures.

In most cases, epilepsy is well managed, and seizures are controlled, but it is a very serious condition and can be life-threatening.

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