

Young people's experiences of epilepsy and mental wellbeing

Summary of survey findings

November 2021

Key findings

Young Epilepsy surveyed young people with epilepsy (aged 25 and under) about how living with epilepsy has affected their mental wellbeing (their thoughts, feelings and how they are able to cope with everyday life). We found that:

- 99% of young people said **living with epilepsy has had an impact on their mental wellbeing** (77% significant impact, 22% small impact).
 - This impact was described as anxiety/worry, depression, life-changing, impact on self-worth/identity, isolation, overwhelming, lack of control, fear, stress and feelings of suicide.
- 52% of young people **do not find it easy to talk** about how living with epilepsy makes them feel.
 - Others said this depended on factors such as who they were talking to and how they were feeling, or that confidence had come over time.
 - Around 1 in 4 (27%) said they did find it easy to talk about.
- Young people with epilepsy said their **mental wellbeing has affected different areas of their life**, including:
 - Time with their friends (77%)
 - Physical health (66%)
 - Employment (63%)
 - Learning (57%)
 - Time with family (50%)
- When young people with epilepsy were asked **what has helped them** with their mental wellbeing, key themes were:
 - Family and friends
 - Physical activity (particularly walking)
 - Talking to someone
 - Therapy (e.g. cognitive behavioural therapy)
 - Music / art / craft
 - Connecting with other young people with epilepsy
 - Mindfulness / meditation
 - Medication
 - Watching tv or films
 - Writing or journaling

- When asked **what advice they would give** to other young people with epilepsy about mental wellbeing, key themes were:
 - Talk to someone
 - Ask for help
 - You're not alone
 - Be kind to yourself
 - Stay strong
 - Keep going, things can get better
 - Try to accept your situation

Young people describe the impact of living with epilepsy on their mental wellbeing

"Catastrophic but nobody cares unless it's about a seizure."

"Debilitating, upsetting, traumatic, painful."

"[Living with epilepsy] has affected all areas of wellbeing, but the mental impact has been the hardest to deal with."

"I feel extremely anxious and isolated and different from my friends."

"Severe anxiety and depression, feel like I have no independence."

"[I'm] constantly anxious about when and how bad my next seizure will be."

"Epilepsy has completely changed who I am as a person, affected my confidence and I have developed a life-long battle with anxiety."

"The constant thought of breaking into a seizure in public and at work causes me nothing but constant anxiety."

"I was scared to go out by myself for a good year and a half. ... My epilepsy has caused so much anxiety."

"Constant feeling of being left out. I'm not able to do what most people around me are able to do."

"[I'm] living in constant anxiety and feeling incredibly isolated which in turn leads to long periods of depression."

"It has made me very self-conscious about whether people may stare or say things if I have an episode. For that reason I do not venture very far from home and spend a lot of time locked away in my bedroom."

"Epilepsy has taken a lot of things from me. It has impacted my life greatly and my mental health has suffered as a result. I now have a diagnosis of PTSD, anxiety and depression."

Young people's advice about mental wellbeing to other young people living with epilepsy

"Take it one day at a time and just know things can get better."

"Be open about how you're feeling."

"Don't put off getting help."

"Talk about your feelings with your epilepsy nurse/doctor."

"Be kind to yourself and don't feel ashamed of your diagnosis."

"If you're struggling, just know you're not alone and you deserve help and to be happy."

"Try and talk to someone. Even if it's just a little thing it does really help."

"Reach out to your friends and family, they love you and will want the best for you!"

"It's okay not to be okay, talk about it and don't be afraid to get help."

"Reach out and find other young people going through the same thing."

"It's hard to talk about, but even if you're crying, go to someone you trust and let it all out, don't ever be afraid of what you are going to say. Because once you have spoken, even if it's just one word, that's where it all gets better."

"Coming to terms with, and accepting, an epilepsy diagnosis is half the battle. Once you have done that, try not to let it hold you back from doing what you love."

"Make people around you aware of epilepsy: it's a weight off your chest and people can often misunderstand what it actually is."

"People don't expect you to be happy all the time, when you're dealing with a life altering condition, so take each day at a time and always talk about how you're feeling. You need to prioritise your needs before anything else."

"Stay strong and try to look at what you can do in life, not what the epilepsy makes difficult/impossible."

"It's okay to feel scared, stressed or worried about seizures but always remember there are always people out there to support you, you just have to ask for it."

Demographics

Young Epilepsy received 244 survey responses from young people with epilepsy across the UK, between 27 May 2021 and 28 July 2021.

The majority of respondents (88%) were aged 18 to 25 years old, whilst 11% were under the age of 18. A small number of responses (1%) were submitted by parents/carers on behalf of a young person with epilepsy.