People with epilepsy fear discrimination according to national charity poll

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Many people with epilepsy don't feel comfortable talking about their condition for fear they will be discriminated against, according to a charity poll. UK-wide charity Epilepsy Action surveyed almost 700 people with epilepsy to explore how they feel about talking to others about their epilepsy.

Of those surveyed:

- one in five (19%) people with epilepsy said they feel uncomfortable or very uncomfortable talking about their epilepsy with friends
- one in seven (14%) feel uncomfortable or very uncomfortable talking about their epilepsy even with their family. One in four feel uncomfortable talking to work colleagues.

The top three reasons people gave for feeling uncomfortable talking about their condition were fear of discrimination (or being treated differently), concerns that people don't understand epilepsy and feeling embarrassed.

Respondents who are not seizure free[1] were more likely to indicate that they feel uncomfortable talking about their epilepsy, especially in a work setting. Worryingly, three quarters (75%) of people who do not feel comfortable talking with their employer, and are not seizure free, said that they fear they will be discriminated against.

The findings come in the run up to Purple Day, the global awareness day for epilepsy, celebrated on 26 March each year. Purple Day was created in 2008 by then nine-year-old Cassidy Megan, a Canadian girl living with epilepsy. She came up with the idea as a way to dispel the myths surrounding epilepsy and raise awareness positively. The event sees purple-themed fundraisers taking place all over the UK, as well as several landmarks turning purple to mark the event.

Philip Lee, chief executive at Epilepsy Action, said:

> “It's frustrating to hear that many people with epilepsy feel embarrassed talking about it, and worry that they will be discriminated against if they do. Epilepsy is certainly nothing to be embarrassed about and these findings highlight why days like Purple Day are so important to those living with epilepsy. The more we talk about epilepsy, the more we can challenge common misconceptions about it and offer the general public a clearer idea of what epilepsy is. We really hope Purple Day inspires people to share and talk about their epilepsy so that more people can begin to understand the condition."

For more information about Purple Day and living with epilepsy, visit epilepsy.org.uk/purpleday or call the Epilepsy Helpline freephone 0808 800 5050.

- ENDS -

Notes to editor:

1. **Epilepsy Action has a range of case studies from across the UK.** For case study details in your area or more information, please contact the press office on 0113 210 8870 or email press@epilepsy.org.uk. For media enquiries made outside normal office working hours, please call 0113 210 8870.
2. Epilepsy Action surveyed 691 people with epilepsy between 5 February and 15 March 2016.
3. There are a lot of public misconceptions about epilepsy. Here are some key facts:
    - Epilepsy is the
      most common serious neurological condition in the UK- affecting over

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600,000 people.
- There are around
  40 different types of seizure and a person may have more than one type.
- Epilepsy can
  affect anyone, at any age and from any walk of life.

4. Around one in 100 people have epilepsy. Epilepsy Action is the leading organisation working with and for people affected by epilepsy. Each year, Epilepsy Action helps around 1.4 million people understand epilepsy and treatment options through its helpline, website and events. The charity improves healthcare by supporting epilepsy specialist nurses and epilepsy research. It improves the lives of everyone affected by epilepsy by campaigning for better healthcare and fairer access to education and employment. Over 95 per cent of this life changing support is funded by donations and fundraising. For more information, visit epilepsy.org.uk

[1] 52% of people with epilepsy can control their seizures with medication. Others continue to have seizures despite receiving medical treatment.

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