45% of respondents indicated that they often or always feel lonely, and being seizure-free did not make a difference.

“A general feeling that you don’t belong, and nobody wants you around. For the years when I couldn’t drive, I lost touch with all my friends, and my introverted self finds it impossible to go out and make new friends.”

“Recognizing faces is very hard (surgery side effect) – that is a huge liability.”

“My husband has a limited and difficult memory, gets angry and frustrated easily, and struggles with his mood...If doctors would support the mental aspects of epilepsy, maybe the isolation wouldn’t be so prevalent.”

“...It’s a constant worry thinking if adults around him will know if he is having a seizure and know how to handle it. Giving him social, recreational and educational independence is so much more complex.”

“...some of the after-seizure anger and depression, and the moody side-effects from medication have driven away some of his social circle because they don’t understand.”

“Inability to drive limits income. Lack of income limits ability to do any activities...”

“My husband and I are isolated from the rest of the “normal” population. We can’t go out with friends, we can’t go on a date together, we need to provide constant supervision for our almost 18 year old daughter.”

“...I am also worried about people making fun of me or changing their relationship with me after they see a seizure...”

The five most widespread barriers to social activity
1. Stigma & misunderstanding in the public (75%)
2. Cognitive problems (75%)
3. Medication side effects (72%)
4. Difficulty making friends (70%)
5. Depression (68%)

The five most substantial barriers to social activity
1. Lack of transportation (47%)
2. Lack of money (32%)
3. Cognitive problems (31%)
4. Fear of having a seizure in public (27%)
5. Medication side effects (25%)

*from a list of 16 possible barriers; “widespread” refers to percentage for whom the barrier limited social activity at least a little; “substantial” refers to percentage for whom the barrier limited social activity “quite a bit” or “a lot”

Impact of Not Being Able to Drive

64% of non-drivers indicated that social isolation limited their quality of life “quite a bit” or “a lot”; as compared to 32% of drivers (p<.05).

73% of drivers accessed social activity through classes, clubs, or teams, as compared to only 49% of non-drivers (p<.05).

Non-drivers were less likely to be employed full-time (16%) than drivers (43%) (p<.05).

Online Survey with 125 respondents: 52% people with epilepsy, 22% parents of child with epilepsy, 17% parents of adult with epilepsy, 9% other (all responses referred to the person with epilepsy)