

# Epilepsy and Social Isolation: Survey Highlights



**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...”*

## BARRIERS

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%)

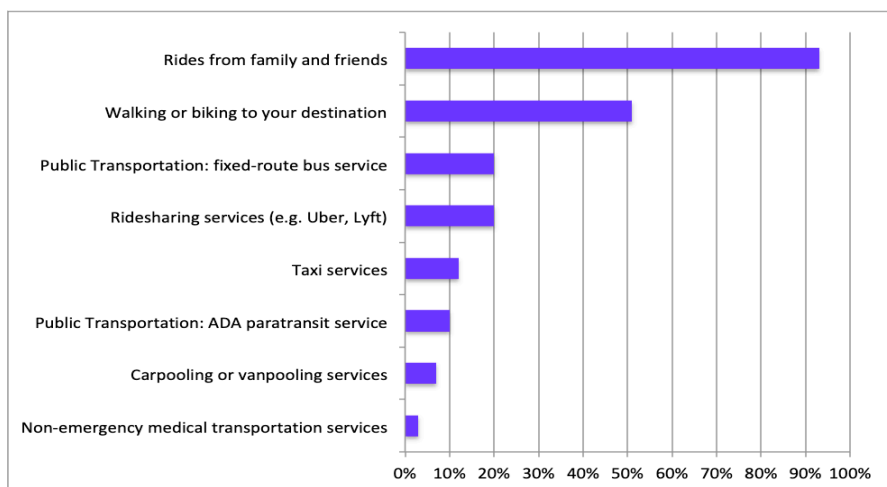
The five most *substantial* barriers to social activity

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

Use of Transportation Options by Non-Driving Adults with Epilepsy



Percentage of non-driving adults with epilepsy who use each service “sometimes,” “often,” or “always”

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)