

Life Transitions and Independence: Survey Findings



We surveyed people with epilepsy and family members to learn more about concerns and barriers associated with the transition to increased independence. The following are some key findings:

	Parents of teens with epilepsy preparing for college, employment, or adulthood	Adults with epilepsy (& caregivers) seeking a more independent living situation
<p>Concerns</p> <p><i>For parents of teens, the percentage of respondents who were "very concerned" ranged from 92% at the top of the list to 42% at the bottom</i></p> <p><i>For adults and their caregivers, the percentage of respondents who were "very concerned" ranged from 64% at the top of the list to 24% at the bottom</i></p>	<p>Social/Emotional wellbeing</p> <p>Self-advocacy skills</p> <p>Safety</p> <p>Transportation</p> <p>Getting accommodations</p> <p>Responsibilities of adulthood</p> <p>Finding an appropriate living situation</p> <p>Responsibility for epilepsy self-management</p> <p>Financially self-sufficiency</p> <p>High school's ability to prepare the teen for transition</p> <p>Transitioning from pediatric to adult neurology</p> <p>Guardianship or alternatives to guardianship</p> <p>Getting support services (e.g. direct care providers)</p>	<p>Transportation</p> <p>Financial self-sufficiency</p> <p>Social/Emotional wellbeing</p> <p>Safety</p> <p>Getting accommodations</p> <p>Getting support services</p> <p>Responsibilities of independent living</p> <p>Self-advocacy skills</p> <p>Finding an appropriate living situation</p> <p>Responsibility for epilepsy self-management</p>
<p>Barriers to Independence</p> <p><i>For parents of teens, the percentage of respondents who said the barrier limited independence "a lot" ranged from 75% at the top of the list to 25% at the bottom</i></p> <p><i>For adults and their caregivers, the percentage of respondents who said the barrier limited independence "a lot" ranged from 44% at the top of the list to 18% at the bottom</i></p>	<p>Cognitive Problems</p> <p>Discrimination</p> <p>Lack of jobs/accommodations</p> <p>Limited job training/placement</p> <p>Lack of appropriate college options</p> <p>Limited funding for college</p> <p>Social/Emotional problems</p> <p>Limited residential options</p> <p>Limited government benefits/supports</p> <p>Lack of transportation</p> <p>Seizures</p> <p>Lack of support from school system</p> <p>Medication side effects</p>	<p>Transportation</p> <p>Lack of jobs/accommodations</p> <p>Social/Emotional problems</p> <p>Cognitive Problems</p> <p>Medication Side Effects</p> <p>Discrimination</p> <p>Limited funding for college</p> <p>Seizures</p> <p>Limited job training/placement</p> <p>Lack of appropriate college options</p> <p>Limited residential options</p> <p>Limited government benefits/supports</p> <p>Lack of support from school system</p>
<p>Comments</p>	<p><i>Something I'm really starting to worry about is my daughter being able to pay for her drugs someday. Currently, I pay \$600/month out of pocket. I believe I will have to pay this for the rest of my life. It seems so unfair for her to have to take on the cost when she's getting started in life.</i></p> <p><i>My daughter is not able to push through being tired or exhausted. If she tries to push through it results in a migraine or seizure. She misses a lot of school & gets by because of her accommodations. I'm not sure how she's going to be able to hold down a job someday,</i></p> <p><i>As older parents, we're constantly concerned about our child's future. Cognitive impairment and visual impairment complicate her intractable epilepsy.</i></p> <p><i>I very much worry about discrimination in the workplace in my daughter's future. I've taught her to be upfront about her epilepsy and to never be ashamed. I've taught her to fight for others with epilepsy. All that said, I know in my heart she absolutely will face discrimination at some point.</i></p>	<p><i>I'm not sure if I can see him living by himself unless things change and seizures also are under better control. He says he would like that eventually, but I think he would feel very alone and isolated. He is very introverted by nature. I would probably be checking in on him constantly.</i></p> <p><i>Discrimination. Inability to find work because of her epilepsy or the perceived additional risk of hiring someone with epilepsy.</i></p> <p><i>Her inability to drive can be costly, and I would need to be sure she has the financial and transportation support to get to and from work.</i></p> <p><i>I would have problems or concerns with trying to live on my own because I have my seizures in my sleep. Also, I will have an issue with timing my seizures to communicate with my doctors how long they were.</i></p> <p><i>Lack of responsible staff who are consistent and reliable</i></p>