



## **Awareness and Communication of Sudden Unexpected Death in Epilepsy**

To mark [SUDEP Action Day 2020](#), Epilepsy Ireland is announcing the results of a survey of over 300 people with epilepsy on awareness of sudden unexpected death in epilepsy ([SUDEP](#)) among people with epilepsy and about communications between them and their healthcare team about SUDEP.

SUDEP is defined as "sudden unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in an individual with epilepsy, with or without evidence of a seizure and excluding documented status epilepticus where post-mortem examination does not reveal a cause for death". Based on international data, we estimate that there are at least 40 cases of SUDEP in Ireland each year.

In total, 323 people with epilepsy took part in the online survey. 40% were aged 18-35; 49% were aged 36-55 and 11% were older than 55 years. 73% of respondents were female; 26% were male and 1% other.

55% said that they experienced tonic-clonic seizures which is a risk factor for SUDEP; 41% had absence seizures; while 53% had focal seizures (complex or simple partial). Other seizure types included atonic, clonic and myoclonic.

83% of respondents had discussed their epilepsy with a neurologist in the past three years; 56% had discussed it with their GP and 43% with an Epilepsy Specialist Nurse. 32% of respondents had not had a seizure in the previous 12 months, although 28% had experienced more than 10 seizures. Uncontrolled seizures are also known to increase the risk of SUDEP.

### **Awareness of SUDEP**

57% of people said that they had an understanding of SUDEP prior to taking the survey while 43% said they did not. Women with epilepsy were more likely to be aware of SUDEP. Overall 60% of women in the survey had a prior knowledge of SUDEP compared to 47% of men.

The age group with the highest awareness was women aged 18-35 (62%) although there were only minor differences across age categories. In men, the highest levels of awareness were observed in the 36-55 age group (53%). It is particularly worrying that a majority of men in the at-risk 18-35 group were unaware of SUDEP prior to the survey. It must be noted, however, that far more women than men (237 v. 83) took part in the survey, making comparisons on gender less reliable.

When we looked only at respondents who experienced tonic-clonic seizures (regarded as being at higher risk) we observed slightly higher levels of awareness compared to all respondents. 66% of women in this category had prior awareness of SUDEP, as did 50% of men. However, the sample size here was significantly smaller (117 women and 42 men) making it difficult to draw any firm conclusions.

### **Respondents' preferences on being made aware of SUDEP**

In analysing the preferences of people with epilepsy, we split the data into two groups: those who did not previously know about SUDEP and those who were aware of it.

#### 1. Respondents not previously aware of SUDEP

Of those that did not previously know about SUDEP, the vast majority (86%) said that they would have liked to have been made aware of it. There were no differences between the percentages of women and men in terms of their preferences, and there were also no significant differences when we looked at this in the sub-group who had tonic-clonic seizures. The preferred communicator about SUDEP for this group was the neurologist (50%) and a third of people would have liked the discussion to have happened with their ESN. A minority of people wanted to hear about it from their GP or from Epilepsy Ireland.

Over half of this group (53%) said they would have liked to have been told about it at the point of diagnosis. Women were more likely to want to be told as early as possible. 57% of female respondents who were not aware of SUDEP said they would have liked to have been told at diagnosis. Men are less keen to be told at the point of diagnosis. 41% wanted to be told immediately, while 41% also said they would prefer being told at a later stage within one year. Overall, 78% of women and 82% of men said they would have liked to have been made aware of SUDEP within a year of being diagnosed. Again, it must be noted that our sample size here is quite small, with just 76 women and 34 men included.

Of respondents who said they did not want to be made aware of SUDEP (14%), the most common reasons given were anxiety and a perceived lack of control.

#### 2. Respondents who were previously aware of SUDEP

In the group of respondents who were aware of SUDEP before the survey, 58% said that they were never told about it by a medical professional but had read about it or found out online. Of those who had discussed SUDEP with a health professional, 24% had discussed it with a neurologist, 21% with an ESN, 9% with Epilepsy Ireland and 6% with a GP.

People were told about it at different stages, although it was less common to be told at diagnosis compared to within the first year or later. Of those

who were told by a professional, there were equal numbers who were satisfied and unsatisfied with the information and how it was conveyed.

Only 15% of respondents said that they received information to take away with them. Young men (highest risk demographic group) appear less likely to be given information on SUDEP to take away. The reasons are unclear although this may be related to the small sample size. It was also notable that a small number of people had first come across SUDEP due to a family member's death.

We also asked people who were aware of SUDEP to look back and say who they would have preferred to have been the first person to raise SUDEP with them. 55% of people wanted this to be their neurologist, 29% said the ESN, while others included Epilepsy Ireland, the GP and family members.

54% said that they would have liked to know at the point of diagnosis, while only 14% said that they would have preferred not to know about it for at least a year after diagnosis.

### **Does knowledge of SUDEP affect behaviour?**

55% of respondents stated that being made aware of SUDEP had influenced their behaviour and perceptions of managing epilepsy. While some people commented that their behaviour had changed in a positive way e.g. taking medications on time, using anti-smother pillows, getting adequate sleep etc, other people referred to the stress and mental health effects that knowledge of SUDEP had brought.

### **Views on importance of communicating SUDEP**

Of all respondents, just 1% felt that it was not important for medical professionals to discuss SUDEP with people who have epilepsy. 13% felt that it was an important point to discuss but only with people at high risk, while 81% felt that it was an important point to discuss with people whether they were at high or low risk.

### **Conclusions**

While the small survey size made it difficult to analyse differences across different demographic and seizure categories, there is much to learn from these results.

Over 40% of people with epilepsy, even those in contact with Epilepsy Ireland and hospital teams are not aware of SUDEP, yet there is an overwhelming preference for being told about it.

There is also a strong preference for being told by medical teams, particularly neurologists. It is also clear that people want to know early - either at the point of diagnosis or soon afterwards. These findings were consistent among both the groups who were aware of SUDEP prior to the survey and those who were not.

There is also very strong support for communication on SUDEP with ALL people with epilepsy, whether at high or low risk.

The results challenge many traditionally held beliefs that people do not want to know about SUDEP or that it can have a negative impact to discuss it. While some respondents do feel this way, it seems that attitudes towards SUDEP among people with epilepsy may have changed over time.

We hope that the results are of particular interest to healthcare professionals, in helping them understand people's preferences about SUDEP communications. Over 96% of respondents had met their neurologist, ESN or GP in the previous three years to discuss epilepsy – yet just 57% were aware of SUDEP, the majority of whom found about it online rather than from a trusted source.

We need to ask if this is desirable, or if more efforts need to be made to proactively discuss SUDEP in one-to-one community and hospital settings where concerns can be addressed promptly by an expert.

We hope that this survey can help kick-start a new conversation in Ireland about how to communicate SUDEP and improve SUDEP knowledge among people with epilepsy.

*Our survey ran online from October 23<sup>rd</sup> to November 9<sup>th</sup> 2017. We want to thank Cleidi Hearn, Psychology student at the UCC School of Applied Psychology and the UCC Community-Academic Research Links initiative ([CARL](#)) for their assistance on this project.*