

Welcome to the latest issue of the Epilepsy Foundation Research News

It is hard to believe that 6 months of the year has passed already and that Winter is well upon us. This edition of the research news highlights the findings from the recent longitudinal survey looking at services and supports to improve the quality of life in people with epilepsy (Wave 4).

Also, have you noticed that the website has recently undergone a facelift? To find the research page go to the **About Us** menu and scroll down to **Research**.

As always we would like to thank you very much for your continued support and contribution to the Australian Epilepsy Research Register which continues due to funding from UCB Australia. Keep an eye out for the next newsletter due at the end of November!



The research team at the Epilepsy Foundation

Research Round-up

Plain language summaries

Some interesting studies have been published over the last 6 months. We have taken four and produced a plain language summary. The topics include—

- ⇒ Medicinal cannabis
- ⇒ Mindfulness or stress reduction methods
- ⇒ Post-traumatic epilepsy
- ⇒ Epilepsy in later life

These summaries take complex research information and make it clear, easy to understand and read about what was done.

Check them out under the **Research** section of the website or please contact us for a copy.

Technology

Epilepsy Xplained

Medicine X in collaboration with the Epilepsy Foundation have launched an animation

about the story of a young woman called Emily as she is diagnosed with epilepsy. The animation can be viewed online or downloaded as an app. This was produced to assist the community in breaking down the medical jargon and confusion

Check it out and share it with your family and friends -

<http://www.epilepsyexplained.com.au/>

MyEpilepsyTeam

My Health Team in the USA in collaboration with the Epilepsy Foundation have launched MyEpilepsyTeam in Australia. It is a free online social community for people with epilepsy and families to connect and talk about any issues that may be on your mind. Over 400 people have joined since February, with a total of over 1600 people.

Check it out - www.myepilepsyteam.com/about

What are your views about epilepsy research?

Let us know by taking a few minutes to complete the survey - <https://www.surveymonkey.com/r/3L33CZH>. Your feedback is important and much appreciated.



Contact the Epilepsy Foundation

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Surrey Hills, VIC, 3127
Phone: (03) 8809 0600

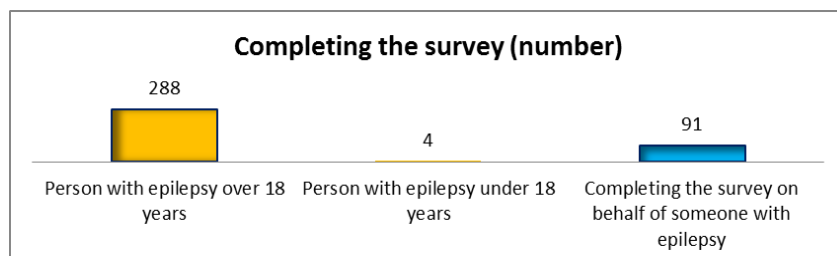
Email: research@epilepsyfoundation.org.au

Visit our website: www.epilepsyfoundation.org.au

Thank you for completing the 2017 Survey!

In 2017, **393 people** on the Australian Epilepsy Research Register completed Wave 4 of the Australian Epilepsy Longitudinal Study (AELS). Your responses help the Epilepsy Foundation understand more about the 'access to services that improve quality of life for people with epilepsy and their families.' In Wave 4 there was a response rate of 30%. More than 75% completed the survey as a person with epilepsy (see graph).

The average age was **42 years** ranging from 1 – 83 years. There were more than twice the number of females (n=258) to males (n=126) and one intersex. Less than half (n=176) were in paid employment.



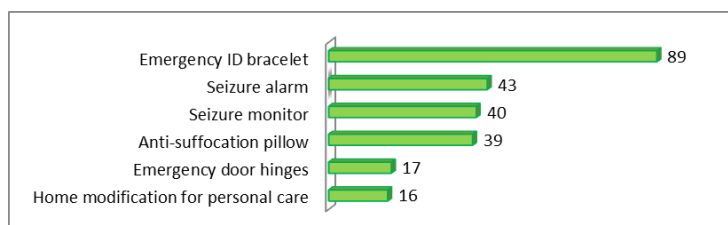
This is a summary of what you told us:

- **Seizures** - More than half had experienced seizures over the past month; with 15% having one or more per month; and 16% having one or more per week
- **Number of epilepsy drugs** - The greatest number took one drug. No drugs 7%; one 37%; two 28%; three 18%; four 6%; five 2%; and six or more 2%
- **Surgery** - 53 (15%) had had surgery for epilepsy
- **Impacts on daily living** - 45% said it affected their ability to drive; 36% said it affected the kind of paid work they could do and 33% said it affected their plans and ambitions for the future
- **Injuries** - 131 (37%) had been injured as a result of a seizure in the past 3 years. 37% of these required hospital treatment

Your responses showed that your experience of health and quality of life was midway between excellent and very bad.

Supports and services

The number of people said they needed but did not have the following equipment (see graph). Those who cannot afford to purchase equipment needed - Seizure monitor n=29; seizure alarm n=29; emergency ID bracelet n=24; anti-suffocation pillow n=18; emergency door hinges n=9.



People were least satisfied with education sessions on community awareness 52%; symptom management 40%; and with managing risk with epilepsy 35%. People were generally least satisfied with information on what government and council services are available 55%; including information on financial assistance; 52%; and on welfare and benefit entitlements 47%.

People felt they needed support mostly with transport n=84; attending/making appointments n=53; social activities n=52; and domestic duties n=49 and who provides support - partner/spouse for 42%; other family/friends 33%; and 11% had no one to help.

Epilepsy Research Clinical Trial Corner - Modified Atkins Diet for the treatment of epilepsy in adults (MADE)

A new clinical trial being run at the Royal Melbourne Hospital will test the effectiveness of a low carbohydrate, high fat diet for the treatment of epilepsy in adults. This trial is open for **adults** diagnosed with epilepsy who are **drug-resistant** and experience **2 or more** seizures a month (whether taking anti-epileptic drugs or not).

Although traditionally used to treat paediatric epilepsy, there is growing research that the Modified Atkin's diet may be effective in adults too.

For further information please contact **Neha Kaul 9342 4658 or made@mh.org.au**