

Epilepsy Foundation

Wave 5 Survey Report

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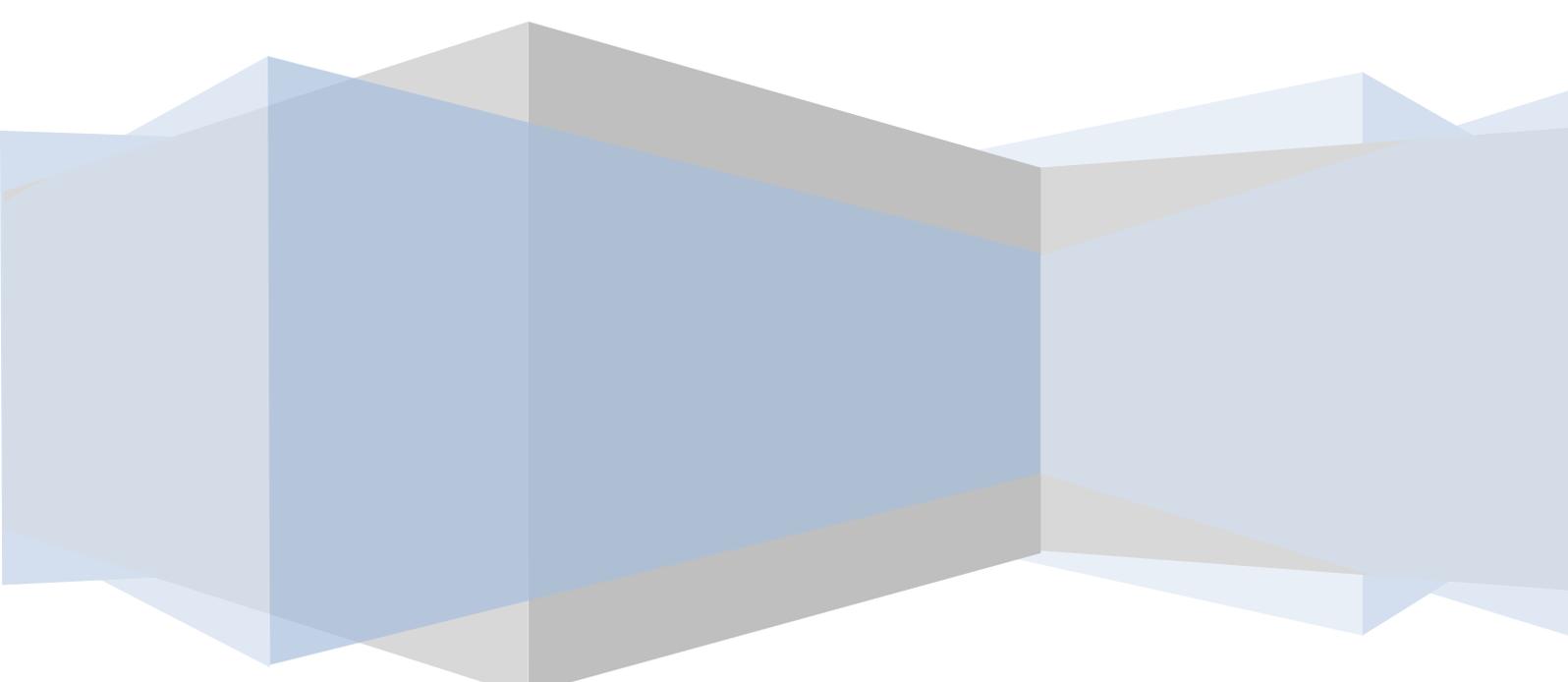


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The 2019/2020 Wave 5 Survey

1. Establishment of the Register

In 2006 the Epilepsy Foundation (then the Epilepsy Foundation of Victoria) established a Research Participants' Register (RPR) to enable it to collect data from registrants regarding the social impact of living with epilepsy. In 2011 the Register was expanded to people in other Australian states in order to collect data from a large and representative sample of people living with epilepsy, their families and carers. Epilepsy Australia and all state and territory associations are supporting recruitment to the new register, which is now called the Australian Epilepsy Research Register (AERR). Joining the AERR is voluntary. The Register complies with Deakin University Human Research Ethics Committee.

All people joining the Register are informed their privacy will be respected and that their details will not be shared with anyone outside the EFV research unit. They are also informed that from time to time surveys will be sent to them, and that it remains their choice to complete the survey.

2. Prevalence of epilepsy in Australia

The formal definition of epilepsy endorsed by the International League Against Epilepsy is having at least two unprovoked seizures, or with at least one unprovoked seizure followed by at least two over the next ten years, and/or having a diagnosis of epilepsy (Fisher et al., 2014).

A recent burden of disease study was conducted by Deloitte examining the prevalence of epilepsy in Australia in 2019 (Deloitte Access Economics, 2020). In Australia, there is approximately a 10% population prevalence of individuals who have experienced one seizure during their lifetime. However, as per the International League Against Epilepsy's (ILAE) definition, a single seizure is not synonymous with a diagnosis of epilepsy.

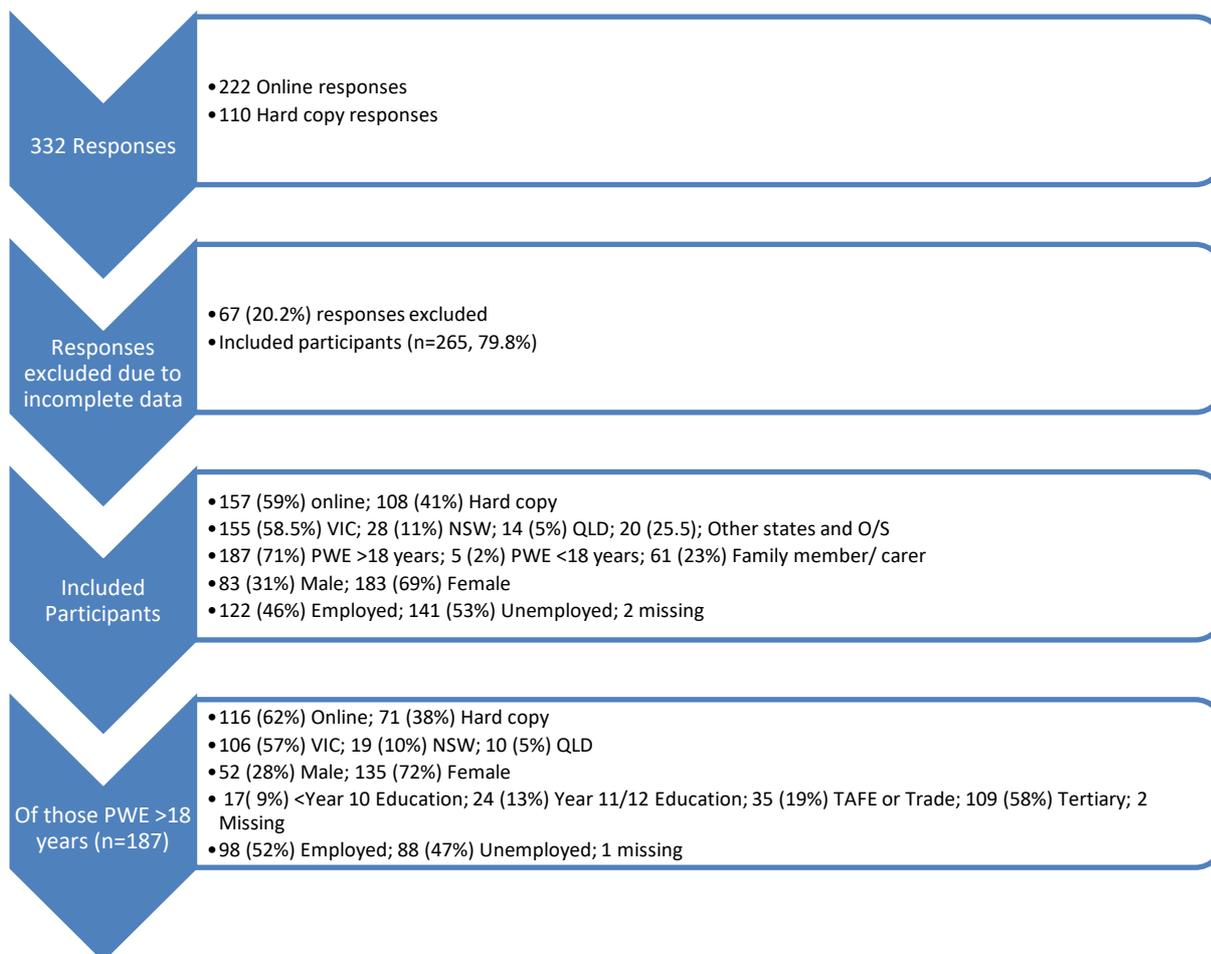
Based on the ILAE definition of epilepsy (above), it has been estimated that approximately 3-4% of the Australian population will develop the condition *at some stage* in their lives. When considering only cases of *active* epilepsy (i.e., not including those who have gone into remission etc.), the Australian Bureau of Statistics (ABS) Nation Health Survey (NHS) estimated that 0.6% of Australians of all ages were estimated to be living with epilepsy in 2017-18. This equates to approximately 142,740 people living with active epilepsy in Australia, with an estimated 14,603 new cases per year.

Living with epilepsy does not just involve managing seizures. Epilepsy is a serious neurologic condition that carries with it experiences of stigma, psychiatric and cognitive comorbidities. In terms of the economic burden, it has been suggested that epilepsy is the second most burdensome neurological condition, after dementia, accounting for 14.6% of the burden of disease of all neurological conditions (Deloitte Access Economics, 2020). According to the World Health Organisation (WHO) epilepsy accounts for over 13 million disability-adjusted life years (DALYs) and is responsible for more than 0.5% of the global burden of disease (GBD) (World Health Organisation, 2019).

3. Overview of survey responses

The following report provides a brief overview of some of the trends noted in the data collected in the AELS Wave 5 Survey. Further research will be conducted to examine depths within the Wave 5 data, as well as between Wave 5 and previous waves, in more depth.

3.1. Snapshot of respondents



*Note. PWE>18 years refers to those under the age of 18 who completed the survey themselves. In cases where surveys were completed by a family member, 10 reported the PWE was ≥18 years taking this to 15 (6%).

The following sections provide an outline of all participants who completed the full survey (n=265). Complete details of demographics and responses for all responses, both complete and incomplete (n=332) can be found in the Appendices.

4. Clinical and sociodemographic factors

The following provides an outline of all of those participants who completed the full survey (n=265). The majority live in the city (n=184, 69%), and were female (n=183, 69%).

4.1. Age distribution

Mean current age (see Appendix for calculation) was 47.5 years (SD = 16.1; Range = 10-85 years).

4.2. Education profile

The sample overall appear well educated with approximately 60% have completed higher education (Trade certificate or University degrees; see Table 1) and n=20 (8%) are still studying.

Table 1. Level of education of those participants who completed the full survey (n=265)

Education Level	Frequency	Percent	Cumulative Percent
Year 7 or below	12	4.5	4.7
Year 8	6	2.3	7.0
Year 9	8	3.0	10.1
Year 10	17	6.4	16.7
Year 11	12	4.5	21.3
Year 12 or equivalent	30	11.3	32.9
TAFE certificate	34	12.8	46.1
Trade apprenticeship	9	3.4	49.6
Diploma	31	11.7	61.6
University degree	54	20.4	82.6
Postgraduate qualifications	45	17.0	100.0
Total	258	97.4	
Missing cases	7	2.6	

4.3. Employment status

In terms of employment status, <50% are in paid employment and n=121 (46%) are receiving a Centrelink payment, suggesting underemployment. The lower rate of employment may be due to the proportion of respondents who have retired (n=35, 13%), are either currently seeking employment (n=25, 9%) or are home makers (n=21, 8%). Around 14% reported not being able to work due to epilepsy and/or a disability or illness and n=63 (24%) were absent from school or work (for an unknown period) due to their epilepsy in the past 12 months.

Approximately 55% of respondents were earning <\$749 per week before tax. The majority of respondents (>60%) reported “just getting along” or feeling “reasonably comfortable” in terms of finances (Table 2).

Table 2. Respondents’ self-reported prosperity

Self-reported prosperity	N	Percent	Cumulative Percent
Prosperous	8	3.0	3.1
Very comfortable	49	18.5	21.8
Reasonably comfortable	103	38.9	61.1
Just getting along	90	34.0	95.4
Poor	6	2.3	97.7
Very poor	6	2.3	100.0
Total	262	98.9	
Missing	3	1.1	

5. The impact of seizures

5.1. Details of seizures

Mean age of seizure onset for all respondents was 16.12 years (SD = 13.9; Range = 0 to 69 years) and mean age of diagnosis was 18.23 (SD = 14.57; Range = 0 to 69 years), suggesting only a slight delay in time to diagnosis.

Overall, respondents were experiencing reasonably well controlled epilepsy, with n=119 (45%) having no seizures in the past 12 months. A further n=59 (22%) had experienced less than 1 per month over the past 12 months.

5.2. Treatment of epilepsy

In terms of treatment, the majority of participants are currently taking AEDs (Table 3). A small number are also utilizing other treatment methods including clinical trial medications (n=9, 3%), VNS (n=6, 2%), the Ketogenic Diet (n=6, 2%) or MAD (n=5, 2%), or DBS (n=1, 0.4%). There were ~10% who had undergone a single surgery and a further ~10% who had undergone more than one surgery for the treatment of their epilepsy.

Table 3. The number of participants using AEDs

Taking AEDs	N	Percent	Cumulative Percent
Yes	244	92.1	94.2
No	15	5.7	100.0
Total	259	97.7	
Missing	6	2.3	

6. Quality of Life Responses

An overview of the QOLIE-31 scores for the entire sample can be found in Table 4.

Table 4. Mean scores on the QOLIE-31 for those who completed the survey (n=265)

QOLIE Scale/ Sub-scale	N	Missing n	Minimum	Maximum	Mean	SD
Total QOLIE-31	206	59	7.10	94.25	54.85	20.30
Seizure Worry	250	15	.00	100.00	57.75	30.61
Quality of Life	253	12	5.00	100.00	64.23	19.33
Emotional Well-being	253	12	.00	96.00	57.93	21.08
Energy	253	12	.00	90.00	38.18	20.79
Cognitive Functioning	246	19	.00	100.00	51.04	27.31
Concern about Medication	254	11	.00	100.00	46.90	32.22
Social Functioning	225	40	.00	100.00	59.37	31.20
Physical Health	258	7	0	100	57.17	21.30
Valid N (listwise)	205					

6.1. Sociodemographic factors impacting quality of life:

There was a significant difference in QOLIE-31 based on who completed the survey with those completing it on behalf of someone else reporting significantly lower quality of life on the following; total QOLIE-31 ($F(3)=3.03, p=.030$); Quality of Life ($F(3)=2.9, p=.034$); Cognitive Functioning ($F(3)=5.6, p=.001$); Social Functioning ($F(3)=6.7, p=.000$) and Physical Health ($F(3)=2.8, p=.039$).

In line with the above, there was also a significant effect of gender. With female respondents reporting lower scores on Seizure Worry (indicating greater seizure worry) ($t(248)=2.51, p=.013$), Emotional Well-being ($t(251)=2.64, p=.009$), Energy ($t(251)=3.42, p=.001$), and Concern about the Effects of Medication ($t(252)=2.03, p=.044$). One possible explanation is that females make up more of the caregivers who are filling in the survey on behalf of a child/ partner who may have more severe or complex epilepsy, hence increased worry on their behalf.

There was a significant impact of employment status, with those unemployed reporting significant poorer quality of life on the following subscales; Total QOLIE-31 ($t(203)=3.67, p=.000$), Quality of Life ($t(249)=3.71, p=.000$), Emotional Well-being ($t(249)=2.57, p=.011$), Cognitive Functioning ($t(242)=2.10, p=.037$), Social Functioning ($t(222)=5.41, p=.000$), and Physical Health ($t(254)=4.02, p=.000$).

6.2. The impact of epilepsy-related factors on quality of life:

Those respondents taking AEDs had significantly increased seizure worry compared to those who do not ($t(247)=-3.29, p=.001$).

In line with the literature, experiencing more frequent seizures also had a significant impact on all QOLIE-31 subscales, with poorer quality of life found for those with more frequent seizures (Table 5).

Table 5. Scores on the QOLIE-31 based on seizure frequency for the final included participants (n=265). Higher scores reflect better quality of life.

QOLIE-31 Scale	Seizure Frequency	N	Mean	SD	F	p
Total QOLIE-31	None	97	63.6907	17.03074	18.4	.000
	Less than 1 per month	50	51.3913	19.55815		
	1 or more per month	24	47.9875	19.52496		
	1 or more per week	31	38.3480	16.64141		
	Total	202	54.8913	20.12589		
Seizure Worry	None	116	70.7629	26.93023	18.5	.000
	Less than 1 per month	58	49.3859	28.07339		
	1 or more per month	30	51.3880	29.12386		
	1 or more per week	42	36.9590	29.36806		
	Total	246	57.5886	30.72910		
Quality of Life	None	117	71.5171	18.04555	15.7	.000
	Less than 1 per month	59	62.7542	16.27945		
	1 or more per month	31	58.3065	17.52839		
	1 or more per week	42	50.9524	19.01502		
	Total	249	64.3273	19.26247		
Emotional Wellbeing	None	117	62.4274	18.87130	3.8	0.11
	Less than 1 per month	57	56.2105	21.55950		
	1 or more per month	31	51.7419	20.85980		
	1 or more per week	43	52.7442	23.74878		
	Total	248	57.9839	21.00317		
Energy	None	116	43.3621	21.71731	6.0	.001
	Less than 1 per month	57	36.1404	19.20327		
	1 or more per month	31	32.0968	17.78455		
	1 or more per week	44	30.1136	18.84726		
	Total	248	37.9435	20.81354		
Cognitive Functioning	None	113	60.1310	25.09267	9.9	.000
	Less than 1 per month	56	46.9289	27.33630		
	1 or more per month	31	44.6134	25.48251		
	1 or more per week	42	37.0242	25.78921		
	Total	242	51.0779	27.19113		
Concern about Medication	None	116	56.8948	30.03544	8.9	.000
	Less than 1 per month	58	38.1684	30.50462		
	1 or more per month	31	43.8161	33.91477		
	1 or more per week	44	32.9523	29.63971		
	Total	249	46.6738	31.99793		
Social Functioning	None	108	75.1944	23.08718	32.0	.000
	Less than 1 per month	51	53.5098	29.40570		
	1 or more per month	25	47.1600	30.92017		
	1 or more per week	37	29.8378	25.47713		
	Total	221	59.4253	30.99648		
Physical Health	None	117	65.21	18.411	15.0	.000
	Less than 1 per month	58	55.17	20.540		
	1 or more per month	31	51.29	22.172		
	1 or more per week	47	43.40	20.880		
	Total	253	57.15	21.450		

7. Social Support

Responses from participants revealed the importance of social support, including support from family and friends as well as peer support, for participant well-being.

7.1. The importance of social support

In terms of the types of support that people found useful to help them manage their epilepsy, positive social interaction was the most useful (n=59, 22%), followed by emotional information (n=53, 20%), affectionate support (n=51, 19%), tangible support (n=27, 10%). All forms of support were seen as beneficial and ticked by n=150 (57%) with only n=14 (5%) reporting that they did not need any form of support to help manage their epilepsy.

7.2. Qualitative responses highlighting the importance of positive social interaction

“My neurologist is a believer in the benefit of peer support - and recognised that type of support would suit me at the time. I am so grateful to him for seeking my consent to a visit and coordinating it on my behalf.”

“I would love support for parents who have epilepsy with young children. I can't find support groups apart from forums on social media which are counter-productive and toxic. There is very little literature or education around how to deal with the many issues not only having young children who witness the seizure. It would be great to have Seizure first aid chart for kids to follow specific to epilepsy. I couldn't find many suitable.”

“Epilepsy Support Groups are an excellent way to feel disinhibited about discussing the day to day issues and emotions of living with epilepsy. The epilepsy nurse practitioners were also very educative & I went on to be a support group facilitator in my local area for a few years. I am lucky to attend the free outpatients clinic to see both an epileptologist & a neuropsychiatrist, which has been very beneficial in understanding my condition & treatments.”

The importance of professional psychological support where indicated was also highlighted:

“It's just a practical necessity to talk to a qualified person outside your life but that understands your circumstances. a professional that can be a sounding board and give advice. so many factors effect and influence me because of my epilepsy, the epilepsy comment is complex as well were all having a hard accepting that we have it or trying to manage the list of issues/complexities that come with it- stigma, Centrelink rules and bias, relationship complexities, medication dance, accessibility physically depending where you live if you don't drive just to everyday things or resources when you need help, it's a long list. Sometimes a counsellor physiologist is the closest thing to someone who understands you, or at least where you're coming from...”

“Mental Health Care Plans with psychologists have helped me become more self-aware, identify & reduce stress triggers, and establish better coping strategies in my life. Reduced stress lowers my seizure threshold. I have co-morbidities of anxiety & depression due to location of lesion in my temporal lobe & also a family history of mental health issues.”

Some respondents also felt that it is difficult for others, including family members, to truly understand their epilepsy and its comorbidities:

“People don't understand what epilepsy and having seizures, do to you physically, mentally and emotionally, so I find it hard to talk about with anyone.”

“Husband is fantastic but doesn't really understand. Parents died years ago along with brother and best friend. No one really left to discuss it with. Neurologist isn't much help.”

7.3. The importance of social support for good quality of life

Family was the most common source of support, particularly partners (n=122, 46%) and parents (n=64, 24%). Based on early analyses, those respondents who were able to rely on a partner/spouse for emotional support appeared to show the highest quality of life.

7.4. Formal psychological/ emotional support

In terms of more formal emotional support, the majority of respondents had never used psychological assistance (n=126, 47.5%) or mental health service support (n=172, 65%), as well as counselling for self (n=125, 47%), family counselling (n=209, 79%), relationship counselling (n=215, 81%) or counselling for children (n=204, 77%). The majority also reported never utilising epilepsy organization support (n=150, 57%).

This most likely reflects a lack of need of psychological support as opposed to lack of access because those who reported “Never” needing counselling, psychological assistance or mental health service support all reported significantly higher quality of life compared to those who reported needing this form of support (see Figure 1). This effect was evident but not quite as strong for family counselling, relationship counselling or counselling for a child.

NB. It should be noted that while depression and quality of life are commonly negatively correlated, they are not synonymous. As such, we cannot state conclusively whether those who did/ did not require counselling were also those who are experiencing greater mood difficulties.



Figure 1. Participant quality of life based on how frequently they access counselling (top), psychological support (middle) or mental health assistance (bottom). Those who never utilize these services report the best quality of life.

8. References

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