



**Allison Clarke**

**While studying for her doctorate in health psychology, Allison Clarke developed a particular interest in the effect of chronic illness on young people. With little research done on the psychological impact of epilepsy in adolescence, and with ongoing support from the Epilepsy Foundation of Victoria, Allison has just published her thesis titled *The impact of Epilepsy on the Psychosocial Functioning of Young People*.**

**The Epilepsy Report is pleased to present this summary of her research.**

# The Impact of Epilepsy on the Wellbeing of Young People

## Background

It has been estimated that there are 100,000 Australians with epilepsy and that 20,888 of these are aged between 12 and 24 years [1, 2]. However it is not possible to be definite given that epilepsy is not a notifiable condition and at least some Australians with epilepsy prefer to conceal their condition for fear of stigma and to avoid driving restrictions [3, 4].

Many young people with epilepsy experience some difficulty in the developmental transition from childhood to adulthood. It is a period dominated by “firsts”, the first time for being out of the direct control of parents, the first time for living away from home, the first time for forming sexual relationships, and the first time transitioning from school to work. All of these critical transitions can be made more difficult as a result of epilepsy and its treatment. Young people who have epilepsy often find that their epilepsy becomes more unstable due to difficulties in balancing anticonvulsant medication in the context of puberty, including hormonal and weight changes [5, 6]. Moreover, epilepsy may impede their opportunities for social interaction. It can interfere with school attendance and involvement in recreational activities such as swimming and team sports due to seizures or safety concerns. It can also affect participation in social events as a result of limitations on the quantity of alcohol that can be safely consumed. Young people with epilepsy may also have difficulties gaining and maintaining a driving licence [7].

## Aim of this research

The aim of my doctoral research was to develop a model that identified which demographic, medical and psychological factors that discriminate between good and poor wellbeing amongst young people with epilepsy. It is hoped that we will be able to target these factors in future interventions so that young people who really struggle through this period today might be able to function better tomorrow.

## Research design

Participants were to complete either paper or Internet versions of a self-report survey that asked questions about the participant, their medical condition, and how they lived with their epilepsy.

The survey was designed in two parts. The first part focused on demographic and medical information and the second part included a series of psychological scales that measured family functioning, coping skills, anxiety and depression, sense of coherence, quality of life, and concerns about epilepsy.

## Who participated

My sample included 114 young people aged between 10 and 24 who had self-reported epilepsy.

Of the total 114 participants, 74 were female with an average age of 8.5 years and 40 were male with an average age of 16.9 years. Seventy six resided in Australia (66.7%), eight resided in New Zealand (7.0%) and 30 resided in other countries (26.3%), including USA, UK, Canada and Ireland. Fifty per cent were classified as living in a metropolitan area, 16.7% in an inner regional area, 21.9% in an outer regional area, 6.1% in a remote area and 5.3% could not be classified due to insufficient information using the Australian regional profile system [8].

Thirteen Australian participants received assistance from a parent or carer in completing their paper survey. Fifty-one Australian participants completed a paper survey without any assistance. Twelve completed Internet surveys. Eight participants resided in New Zealand and of these four completed a paper survey unassisted, one completed a paper survey with assistance and three completed an Internet survey. Participants from all other countries completed Internet surveys.

## Analysing the data

As would be expected for this age group, the majority of participants lived with either one or both of their parents and their siblings. Three participants lived alone and seven lived with a partner. Over 40% of the sample was attending TAFE or university. Twenty-three per cent had received integration assistance during their education. Three participants identified themselves as intellectually disabled.

The participants were first diagnosed with epilepsy between birth and 22 years of age, with an average age of 10.3 years at time of diagnosis. Of the total sample, 8% had been diagnosed within the previous year and 10.6% within the previous two years. The average duration of the condition was 7.6 years. Of the 114 participants, 57 were classified as having generalised seizures, 48 were classified as having partial seizures and nine could not be classified due to insufficient information.

Additional medical characteristics are shown in the following table.

**Table 1. Medical characteristics of the study sample**

Variable	Percent
Family history of epilepsy	34.8%
Other chronic illnesses	27.9%
Seizure in last year	83.3%
Seizures in last month	48.2%
High seizure severity	64.9%
Lost consciousness from a seizure	28.1%
Hospital stay due to seizure	14.2%
Video monitoring for seizures	45.6%
Changed medication in past 3 months	51.4%
Medication adherence problems	58.6%
Other traditional treatments (e.g. brain surgery, ketogenic diet, vagal nerve stimulator)	16.7%
Complimentary and alternative treatment	37.0%

In addition to epilepsy, thirty-one participants had one or more chronic illness. Ten had asthma, six had headaches, five had allergies, including hayfever and eczema, four had diabetes and three had arthritis.

Naturopathy and relaxation or meditation were the most common complementary and alternative therapies used. Other therapies included: acupuncture, Bowen massage therapy, chiropractic care, counselling, hypnotherapy, osteopathy and vitamin or herbal supplements.

After excluding cases that had significant missing data, there were 98 cases available for analysis. The four outcome measures, anxiety, depression, health-related quality of life and concerns about epilepsy, were subjected to a cluster analysis that revealed two groups.

The first group was strongly representative of participants with higher levels of psychosocial function, with lower anxiety, higher health-related quality of life and lower concerns about epilepsy.

The second group had the reverse pattern and was strongly representative of participants with lower levels of wellbeing.

To predict membership of the good or poor wellbeing outcome groups, the independent variables were entered into a series of hierarchical logistic regression models. The final

model was a good fit with the data and explained 66% of the variance in wellbeing. The model correctly predicted 84.1% of cases.

## Conclusion

Participants were more likely to be members of the poor wellbeing group if they had had a seizure in the last month, had poorer family functioning and made greater use of emotion-focused strategies. The psychological factors did make a unique and significant contribution to wellbeing in addition to the medical and demographics factors.

It would be worthwhile to design and implement intervention studies that focused on seizure management, family functioning and emotion-focused coping. For more difficult-to-manage epilepsy, psychosocial variables are likely to be more amenable to change and facilitate increases in health-related quality of life [9]. Much can be gained from the successful management of epilepsy during this critical period of development. Unfortunately, much can also be lost when epilepsy is not successfully managed. The impact that epilepsy can have on young people's capacity to form strong social networks, complete formal education, move from school to work, develop a goal-oriented view of the future and gain the self-sufficiency of adulthood may prove costly for the affected individuals, their families and, ultimately, their communities.

## References

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*Allison Clarke completed her Doctorate in Psychology (Health) at Swinburne University of Technology under the supervision of Dr Christine Critchley. Approval to conduct this study was received from the Swinburne University of Technology Human Research Ethics Committee.*

*Now living in Canberra, Allison is a registered psychologist in private practice with Optimal Health and Performance. Allison is also a member of the board of Epilepsy ACT.*

*If you would like find out more about Allison's research, her doctoral thesis can be accessed at the Swinburne Research Bank website <http://researchbank.swinburne.edu.au> or email [alclarke@iinet.net.au](mailto:alclarke@iinet.net.au)*