



a charity dedicated to improving lives affected by eosinophilic disorders

ausEE Social Impact of EGIDs Survey Results

Summary

In 2013 we conducted a survey of our members about the impact of eosinophilic gastrointestinal disorders (EGIDs). 72 people responded from across Australia (except Tasmania and the Territories) and from 6 other countries. 78% of respondents were parents or carers and they told us that EGIDs were causing significant social issues.

This year, we decided to rerun the survey, with some additional questions, and see what may have changed over the past six years. We think you'll find the results as interesting as we have.

In 2019, 108 members responded to our survey, which included some additional questions. Responses were received across the Australian states and Territories (except for NT) as well as 3% from NZ and 6% from 3 other countries (United States, Canada and The Netherlands). 70% of respondents were parents or carers of a child/children with an EGID and 26% were living with an EGID themselves.

The responses on the questions we asked on the impact of EGIDs are summarised in the below table.

Impact of EGIDs	2013	2019
Difficulty going to a restaurant	98%	89%
Difficulty going food shopping	83%	80%
Anxious about attending social gatherings	81%	77%
Difficultly attending a social occasion like a wedding or a birthday party	96%	88%
Left out of a social activity because of their EGID	48%	49%

The cost of food

In 2019 we asked about food budgets and 91% of respondents said that EGIDs impacted and 71% reported spending more than \$35/week extra to buy special foods. A staggering 9% spend more than \$100 every week on special foods. Medicines and supplements for EGIDs also have a significant cost impact for 81% of respondents with 26% of respondents spending more than \$35/week.

Work and family

36% of respondents in 2019 were currently working full-time and 37% were in part-time employment. 55% of respondents said that having an EGID or caring for someone with an EGID impacted on the number of hours they could work. This is significant in light of the additional costs families face with food, medicines and supplements. 18% of respondents said they were full-time carers (including home and family duties).

Whist it was encouraging to see that 58% of respondents reported they had some support from family and friends, devastatingly, 34% said that they were largely managing on their own with 8% reporting that family and friends sometimes made it harder for them.



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The hardest part of EGIDs

In response to the question *In your own words, what do you feel is the hardest part about social activities when living with an EGID?* there were some recurring themes. These were clustered into eight themes with social impact being the strongest theme (some comments had more than one theme and therefore the totals are greater than 100).

	Impact	2013	2019
bring safe food		24.14% 14	23.16% 22
cant eat same food		24.14% 14	27.37% 26
dont know enough		1.72% 1	2.11% 2
health impact		18.97% 11	4.21% 4
monitoring food		10.34% 6	15.79% 15
other		1.72% 1	3.16% 3
Others misunderstanding		13.79% 8	21.05% 20
social impact		46.55% 27	47.37% 45

Conclusion

The results showed that little has changed on the social impact of EGIDs from when the survey was first run in 2013 to our recent survey in 2019.

Families are facing major on-going social, financial and employment issues as a result of EGIDs. This highlights the importance of ausEE's goal to raise awareness to promote inclusion and inform the community of the simple things that others can do to help. There is a need for the provision of greater financial and practical support to families to reduce the impact of EGIDs so they can focus on getting well and living the best life possible.