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Results of ausEE Survey on Using Elemental Formulas

Summary

Elemental formula is an important treatment option for some people with EGIDs and it can significantly improve health for some. However, there are some challenges for children and adults using elemental formula including social, financial, palatability, portability and availability.

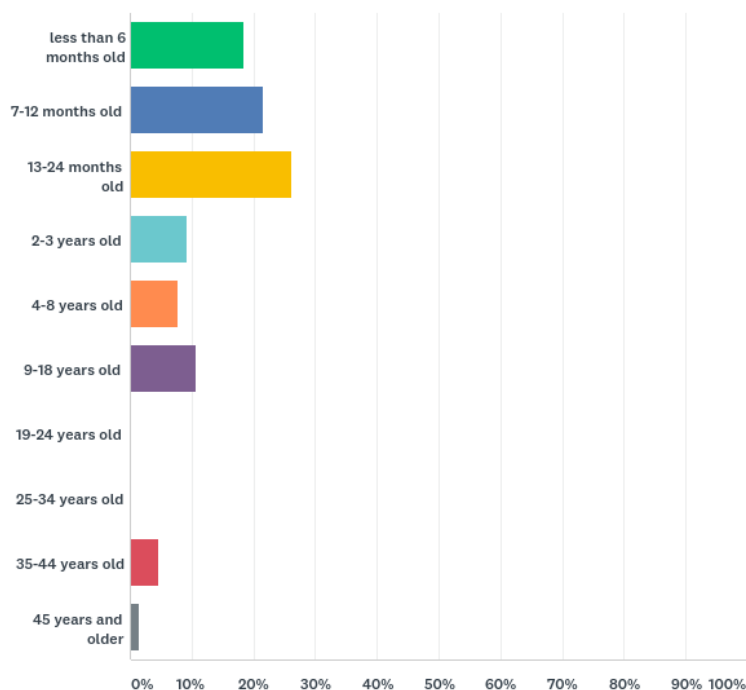
There were **114 total responses to our survey** of whom 70 (61%) respondents advised they had previously used or were currently using an elemental formula.

There were **65 respondents** who answered questions about their experience using elemental formulas. To the question about the number of people in their family currently or previously using elemental formula, 85% had one family member with an EGID on formula and 15% had two family members using an elemental formula.

85% had been recommended the elemental formula they were using by a clinician including a doctor, dietitian or specialist and 22% had tried other elemental formulas first but did not tolerate them.

66% advised they had commenced elemental formula when they were under two years of age.

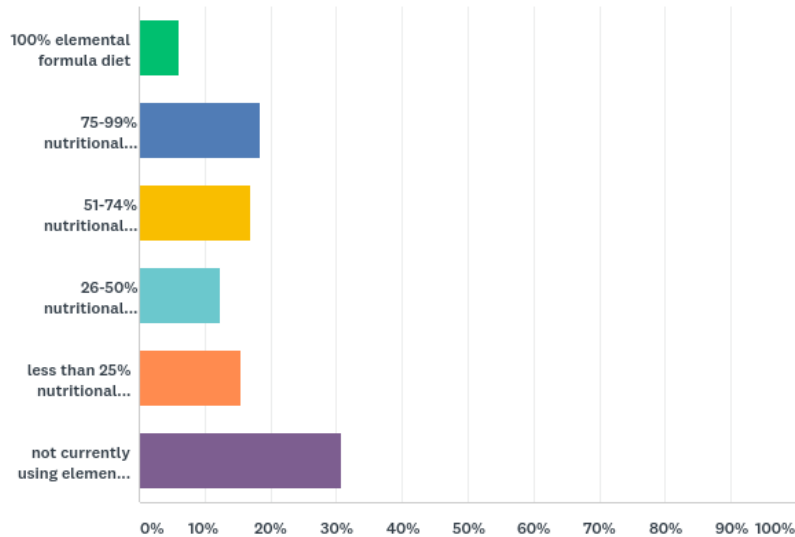
At what age were you (or your child with EGID) FIRST put on elemental formula?





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How much formula are you or your child currently having?



38% of respondents were still on formula at the time of the survey with 42% advising that formula made up over 50% of their nutritional needs.

81.5% consumed formula orally, 9% of respondents consumed formula orally and via a NG-tube, 5% consumed formula orally and via a G-tube, 1.5% by G-tube only and none used NG-tube only.

Our respondents told us that 30% were on elemental formula for between two and five years. This is significant, particularly in light of the social and financial implications.

29% of respondents spent \$51-\$100 per month on formula with 3% spending more than \$150 a month on elemental formula. Elemental formula is not currently covered under the Pharmaceutical Benefits Scheme (PBS) in Australia for adults with EoE over 18 years and 94% of respondents believed that it should be covered by the PBS. 24 respondents who were adults living with an EGID, said they would be interested in using an elemental formula as a treatment option if it was included on the PBS for patients over 18 years.

41% of respondents reported their children needing to consume elemental formula at childcare or school and 42% advised they felt nervous or embarrassed about consuming formula in public.

For adults on elemental formula they described the biggest issues as taste and cost, with one respondent reporting it costing them almost \$20,000 a year to be on elemental formula.

For children, taste and cost were also significant factors along with availability. It was suggested that the elemental formula be made available in a larger size tin and in portable premixed varieties like a tetra popper pack to provide the option of taking it out with them easily and not having the child feel like they are any different.

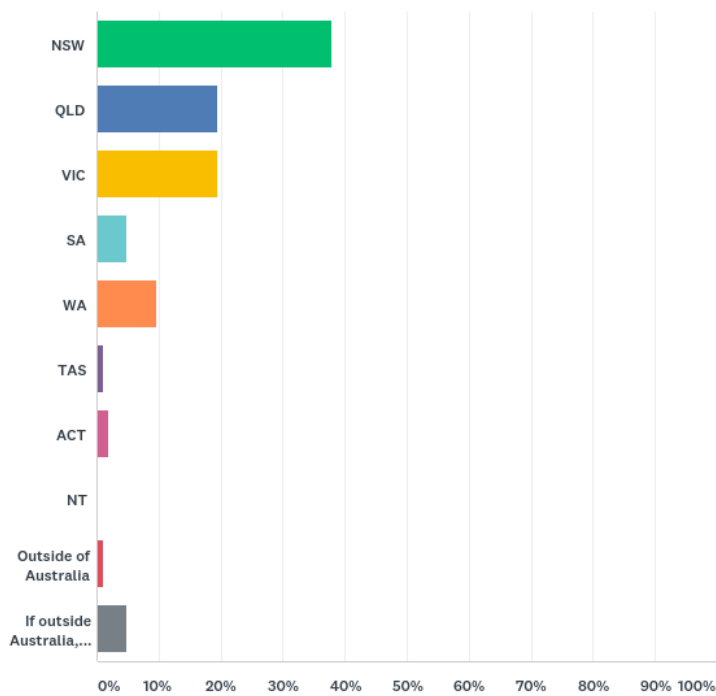
10% of respondents advised that their elemental formula was not always readily available.



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103 respondents answered these additional location questions showing that participants of this survey were from all Australian states and territories except the NT. There were also responses from four other countries with two responses from New Zealand and one from Singapore, Iceland and the UK. Responses were also distributed across metropolitan, regional, rural and remote areas.

Where do you live?



What type of area do you live in?

