



a charity dedicated to improving lives affected by eosinophilic disorders

ausEE Tube Feeding Survey Results

Summary

74 people responded to our tube feeding survey from across Australia (**NSW/ACT 44%; QLD 22%; Vic 20%; SA 4%; WA 4%; TAS 3%; other 3%**).

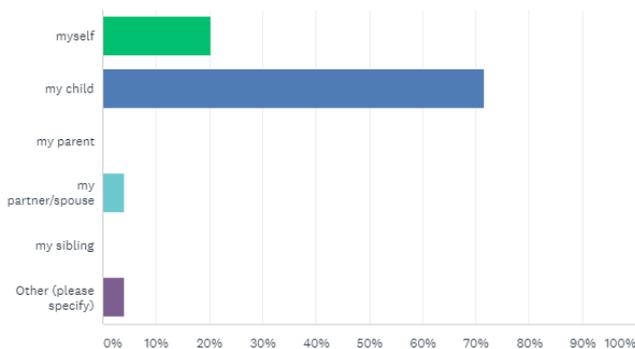
Of these, **62% of the people with feeding tubes were under 5 years of age**. Just over 13% needed the feeding tube for EoE or EG. More than 85% needed the feeding tube because of another condition.

Almost **30% had the tube for less than one year with 31% up to 2 years**. Almost 30% needed the feeding tube for 3-5 years and 9.5% needed it for more than 6 years.

The out of pocket costs of tube feeding are very high with **18% of participants reporting they spend more than \$200/month**.

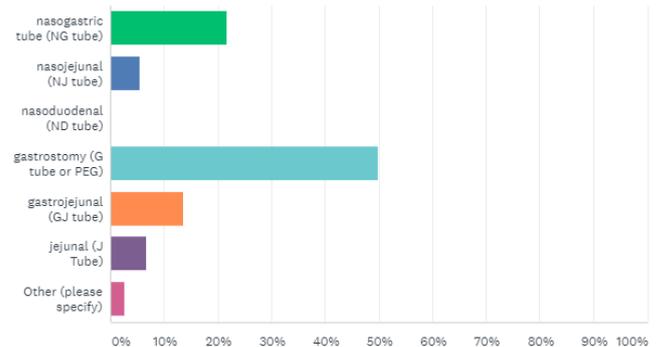
Who has/had a feeding tube in your family?

Answered: 74 Skipped: 0



What type of feeding tube do they have/did they have?

Answered: 74 Skipped: 0



Many challenges are experienced by people with a feeding tube and/or their carers including: **persistent pain; social stigma and associated anxiety; poor understanding and limited help from health care professionals; judgement and lack of support from family and community members; and the time and cost associated with using and maintaining the tube.**

Despite this, many participants expressed gratitude for the tube as it sustained life.

Participants reported mixed responses from childcare and schools. Some were very supportive. Many Centres/Schools were unable to use the feeding tube and associated equipment effectively which impacted on parents/carers who had to attend to assist with meals. A number of participants reported that they could not secure care for their child because of the feeding tube. This impacted on parents and carers capacity to maintain employment. For children with a feeding tube starting school seems to be pretty complex. This requires some policy and training action from governments to ensure these children have the best start possible (feel welcomed, have trained teachers and other staff, access to social and education support) and the chance of a good education.

Participants reported that they needed more practical support such as respite, simple training/information for family members and other potential carers, financial support and greater community understanding/awareness.

ausEE will share the findings of this survey with Rare Voices Australia and state/federal governments to try and improve things for people with feeding tubes and their carers.