



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%**).

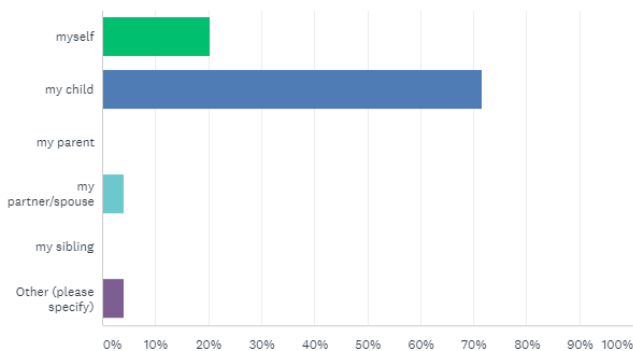
Of these, **62% of the people with feeding tubes were under 5 years of age**. Just over 13% needed the feeding tube for EoE or EG. More than 85% needed the feeding tube because of another condition.

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**.

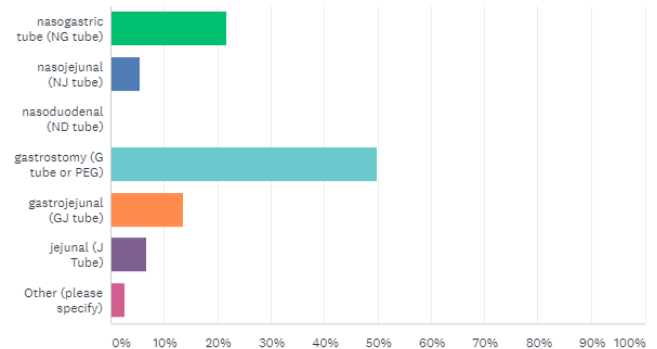
Who has/had a feeding tube in your family?

Answered: 74 Skipped: 0



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

Answered: 74 Skipped: 0



We asked... **If you could choose one thing to make it easier for your family to manage tube feeding, what would it be?**

- Education on tubes for employers and school. Easy way of getting supplies
- Having a discreet surgical tube which can be hidden underneath a shirt
- An IV pole to help roll my feeds around the house with me. It's hurting my back and shoulders carrying my backpack everywhere
- Financial assistance. I find it very frustrating that some states get tube feeding completely covered while other states have to pay 100% out of pocket
- More help from experienced people
- The financial burden as I have many other medical costs at the same time
- Someone able to manage his tube who could come and give us a break for a few hours. Family member near us won't take him as intimidated by his tube so we get no breaks.
- Easier to access more than one at a time. 5 faulty/leaky tubes in a row, still leaking now
- No tube
- Easier to get more natural formulas and real food formulas, more supportive medical team and doctors
- Reduce costs
- Everybody else's support and 'advice'
- Access to regional outreach GI team, rather than relying on the state capital hospital for assistance.
- Accessibility in a rural environment
- Have a weaning plan
- More support for blended food diets, less pressure to use formula
- Local support group



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- Family counselling. Realising the impact it has on all members. Real support would be nice & family funding.
- More advice and funding
- More compact for when out and about
- Pre-packaged blended diet meal
- Quieter pump
- Be able to order supplies online (phone orders only)
- Nothing. We have it in hand now.
- Smaller pump to travel with
- Better access to radiology replacement. More tubes funded, they wear.
- Funding for mobile feeding sets, funding for extra extensions as they don't last a month
- Better education to family members
- It'd be nice if he could never pull out his peg. It'd be great if the feeds could be faster.
- Less judgement from others
- Fix my problem
- Weaning her off the tube
- Cost
- Easier for the crawling and learning to walk children to get around. More courses/info.
- Stronger extension tubes that don't disconnect and leak
- Better support and understanding
- Just making it less scary. People didn't want to do it because they were scared of doing something wrong or hurting my child. Maybe an easy, universal guide that everyone can use to learn how to use it.
- Feeding bottle and hanger
- More understanding and education for extended family
- Correct funding and care plan
- More understanding for close family members on why tube feeding is required and how to administer a tube feed
- More readily available supplies
- For our child to be able to feed himself
- Support financial
- Respite for carers
- It's really no big deal
- Support for them or somewhere they could have contact with other families/people who understand tube feeding
- Free feeding equipment
- Nutrition department who worked with me not against and paid for supplies they should have
- Greater support from those closest to us
- Where govt helps with paying for tubing etc
- More support. Somewhere to ask questions. Help buying supplies.
- Having support from an allied professional 24hrs. The local hospital doesn't even have a stomach nurse. There should be more awareness and support for this group of people
- Probably to transition my son to a peg sooner
- An easier/better system for carrying everything around including the pump etc for it to hang easily...
- The only thing would be access to better bathroom facilities while driving on tourist routes. The malls we go to have great bathrooms for parents where I can clean the syringe and adapter and it would be great to access something like that when we take a trip.
- Easier access to feeding equipment in our rural hospital
- Stop the Enfit tubes and lines getting stuck together
- We were eligible for enable for 3 yrs before anyone told us... in that time we paid for everything... why???
- One-piece suits with easy access to the g tube. My son pulls at it if he has two-piece outfits on
- Better community understanding of the different reasons a person might have a feeding tube and that it's not necessarily a negative thing to have
- Access to services for regional towns like ours
- Having state governments all agree on one policy for tube feeding to save mass confusion among states and funding
- More support from hospital workers



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## Conclusion

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.