

We all need good nutrition!

Challenges and strategies for children with feeding difficulties



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Intellectual disability has wide ranging effects on health and wellbeing

Approximately 2% of children born each year in Australia¹ and approximately 3% of children globally² live with intellectual disability (ID). Beyond difficulties with adaptive functioning, many children have health issues – parallel health conditions or diseases – that threaten their physical and mental health. Gastrointestinal difficulties are extremely common. Altered movement and muscle control can influence chewing and swallowing, and the presence of gastroesophageal reflux and constipation influence not only oral intake and nutrition but also comfort. Furthermore, many children with intellectual disability find it difficult to eat a nutritious and balanced diet.

Children with severe disability are especially vulnerable to feeding difficulties

Medications to treat epilepsy, sleep or gastrointestinal disorders are difficult to administer, poor fluid intake can exacerbate constipation and any necessary medical management can be suboptimal.³ The consequences of poor feeding in-

clude malnutrition, of macronutrients (fat, protein, carbohydrate) and micronutrients (vitamins, minerals). If the child's swallow is unsafe, there is risk of aspiration of food and fluids into the lungs, recurrent chest infections and progressive lung disease.⁴ Families often spend long periods of each day working to ensure that their child has enough to eat and drink.⁵ However, the child may tire during prolonged feeding with increased risk of aspiration, and parents can find these interactions with their child difficult experiencing high burden and distress.^{5,6}

Supporting feeding difficulties and unsafe swallow

Swallowing is typically assessed using videofluoroscopy, a moving x-ray which shows the swallowing of some food and fluids from the mouth to the oesophagus. If there is aspiration of food or fluids, this can be observed. If the child's swallow is safe and there is no aspiration, nutrition can be boosted by providing nutritional supplement drinks to increase kilojoule intake and thickening fluids to enable safe drinking. It is important to find out the texture and consistencies of foods that the child can safely eat.

If the child's swallow is unsafe, feed may need to be delivered directly into the stomach. The child may trial a nasogastric tube for nutrition. If that is supporting the child's health, gastrostomy insertion clinicians will discuss gastrostomy with parents. This is where a flexible feeding tube is placed through the abdominal wall into the stomach. Feed, fluids, and medications can be delivered through the gastrostomy, bypassing the swallowing difficulty. Gastrostomy is increasingly used in children with intellectual disability, particularly in younger children <3 years of age.⁷ Commonly occurring complications include granulation or inflammation at the wound. More rarely, there may be leakage, infection, migration of the tube within the gut, bleeding or intestinal perforation and peritonitis.^{4,8}

Health outcomes following gastrostomy

Most children will gain weight after gastrostomy insertion⁴⁻⁶ especially in the short term as immediate nutritional deficits are relieved. Monitoring the quantity of enteral feeds with a dietician is required to prevent overweight. Many children however may still follow a growth pathway of underweight, such as those with Rett syndrome.⁹

There is mixed evidence that gastrostomy insertion is associated with changes in hospital admissions. Analysis of longitudinal data in the Australian Rett Syndrome Database (n=98 with gastrostomy) found no change in the rate of hospital admissions.⁹ In contrast, a data linkage study (n=673 with gastrostomy from Western Australia and New South Wales 2002-2010) found somewhat different results.¹⁰ In this study,

1. The incidence of all-cause hospitalizations was lower 5 years after the procedure (incidence rate ratio, 0.63 [95% CI, 0.45-0.86]), possibly reflecting generally improved nutrition and better health.
2. Admissions for acute lower respiratory tract infections remained similar after gastrostomy, suggesting that bypassing swallowing does not prevent lung infection and possibly because of ongoing aspiration of saliva or suggesting that more study of the flow and volumes of feed is needed.
3. Admissions for epilepsy were generally lower, possibly because of greater efficacy in the delivery of antiseizure medications although therapeutic drug monitoring would be necessary to test this hypothesis.

What does having a gastrostomy mean to children and families?

Despite evidence that a gastrostomy could benefit the child, parental decision making in relation to gastrostomy insertion is difficult. Feeding may be stressful and time consuming, but parents may be reluctant to proceed with gastrostomy, to avoid surgery and for their child to retain pleasures derived from eating. Parents may feel uncertainty as to establishing a new feeding routine, their sense of 'good parenting' may be threatened, and there may be concerns about the child's future oro-motor and language development.¹¹ There may also be concerns about relying on a manufactured diet and parents are often relieved to learn that pureed food, breastmilk and water can be used with gastrostomy in addition to synthetic nutrition. Following gastrostomy insertion, parents need to acquire a complex skillset, including new feeding methods and how to recognise and manage problems.¹²

Parents are usually satisfied following gastrostomy insertion, relieved that their child is receiving adequate nutrition and prescribed medications, is gaining weight and there is less stress.^{5,6} In a qualitative study, parents described improved child and family quality of life.¹³ For example, parents have described value for both the child and the family to be able to participate more in the community. Some have described problems in relation to gastrostomy, such as inadequate information, the burdensome nature of the feeding equipment, and their need for strong advocacy if there were equipment problems.¹³

A new resource for supporting parents

Parents need to learn a unique skillset, including methods of feeding and how to recognise and manage common problems, and to develop new routines and ways of living. Working in collaboration with Perth Children's Hospital, my team has developed an online resource known as Nourish. Nourish was based on caregiver reported needs for gastrostomy education. It was co-designed with parents and clinicians from Perth Children's Hospital, and with advice from other healthcare institutions around Australia. Nourish includes a series of videos and 'Ask and Do' exercises to support families in learning about gastrostomy. There are 3 modules that cover a variety of topics and stages along the

Why do physiotherapists need to know this?

1. To understand the complex health needs of children with severe neurodevelopmental impairments and how different health issues may affect child and family wellbeing.
2. To inform considerations for how activity and community participation are compatible with gastrostomy and other forms of enteral feeding.
3. To be able to connect parent caregivers and support workers with available information.



Artwork by Nada Murphy, presented in Nourish.

way: 'Learn & Decide', where parents share their experiences; 'First Steps in Hospital', which offers insights into the gastrostomy procedure and what happens next; and, finally, 'Living Well with Gastrostomy'.

Find Nourish here: <https://ddwa.org.au/online-learning/nourish-with-gastrostomy-outline/>

Parents and clinicians use Nourish together, to support clinical counselling and training, and in telehealth consultations to train and support parents who live in rural communities and for whom attending the hospital is difficult. Nourish is unique because it was made by families and for families, with clinical support, and based on evidence from research. For one mother, the new resource and support have been life changing, illustrating that quality of life is a critical focus of management.

» Nourish helps families to make an informed choice as to whether a gastrostomy will be suitable for their child. It takes a 3-pronged approach. It promotes awareness, it provides a full picture of the gastrostomy journey, and it shows practical steps and tips that make living with a gastrostomy easier. For our family, these are all important considerations because we want our child and our family to live well.«

Artwork by Nada Murphy, presented in Nourish

En komplet referenceliste findes på side 32.

