

MEDIA RELEASE



Government of South Australia
Children, Youth and Women's
Health Service

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Food for thought: Parents' experiences of their child's tube-feeding

Mealtimes are everyday events for children and families and should be happy stress-free times. However, some children need special help with food and are fed via a tube. We know a lot about medical ways to help these children, but little about how their parents manage tube feeding.

A study was conducted at the Women's and Children's Hospital involving interviews with 34 parents of children who require tube feeding. These parents were asked about their experiences when their children were tube-fed.

The children had a variety of medical conditions such as severe reflux and major problems with swallowing that prevented normal eating and drinking. Instead, their nutrition was provided by formula given either through a tube in the nose into the stomach (nasogastric) or a tube directly into the stomach (gastrostomy).

Prof Philip Darbyshire, Head of Nursing and Midwifery Research and Practice Development at the Hospital says that the public scrutiny parents faced, when going out in public with their child, was a traumatic issue for many.

"Parents described problems with the equipment such as leakage and tubes falling out, and having to feed the child constantly throughout the day and night," Prof Darbyshire said.

"These were difficult issues to manage, but the biggest problems were often the attitudes and behaviours of the public. A simple shopping trip could become a distressing event. People would stare or laugh at the child, comment on their tube, and even ask what the tube was for or why they were taking a child like that out in public.

"Parents became reluctant to do normal, everyday things in life and were left feeling extremely vulnerable and angry.

"This study provides 'food for thought' about these parents and their children who deserve greater understanding. By raising public awareness of tube feeding and its importance, we hope to alleviate some of the stress these families have to endure," Prof Darbyshire said.

Parents wanting more information can contact Dr Jenny Fereday at the Women's and Children's Hospital on 8161 6488.

To organise interviews please contact:

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