

**THE WOMEN'S AND CHILDREN'S HOSPITAL  
HOME ENTERAL NUTRITION SERVICE:**

**THE SUPPORTING ROLE IT PLAYS FOR THE  
CHILD, PARENT AND CAREGIVER**

**DANA WRIGHT**

**RN, BNg, Grad. Cert. Health (CCAFHN)  
Clinical Nurse - Home Enteral Nutrition Service  
Women's and Children's Hospital, Adelaide.**

Until recently, nutritional balance and rehabilitation of children with certain chronic medical conditions was only able to be achieved with long periods of hospitalisation. With the development of new endoscopic techniques (such as percutaneous endoscopic gastrostomy), parent education programmes, follow up and support by a home enteral nutrition nurse and the latest home feeding equipment, our Home Enteral Nutrition Service (HENS) is made possible.

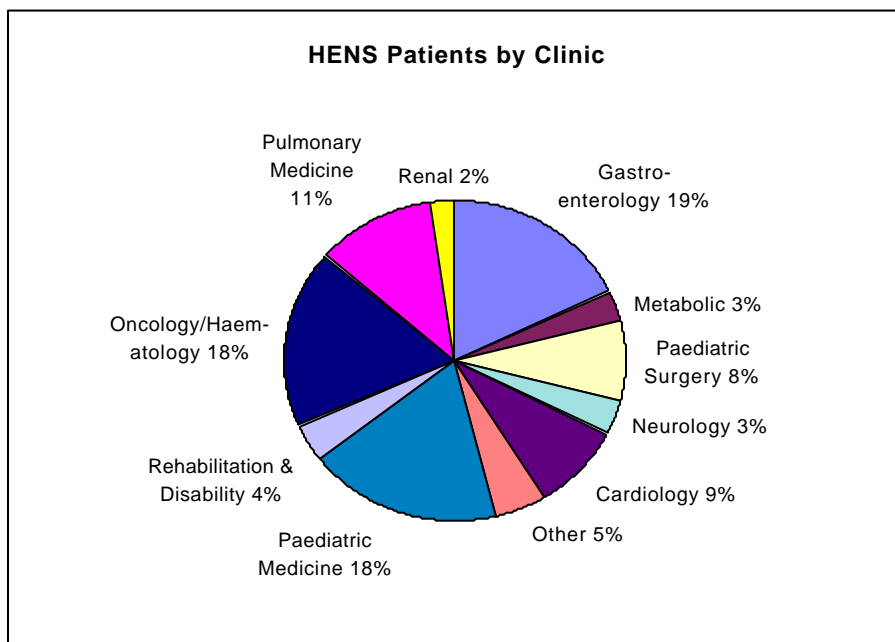
The main indications for home enteral nutrition are conditions which lead to failure to thrive, such as cerebral palsy, cystic fibrosis, malignancies, metabolic disorders and various major congenital abnormalities. Australian figures regarding the number of children using home enteral nutrition are not available, however the estimated growth rate across all ages in the United States and the United Kingdom is 20-25% per year (1) and children make up approximately 30% of this population. This paper will look at the service in general, look at statistics relevant to our client groups and results of our satisfaction surveys. It will conclude by discussing two major achievements of the service over the last twelve months, the setting up of a support group for gastrostomy families and the making of an information video.

The Australian Society for Parenteral and Enteral Nutrition (Auspen) have recently developed clinical practice guidelines for Home Enteral Nutrition and recommend use of a multidisciplinary team to provide best patient care. (2) This results in decreased complications, better attainment of nutritional goals and is more cost effective (3,4).

Prior to the HENS service in Adelaide in 1996, background research showed the child and family were submitted to long periods of hospitalisation, often with poor discharge planning and frequent readmissions or outpatient visits. (5) Education was adhoc and lacking a co-ordination of services. The service was set up in 1996 through an ambulatory care project grant from the South Australian Health Commission. The service has since become hospital funded. It now provides a unique service that includes a multidisciplinary team, comprising a specialist clinical nurse, gastroenterologist and dietitian, all whom work with the child's primary physician. They also work with other allied health staff, such as social workers, stomal therapists, outside agencies like district nursing, general practitioners and Child and Youth Health nurses. The team see all children who are to go home on enteral feeds, either via nasogastric tube or gastrostomy device.

The objectives of the service are to provide earlier discharge, prevent readmission, maintain nutrition in the home environment and provide a normal lifestyle, optimal education for the family, reduce cost to the family, provide a coordinated multidisciplinary approach and increase standards of care of enteral nutrition. As part of the setting up process, a database was established for HENS patients and has enabled the service to keep up-to-date, accurate statistics. Over a three-year period it can be seen that the main users of enteral nutrition have been Gastroenterology, General Medicine, Pulmonary Medicine, Cardiology, Paediatric Surgery and Oncology. It has become obvious, particularly over the last twelve months, that Oncology are increasingly using enteral nutrition in their children albeit on a short term basis, usually while going through chemotherapy treatments (Figure 1).

Figure 1. Referral patterns by patient clinic (Home Enteral Nutrition Service Database, W&CH)



The age groups depicted show an age that the child commenced on feeds and the one- to five-year old makes up a large proportion of home enteral feeders (Figure 2). It can also be seen that the length of time a child was on feeds for the majority was short term, one to two months, or the very long term, greater than twelve months. It can be assumed that a large proportion of the children who are in the greater than twelve month category would still be using enteral nutrition and continue to do so for a long period of their lifetime (Figure 3).

Figure 2. Breakdown of patients by age (Home Enteral Nutrition Service Database, W&CH)

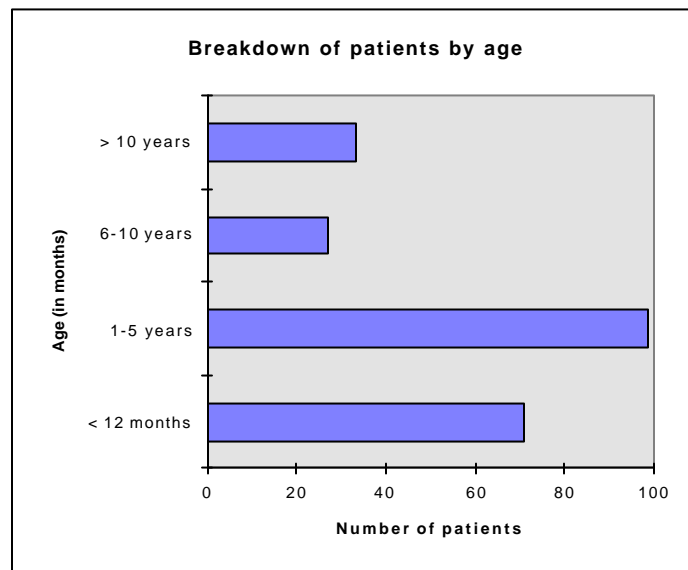
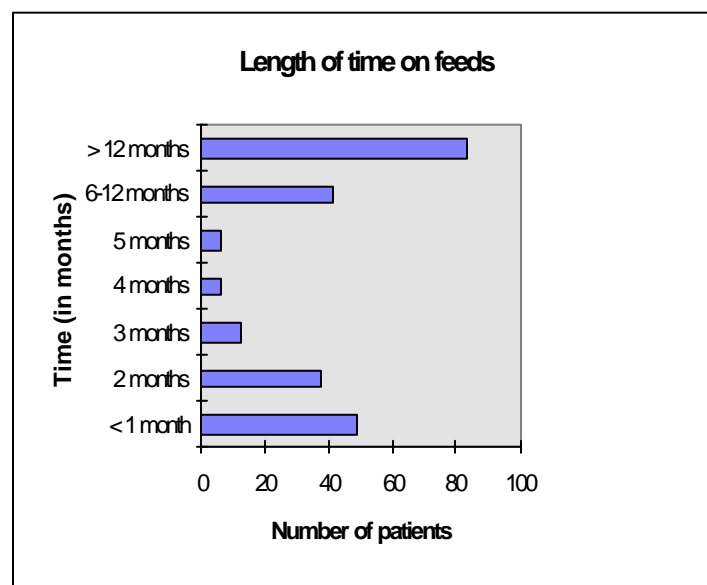


Figure 3. Length of time patient received home enteral nutrition (Home Enteral Nutrition Service Database, W&CH)



The services we provided can be broken up into inpatient and outpatient. Inpatient services take on a coordinating role regarding all aspects of discharge planning, in conjunction with ward staff and other multidisciplinary staff which includes education, support and counselling, patient care, providing discharge equipment and preparation for home follow up as required. Other services include gastroenterology and dietetic consultation and inservice to hospital staff.

The nurse plays a large role in relation to outpatient services, include regular follow up by phone call, home visiting and outpatient clinic appointment. Support can vary widely from small things such as where to obtain a piece of equipment, reinserting a nasogastric tube or gastrostomy skin care, to complex issues needing referral back to the surgeon or other relevant health professional. The service liaises with outside agencies acting as an advocate for the family which may include issues such as gaining financial assistance, helping with child care and schooling issues, or arranging referral to allied health in the community. As experts in paediatric enteral feeding the service also acts as a resource to outside agencies.

As both a quality improvement exercise and qualitative measure satisfaction surveys were used to assess the quality of care of the patient and family receiving enteral nutrition, by measuring the level of satisfaction with the care provided. Surveys were sent out 3 month after the child had been discharge from hospital on feeds as this was felt to be a good length of time for the family to reflect and assess the service. The response rate was around 60%. The results were looked at on a continuing basis and tend to show a similar pattern of information. Discharge preparation was seen as providing good discharge planning, adequate information and time to learn. Parents or caregivers felt confident on discharge and the service was seen as very supportive. The few negative comments fed back were used to positively influence and improve the service. Some common themes were a lack of knowledge by ward staff regarding feeding equipment and one family not feeling ready for discharge (5).

The home services section was seen by families as a very important, necessary resource which gave the families confidence, was less time consuming and less stressful than always coming into hospital. Follow-up was described as excellent. Some of the comments by parents highlighted were that they felt happy because they were contacting someone who knew their child's condition and history, thus not having to repeat 'their story' each time to a different person and building up a trust with the staff over time that led them to feel confident to learn different procedures, such as inserting their own child's nasogastric tubes. Negative comments tended to pool around a small number being lost in the follow up processes and has led to tighter follow up protocols (5).

As a follow on from this, the service felt it was important to explore this area further through a research project. This project is still very much in the planning stages but hopes to be up and running by early in the year 2000. More needs to be known, not just about whether or not parents are satisfied with the service, but what were the parents' and the child's experiences and perceptions relating to their home enteral nutrition. There is a large body of literature relating to the nutritional, medical and surgical benefits of enteral nutrition, but very few studies have looked at the 'every day' experiences the child and family undergo. The hospital thinks it is doing the best thing by the child and family and see it as something positive but something that should often be asked by health professionals is, 'Do the parents think of this as a positive change in their families life?'. It is hoped that this research will answer many of our thoughts and perceptions and broaden our knowledge and understanding as health professionals.

The nursing role plays a major role within the service and this has been highlighted particularly in the last 12 months with two achievements that have taken place to support the families of our service - the commencement of a support group and the production of an information video.

The Gastrostomy Information and Support Society (GISS) has been active in Victoria for a number of years and it was strongly felt by our service that there needed to be a similar set-up in South Australia, particularly for paediatric families whose supports seem to be lacking greatly. In conjunction with GISS - Victoria and Abbott Australia in our state, the Home Enteral Nutrition Service has played a major role in setting up GISS - SA which now has a large paediatric membership (both families, caregivers and health professionals) and active membership participation at meetings. It has filled a void in the community that now provides regular information evenings and available resources out in the community to assist children and families living with a gastrostomy, thus supporting them to achieve the best quality of life for their whole family.

Secondly, this year saw the creation of a teaching video relating to gastrostomies, designed specifically as a pre-operative information tool for parents as well as health professionals. The need for this video became obvious when a special interest group of parents was formed through the hospital project - Babies and children with eating and feeding difficulties. (6) It soon became obvious that many of our families were involved in this group and one of the needs that shone out was for a video like this to be produced. Miraculously the funds became available and our service, in conjunction with the project coordinator had a large input in the making of this video. It is something the service is very proud of as many of our parents and their children star in it, as well as health professionals from around the state. It is now available for purchase through the Women's and Children's Hospital Health Information Centre and has already sparked interest from health teams in the United States, as such a video is very rare and hard to find anywhere.

So to summarise, the Home Enteral Nutrition Service feels that enteral nutrition is an important area in paediatric care and that a home enteral nutrition service provides a more normal lifestyle for these families, thus empowering them to play a more active part in their child's health care. A successful multidisciplinary team can provide good nutritional support, while keeping the family unit together.

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# ‘FAMILIES FIRST - A SUPPORT NETWORK FOR FAMILIES RAISING CHILDREN IN NSW’

**DIANNE HUDSON**  
**Program Manager, Families First**  
**The NSW Cabinet Office**

Thank you for the opportunity to tell you about Families First.

I am responsible for coordinating the development and implementation of Families First which is a major commitment by the NSW Government to primary prevention and early intervention.

At heart, Families First in NSW is about coordinating existing support and expanding services for families to provide the best support possible to children during their first 3 years.

Today I will give you an overview of Families First, focusing on:

- what Families First is trying to achieve for families
- why have Families First
- *its features*
- the changes needed to how we support families
- the forward direction for Families First.

## **What is Families First trying to achieve for families?**

Families First is about helping all parents to give their children a good start in life. It is a strategy that focuses on improving the environment for children aged 0-3; ensuring that families are fully supported during these years, thus enabling them to nurture their child as fully as possible. It is also about supporting families during their children’s early primary school years.

We want to do this by increasing the effectiveness of prevention and early intervention services. Families First acknowledges that parenting can be a tough job and that all families, at various points in time, need information and support.

Families First has a strategic vision. It is designed to achieve a number of outcomes, covering a number of domains. Many of these outcomes can only be evaluated over 10-15 years.

The outcomes are:

- ⇒ healthier children and parents
- ⇒ better functioning families who are able to enjoy and learn from one another
- ⇒ children who are better prepared to learn and develop when they start school
- ⇒ reduction in the conditions that lead to mental health problems in children (such as conduct disorder)