

The parent's perspective

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The present paper gives an insight from a parent's perspective into the roles of health professionals and service providers in the daily management of a child with complex needs that include enteral feeding. It focuses on the case of a 9-year-old boy and discusses some aspects of his diagnosis and treatment, and the support received. It highlights the need for a multi-agency approach based around the child, in which parents are consulted, the opinions of professionals from the different disciplines are valued by other professionals and professionals do not issue conflicting advice but share knowledge before giving advice. There should be national accessibility to support services and a standardised training programme for carers. Better communication between parents, carers, health professionals and service providers and working together can reduce the stress for the patient and carer, and put less strain on much-needed resources.

Enteral feeding: Daily management and support: Multi-agency approach

The author is married with two children, one of whom is a 9-year-old boy with complex needs. He cannot walk or talk, has microcephaly, global developmental delay, has medication to control seizures, is in a wheelchair and is enterally fed by gastrostomy tube. The child attends a special school and is one of 20–30% of children whose special needs are undiagnosed.

When he was born the child had hypoxia, had fits on the first day and went into special care. There was a 50% chance of the fits recurring, but it was not known at the time that it was hospital policy to inform parents only if they request information. This situation raises many questions, for example: how do parents know when to ask for information? should the professionals provide the information? does not providing the information mislead parents? how will parents react when told? The judgement should come from the professionals, based on their experience. Parents often feel that they have not been given enough information, or sometimes the situation can be so overwhelming that perhaps there is a need to set aside some additional time for a discussion with the parents.

The need for more inter-professional communication

When the child was taken home, the parents were not aware of any problems. Subsequently, he cried at night and screamed when travelling anywhere by car. He was then a few months old. The health visitor had concerns and tried

on three occasions to refer the child, but the general practitioner (GP) did not consider referral to be necessary. It was not until a routine check with the paediatric consultant at the age of 6 months (normal procedure for babies with problems at birth) that he was admitted to hospital for investigation.

This situation is an example of how differences among professionals can create barriers and delays in diagnosing problems. The position could have been improved by better communication between health professionals and an acknowledgement by the various professionals of their individual specialist areas. Each professional's expertise needs to be recognised by other health professionals. The health visitor has an expertise in child development, whereas that of the GP is wider and relates to a broader age range. Health visitors and other professionals in a similar position should be able to refer a patient either to another GP or bypass the GP and refer the patient directly to a paediatrician, thus avoiding unnecessary delay and reducing the stress for the parents. A similar situation, also requiring better inter-professional cooperation, arose subsequently in meetings with the dietitian and the speech and language therapists, and is discussed later (see p. 341).

Training in enteral feeding

On admission to hospital the child was still not feeding well, consuming ≤ 30 ml (1 oz) milk, which is much lower

than the normal intake. However, the various test results, including the pH reflux test (which measures the amount of backward flow or reflux of food and acid from the stomach into the oesophagus), were negative and no reason was given for his vomiting or his failure to thrive.

A naso-gastric tube was inserted and during the many weeks in hospital the parents had their first contact with the procedure of enteral feeding. The introduction to the procedure was gradual, at first being allowed to hold the gravity feed and then becoming more involved, including performing the litmus paper test, transferring the milk into the gravity feed and eventually being given advice on how to prepare the milk, add thickener to try and prevent the vomiting, sterilise equipment, etc. No formal training was provided and the parents were not informed that their son would be discharged with a naso-gastric tube in place (as well as having fits five to eight times daily, which commenced after a few weeks in hospital).

It is apparent that there is no standard formal training programme in enteral feeding available to parents, there are no national guidelines for training and the information that is provided about feeding is variable. Carers appear to receive different levels of 'training'. In the present case 'training' was introduced gradually (although the information seemed to change with each nursing shift), with slightly more formalised training becoming available once a pump had been provided by a homecare company. This training was provided by a community paediatric nurse, who produced a set of notes to follow and a questionnaire to complete to establish competency. In contrast, carers in other parts of the country have been offered a more formal certificated 3 d training course. This inconsistency in the availability and quality of training highlights the need for a standardised nationally-available programme that includes current guidelines and product information.

Discharge planning

The first experience of discharge planning was limited to the discharge sheet and speaking to a discharge planner who provided a (out-of-date) list of nurseries obtained from Social Services, with no information about which nurseries (if any) could look after a child requiring enteral feeding. Eventually, after negotiation, a nursery was found that was willing to have its staff trained in enteral feeding by the community paediatric nurse. However, 2 years later it was discovered that the hospital has a nursery with special needs nursery nurses capable of administering tube feeding.

Although there seems to have been some improvement in the system, there are still carers who are not familiar with discharge planning. Since many parents have limited knowledge of the services available to them, the discharge planner would seem to be an ideal initial point of contact and source of information. For example, support groups, such as Patients on Intravenous Naso-gastric and Nutrition Therapy (PINNT; see Appendix), should be promoted, as they enable parents to meet other carers in the same situation, and they then 'feel normal'. In the present case

PINNT was not encountered until several months after discharge.

Initially, there were also problems in obtaining equipment (gravity feeds, syringes etc.), as information about suppliers was not provided. The GP was therefore approached and a prescription was made out for the pharmacist, who tried to contact the Medical Devices Agency to establish the cost. It had not been explained that the equipment could be ordered and collected from the hospital or that it could be ordered via the community paediatric nurse. A standard regularly-updated information pack should be made available for parents, in which they could hold useful information and add any other relevant information for their child. Basic contact details should be included, such as those for the GP, health visitors, consultants, hospital and Child Development Centres, as well as support groups, and information about where to obtain enteral feeding equipment, syringes etc. It would also be useful to have the pack available nationally, with local information being provided by local support groups, such as the Princess Royal Trust for Carers groups.

Childcare Information Services should also be able to keep records of which nurseries, childminders and out-of-school-hours projects have special needs nursery nurses or learning disability nurses. While these services all claim to provide places for disabled children, the picture changes when 'enteral feeding' is mentioned, and places can be withdrawn. More staff must be trained to administer enteral feeding so that such children can fulfil the government's inclusion policies, and to enable this training to be undertaken more funding needs to be made available.

Home and community

Community paediatric nurses

When the child was discharged and at home the parents were put in contact with the community paediatric nurse, who had short-term funding and trained the parents and the staff at the local hospital in enteral feeding. This service is vital for parents, and should not be available on the basis of a short-term contract; it should be a standard accessible service. Nursing staff and equipment need to be made available in the community to enable patients to lead a more normal life.

There have been many local reports of problems in emergencies associated with the detachment of the gastrostomy tube. In this situation the instructions are to contact the emergency ambulance service and ask to be taken to the local Children's Hospital. However, if ambulance personnel have been instructed to take patients to the nearest hospital and the hospital staff are unable to deal with the gastrostomy tubes, a second ambulance may be required. This situation can be very stressful, particularly when parents are told that the gastrostomy tube needs to be replaced within 2 h of becoming detached. In the present case the parents have learned to replace the gastrostomy tube; however, other parents have not necessarily been trained, or have not wanted to be trained, but they should be given the opportunity.

Home care and home delivery

In the present case the equipment was initially supplied by the hospital and was subsequently obtained from the school nurse, who collected it from the local hospital. Currently, equipment is supplied by both the homecare company and the school nurse.

After a tiring few years of making and administering the feeds (over a period of 1.5 h; no explanation had been given about how quickly the feed should pass down a gravity feed), it was a relief to find that pumps are available. The pump and the monthly equipment supply (containers and connectors), as well as prepared feed, are now delivered by the homecare company. Generally, this system works well; the company contacts the parents to confirm details of their requirements.

One particularly difficult time has been the Christmas period. As the homecare company are closed for 2 weeks they require two prescriptions in order to provide sufficient feed and equipment for this period. An oversight at the GP's surgery resulted in only one prescription being provided; another example of the need for communication, where perhaps it would have been appropriate for the surgery to contact the parent.

Homecare provision: PINNT/Novartis survey

PINNT/Novartis (2000) have published the results of a recent survey of patients' satisfaction with enteral homecare services. The responses to questions about delivery services and homecare coordinators have indicated that the majority of patients (92–93%) are satisfied. Such positive responses indicate that parents are receiving an acceptable service, which is particularly important because it is just one of the many aspects of the patient's care that must be managed.

However, 7–8% of respondents have indicated that they are not satisfied and believe that delivery or service could be better. Such responses need to be considered not as negative comments but as situations that require solutions. Homecare companies could facilitate regular feedback from parents and patients by providing questionnaires at the point of delivery.

The survey has also shown that provision for enteral feeding can vary nationally. Deliveries of equipment can be made by different sources (nurses, pharmacies, homecare companies, schools, etc.) or a combination of sources.

Although it is evident that the different participants in the enteral homecare service appear to interact well with patients and parents, there are also cases where the individuals involved need to work together, or actively encourage feedback to improve the service.

Multi-agency working: a holistic approach with patient and carer

One of the ways forward, particularly if a child has complex needs, is a multi-agency approach, which involves all the professionals meeting with the parent and child at one location (or at least at one meeting). This procedure reduces time and travel, and also allows the professionals

to share information. Currently, this approach is being promoted by the development of the 'Team-around-the-Child' model (Limbrick, 2001) to help support disabled children and their families. For children and patients requiring enteral feeding the PINNT/Novartis survey (PINNT/Novartis, 2000) has shown that although generally the professionals, providers and carers work together, there are still gaps or failures in communication.

It is important that professionals consider the parents and their needs as well as those of the special needs child. A holistic approach (i.e. investigating all physical, intellectual and emotional needs) is required for both the child and the carer. Health professionals need to be aware that parents of children with complex needs can experience considerable stress, and do not necessarily have adequate respite.

Intercommunication not conflict!

The multi-agency approach can facilitate increased communication between professionals and reduce the amount of conflicting advice that may otherwise be given. In the present case the parents attended a Child Development Centre, where meetings were regularly held for all the staff, but the health professionals were seen individually. An outcome of this situation was that while the dietitian emphasised the provision of energy, the speech and language therapist recommended a correct approach to feeding (which could represent only four spoonfuls). Faced with conflicting advice (feed or starve) the parents compromised and fed their son orally, 'topping up' with enteral feeds. At the individual meetings the professionals expressed concern about the parents' decisions. However, the situation was resolved by a meeting that involved the parents, the dietitian and the speech and language therapist; again, a good case for inter-professional communication. Thus, a solution would be for health professionals to encourage regular feedback, rather than relying on an annual review.

Parents, professionals and homecare companies also need to work together. For example, the dietitian does not necessarily have information about the various feeds and equipment provided by the homecare companies. This information may be available to the parents through support groups such as PINNT, as support group meetings facilitate information exchange and networking for parents, patients and professionals (parents are always advised to consult their health practitioners before acting on such information). On the other hand, some homecare companies have information help lines, but will only provide the information to dietitians, not to parents.

Suggested improvements

National guidelines for enteral feeding, such as those provided by the Clinical Resource Efficiency Support Team (2004; see Appendix), are now available for adults, and should be extended to children (guidelines for children should be available in 2005). These guidelines should be accessible to parents as well as health professionals.

The value of support groups such as PINNT should be more widely recognised and they should receive support (e.g. financial support, provision of meeting venues or attendance by health professionals to facilitate feedback).

The suppliers of feeds and equipment and the health professionals should encourage feedback and should work together with the parents or carers to provide solutions to any problems that may be identified. The supply and delivery of feeds and equipment needs to be more consistent throughout the country. Similarly, training in enteral feeding as well as in replacing naso-gastric tubes or gastrostomy tubes should be made available to parents, if required, in the form of a national training programme.

Guidelines for avoiding infection should be promoted, e.g. washing and sterilising equipment in hospitals as well as in the home. In the present case salmonella infection was contracted during some of the early admissions to hospital as a result of inadequate procedures for cleaning and sterilising equipment, highlighting the need for careful attention to all potential sources of infection.

'I am a carer'

Health professionals should be more aware of the pressures of being a carer and should be encouraged to adopt an appropriate manner. For example, although the local GP surgery advises carers to identify themselves, the staff have not received any training in how to interact with carers. Some basic training in understanding the role of carers would be beneficial, e.g. an opportunity for staff at the surgery to meet carers and discuss their situation.

Tip of the iceberg

The need to provide enteral feeding is just one of many issues faced by the parent carer; other issues include: the disability living allowance; benefits; bills; education; blue badge membership for disability driving; motability vehicles; paperwork; beds; appointments with GP and hospitals; siblings, who often act as young carers; housework; being a working carer. In addition, there is the need to have some leisure time.

With all these issues requiring attention, it is understandable that many carers can present with concerns about their mental health; many are prescribed anti-depressants and β -blockers. However, medication is not the only solution; support should be offered in the form of, for example, counselling, respite care, more play schemes, health walks (simple exercises such as walks have been shown to be beneficial to health, including depression. See Countryside Agency website for details of health walks around the country, www.countryside.gov.uk) and access to leisure activities and support groups. The Office for National Statistics (Maher & Green, 2002) has published information about carers ('people who are looking after, or providing some regular service for a sick, disabled or elderly person living in their own or another household') collected from the General Household Survey of 2000. It was found that among the carers of working age who are providing care for ≥ 20 h/week approximately half are also working, half have a longstanding illness and 39% report

that caring has affected their physical or mental health. A follow-up study by the Office for National Statistics (Singleton *et al.* 2002), which has provided information about the mental health of carers, shows that 6% of working carers have considerable problems with work, 33% of carers have experienced depression and 8% report that caring has had a direct impact on their physical health. It is very important, therefore, that all professionals, working together, consider the needs of both patients and carers.

Work together to make a difference

The management of care for a child with enteral feeding requirements can involve a range of professionals who may offer different advice. There is a need for a multi-agency approach based around the child, in which parents are consulted, the opinions of professionals from the different disciplines are valued by other professionals and professionals do not issue conflicting advice but share knowledge before giving advice. By working together to provide medical advice, discharge planning, delivery of services, the provision of feeds and equipment, and training in procedures it should be possible to achieve consistency, efficiency and economies, reduce the stress experienced by the patient and the parent, and thus put less strain on much-needed resources. It is apparent from experience of being a parent and carer that professionals, homecare companies and parents and carers need to work together to make a difference.

References

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Appendix

Information on support networks

Patients on Intravenous Naso-gastric and Nutrition Therapy (PINNT). PINNT is a support group for individuals who are tube fed. It aims to promote greater understanding of the therapies among patients, potential patients and the medical profession, as well as providing contact between patients, to try and eliminate some of the

problems that arise with treatment, and encourages membership of the group by all patients, parents or carers and health professionals. Further information and membership details can be obtained from PINNT, PO Box 3126, Christchurch, Dorset BH23 2XS, UK; email pinnt@dial.pipex.com or website www.pinnt.com

Clinical Resource Efficiency Support Team (CREST). CREST is a small team of healthcare professionals established through the Central Medical Advisory Committee in 1988. It aims to promote clinical efficiency in the Health Service in Northern Ireland. CREST Secretariat, Room D1 Castle Buildings, Stormont BT4 3SQ, UK; www.crestni.org.uk

Princess Royal Trust for Carers Network. The Princess Royal Trust for Carers was formed in 1991 at the initiative of Her Royal Highness The Princess Royal. The Trust provides training and support for Carers Centres, as well as raising funds for development work and is the largest provider of comprehensive carers' support services in the UK. Through its unique network of 118 independently-managed Carers' Centres, young carers services and interactive website www.carers.org, the Trust provides quality information, advice and support services to 180 000 carers including 10 300 young carers. The Princess Royal Trust for Carers, 30 George Street, Glasgow G2 1LH, UK; www.carers.org/home/

