

Information and Advice Provision for Parents and Carers of Nasogastric and Gastrostomy Fed Children

**Key Research Findings
August 2007**

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Executive Summary

Research Aim

- Research was undertaken to establish the information and advice requirements of parents and carers of children with nasogastric or gastrostomy tube feeding and to identify where gaps in information provision exist.

Methodology

- A qualitative methodology consisting of 10 in-depth interviews with parents and carers of tube-fed children was utilised, with a sample design based along geographic lines. Additional criteria were imposed to ensure a mix of age and, where possible, feeding type.

Main Findings

Key findings were as follows:

1. *Range of Tools*

- Information and advice was found to be delivered to parents in a number of forms with visual information being deemed particularly helpful – parents were reassured by being able to observe correct procedure or problem-solving.
- There was a clear need for simply worded, comprehensible written information.
- Technical information – mainly from manufacturers of nasogastric and gastrostomy equipment - was not perceived to be as beneficial, largely due to its formal tone and volume. This reduced its usability – unless experiencing specific mechanical problems.

2. *Consistency*

- Consistency of advice and training was of concern to many, specifically the difference between training and advice from the hospital and that provided by Community Nurses.
- This caused unnecessary stress for some parents as re-training by Community Nurse was required – causing confusion.
- Reasons for these differences in training need to be communicated to parents to diminish underlying worries regarding quality and accuracy of hospital advice.

3. *Value Attached to Nurses*

- Amongst the parents, a huge groundswell of respect and admiration for Community Nurses. In most cases parents perceived their Nurse as the main provider of advice, information and guidance in all situations relating to tube-feeding their child. All other sources were regarded as secondary – and consequently are perceived of lesser value

4. Parent Typologies

- Three parent types were evident which impacted on their attitudes to information and advice: The “Information Hungry”, The “Get on With Its”, and The “Passive Acceptors”:

- The “Information Hungry”:
 - Gather information from a number of sources
 - Likely to be part of a support group / met parents in similar situations
 - Use Internet to access up-to-date information about child’s condition
 - However, their hunger for information can often make them overly critical of written communications from the hospital, which they routinely perceive as inadequate.

- The “Get on With Its”:
 - Accept all information and advice given
 - Not likely to pro-actively search for additional information
 - May know others in similar situation but lack time to meet up with them
 - Less likely to be aware of new developments unless informed by their Nurse
 - Efficiency means that positive perceptions of previous information and advice linked to clarity and usefulness of advice received

- The “Passive Acceptors”:
 - Rely on Paediatric Nurse for help and advice – first port of call at all times
 - More likely to call hospital out of hours
 - Passively accept all information and advice – do not question
 - Will not actively seek out any other information
 - Do not know anyone else in similar position
 - More likely to be satisfied with all advice and guidance received – see no gaps in provision.

5. Opportunities for Parental Support

- When parents feel better equipped to deal with potential problems and issues that may arise, the more confident they are with the feeding regime. Consequently a significant amount of adequate and accurate information is required prior to initiation of feeding regime – and in the early days
- When parents have become well acquainted with the regime, less information appears to be required – although ongoing visits and enquiries – as always – are still necessary.

1. Introduction and Background

NHS Quality Improvement Scotland (NHS QIS) was established as a Special Health Board by the Scottish Executive in 2003. It was established to act as a lead organisation in improving the quality of healthcare delivered by NHS Scotland (NHSS). The role of NHS QIS is to:

- Report to the public on the performance of NHSS
- Support and facilitate NHSS in improving the quality of care and treatment patients receive

In order to identify and inform clinical improvement priorities to be addressed by the Practice Development Unit (PDU) within NHS QIS, consultation and engagement processes are conducted involving the Nursing, Midwifery and Allied Health Professions (AHPs) Practice Development Networks. As a result of this activity, information and advice provision for parents and carers of children with nasogastric or gastrostomy tube feeding was highlighted as a priority.

An existing Best Practice Statement (BPS) for clinical staff in the area of nasogastric and gastrostomy tube feeding cites research undertaken by Townsley and Robinson¹ in 2000 that highlights a lack of information on the effects of tube feeding on children and their families. The BPS stresses the paramount importance of ongoing assessment to establish the abilities of the child, the parents and carers in managing nasogastric or gastrostomy tube feeding in the home setting.

In light of a review of the above BPS and the identification of information and advice provision for parents and carers as a priority, the PDU commissioned Progressive to undertake a small research study with the primary objective of establishing the information and advice requirements of parents and carers of children with nasogastric or gastrostomy tube feeding and identifying the gaps that there may be in the provision of such information.

Gaining a comprehensive picture of parents' and carers' requirements in relation to nasogastric and gastrostomy tube feeding involved taking into consideration a number of factors pertinent to the delivery of such advice and care, such as:

- The availability and consistency of information across different geographical settings, particularly in relation to parents' and carers' proximity to specialist healthcare units and the information requirements needed
 - This included any issues relating to rural vs. urban settings
- The parents' and carers' personal position regarding their child's requirements - e.g. children requiring such feeding tools for short-term following birth vs. those who require them for a longer time period
- The potentially sensitive subject matter

The following key findings report presents the conclusions obtained from the research. It should be noted that this key findings report details parents' own perceptions of advice and information they have received from a variety of health-related sources. It is not a comprehensive report on the actual advice and information that may be available in each health board area included in the research.

Progressive and NHS Quality Improvement Scotland would like to thank all Community Paediatric Nurses and parents who contributed to the research and made the project possible.

1. Townsley R, Robinson C. Food for Thought? Effective support for families caring for a child who is tube fed. Bristol: Norah Fry Research Centre; 2000.

2. Research Objectives

The overarching objective for the research was to establish the information and advice requirements of parents and carers of children with nasogastric or gastrostomy tube feeding and to identify where gaps in information provision exist.

Specific objectives were as follows:

- confirm the type of advice and guidance that parents and carers are currently receiving and the perceived value of this
- identify examples of good practice as considered by parents and carers
- ascertain what advice and guidance parents and carers would like to receive and how this information might best be presented.

3. Research Approach

3.1 Methodology

Due to the exploratory nature of the objectives, a qualitative approach was adopted for the research. This approach was the most appropriate given the requirement to understand the thought processes and reasoning behind carers' and parents' opinions as it allowed for the provision of rich diagnostic feedback.

Progressive conducted in-depth interviews - specifically couple/paired depth interviews as opposed to focus groups discussions. This methodology ensured a more intimate setting, enabling respondents to be more open and forthcoming than they might otherwise have been in a group scenario due to the potentially sensitive or upsetting nature of the discussion. Furthermore, it would have been difficult to arrange for a number of parents / carers of children who are currently being tube-fed to be brought together in a group situation given the issues they have had arranging home care, babysitting for other children and the long distance they may have had to travel to the group discussion venue.

The sample design was initially based along geographic lines and consisted of 4 paired depths in urban areas, 3 in semi-rural areas, and 3 in rural areas. Additional criteria were imposed upon the sample to ensure a mixture of ages of children and – where possible - feeding type.

3.2 Recruitment and Sample Selection

Two key facets of the nature of this research had particular influence on the recruitment of respondents, namely:

- The sensitivity of the subject matter
- Regulations regarding Data Protection of parents' and carers' details

Due to these factors, an informal approach to the recruitment process was adopted. Initial contact in terms of introducing Progressive and the research project to the respondents was made by support groups and professionals that work directly with parents and carers i.e. the Community Paediatric or Nutrition nurse. This ensured that personal information was not divulged to Progressive without permission and that potential respondents were confident that the research was endorsed by those they are familiar with in the hope of increasing credibility and encouraging participation. After being personally approached or contacted by letter by their respective nurses, those interested in participating were given the researchers details to call and arrangements were made for a mutually convenient date and time for the interview to take place.

Each in-depth interview lasted approximately 30mins-1½hrs - depending on the issues to be discussed - and digitally recorded for analysis purposes. Respondents were informed of the aforementioned at the recruitment stage and permission to record the discussion was sought prior to interviews taking place.

All interviews were conducted in February and March 2007.

3.3 Limitations of the Methodology

This qualitative methodology did have its limitations which led to a lengthy and complex recruitment process. Firstly Progressive had to wait until potential respondents had contacted Progressive due to data protection and research ethics issues. This lengthened the overall timescale originally proposed for the project. Secondly there was reluctance from some parents and carers to agree to take part in the research as experienced researchers did not have the opportunity to give a full explanation of the project first hand. Consequently, some contacts had to be spoken to on more than one occasion to address the concerns of potential respondents.

Further limitations of the methodology were highlighted during the actual depth interviews. Some parents found it difficult to articulate their feelings on the subject of information, advice and guidance they had been given mainly because their child had been tube-fed for a number of years and advice and information tended to be delivered at the initial stages. It is therefore recommended that any further research should include input from Community Nurses who deal with such parents on a weekly basis and can provide an overview of issues they are dealing with.

3.4 Topic Guide

A topic guide designed by Progressive was used to guide the depth discussion. A copy of this can be found in the Appendix. The discussions were captured on a digital recorder before being transcribed into a document post-interview.

3.5 Data Analysis

Our analysis began with the first depth – that is the analysis was done concurrently with the data collection. After the initial depths the project team debated the issues emerging from the discussions and identified key emerging themes as well as the influencing factors and drivers. Each subsequent depth thereafter was discussed and analysed amongst the project team and findings compared with earlier depths allowing identification of the main issues (within the context of the objectives) influencing factors on perceptions of these issues and the prevalence within different individual circumstances. This continuous analysis throughout ensured a more rounded approach in terms of qualitative analysis of a relatively small sample size.

Where appropriate, we have included quotes from parents. However we have not referenced these to a geographic area or child age. As per the Market Research Society Code of Conduct, all respondents were promised confidentiality and anonymity and due to the small sample size we felt that any reference to geographic location or age of the child could identify the family in question.

4. Main Findings

In this section of the report we will consider the key findings of the research including any differences between respondent types.

4.1 Factors that Impact upon Attitudes

The research exposed five main factors that impacted upon shaping attitudes and perceptions towards the information and advice parents had been exposed to regarding tube feeding. These were:

- Parental Type
- History / Background to Current Feeding Regime
- Age of Child
- Geography
- Presence of Support Group

4.1.1 Parental Typology

From the research three typologies were evident and attitudes and perceptions towards information and advice they had received from a variety of sources varied significantly between each typology.

The 'Information Hungry'

Parents falling into this typology were more likely to be within the upper socio-economic groupings, with both parents working, although the mother could possibly be working part-time. The child in question was likely to be their oldest and/or their only child.

We found these parents considered up-to-date information essential and they tended to actively seek out information regarding their child's condition. They were curious, inquisitive, assertive and likely to ask for a second opinion rather than passively accept any information given to them by health professionals:

"We found that the hospital knew very little about his condition, and couldn't answer all our questions... we had to go online to find out more...."

These parents also tended to be extremely organised and were able to refer to a number of files they had compiled during the research (in some cases dated by year and month) relating to their child's conditions, hospital visits and in-patient records.

These Information Hungry parents gathered their information and advice from a number of different sources with NHSS being only one of a range of sources they had accessed since their child's condition was diagnosed. The internet was used extensively to ensure they kept themselves up-to-date on their child's condition. Some parents accessed information from abroad regarding their child's specific issues – including tube-feeding.

In addition, in some cases the Information Hungry have actively searched for, and met new, parents in order to share their experiences with them and access further information. In some cases they may also be in a support group, looking to join one, or have even set one up.

All this searching and gathering information means that the Information Hungry had a great deal of knowledge regarding their child's condition. Consequently some tended to view information given to them by the hospital in the initial stages as inadequate due to the myriad of other information and advice they had accessed since.

With regards to their information and advice needs, these parents are generally happy to acquire information in all formats and from all sources. They are especially keen on detailed information and advice and appreciate being directed to other sources for advice and information and/or new support groups and parents in similar situations.

The "Get On With Its"

These parents are more likely to be in the C1 or C2 socio-economic group. They are busy efficient parents with the child in question having one or more siblings. Although they rely on the Community Nurse for help and advice, they have a tendency to largely cope with all issues to do with the child in question themselves.

Because of their busy lifestyles, they are less likely than the Information Hungry to proactively seek out information themselves. As such, they generally accept information and advice given to them with few questions and although they may know others in a similar position, it is unlikely that they make the time to meet up with them. Subsequently, knowledge of new products or information generally only comes to light when the Community Nurse informs them.

With regards to their information needs, they will usually only ask for advice when absolutely necessary, being of the opinion that they are well-equipped to cope with most circumstances themselves:

"We've been doing it so long now that it's second nature. We rarely have any problems"

This 'Get On With It' attitude means they are usually more than happy with all information they have been given in the past by all NHS sources.

The 'Passive Acceptors'

The Passive Acceptors are likely to be in the lower socio-economic group in a non-working household. They tend to live in urban areas and the child who is being tube-fed will have at least one sibling, although they are likely to have more.

Passive Acceptors have a tendency to rely entirely on the Community Nurse for help and advice and will be the first port of call when there is a problem. Parents within this typology are also the most likely to call the hospital out of hours regarding their child's condition. They accept all information and advice delivered without query, and generally will not take

action to obtain additional information from other sources. It is unlikely that they will know anyone in a similar position and consequently will not belong to, or intend to join, any support groups.

Passive Acceptors' character dictates a preference for face-to-face advice sessions to ensure all is well – and especially for training. They may be concerned about their own ability to articulate their concerns:

“To be honest, I never read the booklet. It was confusing and I didn't understand all the words”

Therefore clear and simply worded information is particularly appreciated. Demonstration videos worked well for this group as the visual back-up to understand how to solve feeding problems for example was deemed extremely useful by such parents:

“The video was good for my wife. She was nervous of cleaning the site and attaching”.

4.1.2 History / Background to Current Feeding Regime

The research discovered that the background to the child's current feeding regime also impacted upon parent's attitude to information, advice and guidance they had been exposed to.

We found that some parents had a long and detailed medical history regarding their child's feeding habits – which had always been difficult - and a gastrostomy was the final decision for a long term solution. These parents were so relieved that something was being done regarding this problem that they happily accepted and appreciated all information and advice from the hospital and their Community Nurse.

However amongst parents whose child's feeding issues were just another problem to add to a number of severe disabilities or illnesses their child was coping with, there was a need to know first and foremost how to deal with this latest issue. In addition due to the other illnesses / disabilities many of these parents wanted detailed information that addressed how this latest problem impacted on both them as parents and their child's other issues.

Finally, among parents who had recently been told that their child will probably never be able to feed normally again – usually younger children - reassurance was the most important thing:

“We've only recently been told that he will have to have a gastrostomy and that this is permanent.... But I have to say I have had little information about what this means in the future.... It's all a little scary just now...”

Information and advice that they were exposed to at this time needed to reassure that this new feeding regime would not be too disruptive. They were looking for information that clearly explained complexities to them and also reassured them that they had no need to worry. All information for these parents needed to satisfy and understand their emotional concerns at such a time:

“I needed something that told me everything that COULD happen and what to do about it, but in a reassuring manner”.

4.1.3 Age of the Child

It was also apparent from the research that the longer the child had been tube-fed, the less likely the parents seemed to be in need of information, guidance and advice. The tube-feeding routine had become so familiar to them that these parents were – by now – aware of all the potential problems that could arise. Consequently such parents had no immediate issues regarding information and advice and – linked to this – were less likely to recall any issues they had with information and advice they received in the initial stages of the current feeding regime:

“The booklet told us everything we needed to know. But after the first week or so I don’t think I ever looked at it again.”

Overall there was a sense among these parents that the regime had now become second nature to them and was just part of dealing with their child’s condition on a daily basis. Consequently they were less likely to require or refer to written forms of communication if they had any problems. If there were any tube or feed malfunctions, these parents know who to contact or what to do. Therefore the information and advice needs of those with a number of years experience of the feeding regime tended to be limited to updates on new equipment or new feed / feeding procedures.

4.1.4 Geography

For those parents living in rural areas, distance was spontaneously mentioned as a factor impacting on their information requirements. There were three main reasons given for this:

- Those who lived in a rural area had a longer journey to hospital when they had a tube feeding issue that needed hospitalisation. For these parents it was vitally important that they had the confidence to deal with a variety of possible tube feeding scenarios on their own.

- The lack of any support groups in the immediate vicinity. The majority of parents we spoke to had never participated in a support group and there was no awareness of any within the surrounding area. If the child was not yet of school age then parents were less likely to know others in similar situations and so had no one to share information or discuss specific issues or circumstances. The lack of a support group or just knowing others in a similar situation meant that such parents were more likely to rely on their Community Nurse for information and guidance.
- Reliance on the Community Nurse led to some parents feeling rather guilty – especially if they had telephoned the nurse on a few occasions within a short period of time. This has implications for ‘ideal’ written communications for those in rural areas as such parents need to be reassured that they need not worry about the number of times they contact their Community Nurse if they have any problems.

4.1.5 Presence of a Support Group

Access to a support group – both formal and informal - could also affect how parents perceived and used information and advice.

It is well-documented that support groups give parents the opportunity to air common concerns, teach each other fundamental coping skills and discuss valuable information. It is reassuring that others are facing equally difficult circumstances and viewed by those who use them as an ideal platform for much needed emotional support.

However, despite being deemed as incredibly helpful, the research did find evidence that support groups could also be the source of potential myths and rumours:

“It was only by meeting other parents that I found out that I could give him little bits of normal food....I was told he wasn’t allowed stuff like that.....”

If the parents have information and advice coming from a variety of different sources, nurses need to be assured that the information parents have received is accurate and suited to their own particular circumstances.

4.2 Advice and Guidance Currently Received

During the depth interviews all parents were asked about the advice and guidance they had received in the past – from all sources - regarding their child’s feeding regime. This may have been given when the procedure was first discussed, after a gastrostomy had been performed or nasogastric tube fitted, or after coming home with their child.

All parents spontaneously mentioned their Community Nurse as the main source of their information and advice:

“She’s the font of all knowledge – the first person I think of when I have a problem”

When further prompted, however, it was clear that parents had additionally been exposed to a variety of sources since they had begun their child’s current feeding regime. The main sources of information and advice were as follows:

- Videos
- Demonstration Dolls
- Written Communication
- Verbal Communication from Manufacturer
- Hospital Nursing Staff
- Community Nurses

These sources are discussed in more detail below:

4.2.1 Videos

A minority of parents received a video from the hospital following their child’s initial gastrostomy procedure. It covered information on how parents should take care of the site, potential problems they may experience during the feeding regime, and solutions illustrating how to overcome these obstacles.

The information in the video supported the training given in the hospital and parents watched it several times during the first few days home from hospital. The video was only mentioned by one set of rural parents but they felt it was beneficial as it eased their sense of isolation and fear of *“doing something wrong”*.

In addition, one family had made their own video detailing how their child’s feeding regime worked and what to do if there were any problems. This video was then copied and given to the child’s school, home carers and other members of the family who may be looking after the child in question at some point.

Overall, the video from the hospital was deemed extremely helpful by parents and thought to be particularly important to those living in a rural area where medical assistance may take longer to arrive. Being able to visually refer to correct procedure or solutions did much to reassure parents. In addition the video appeared to be more accessible and easier to refer to than written material, particularly when they needed to confirm they were conducting the procedure correctly or when experiencing difficulties. It was felt especially amongst the Passive Acceptors that a demonstration video was an excellent training resource.

4.2.2 Demonstration Doll

Some parents mentioned an adapted doll which had been used during discussions with the Community Nurse. The adaptations allowed the nurse to illustrate both what happens during gastrostomy surgery and afterwards and the demonstration itself tended to be carried out before the child's surgery. Parents who mentioned the doll felt it greatly assisted in making the explanation of the procedure more understandable and thus satisfied their need for reassurance before their child underwent surgery.

Unfortunately, although it was perceived as a useful informative resource, it was not a tool that could be referred to in times of difficulty once the child was being tube-fed, and it had little or no use to those who had been tube feeding for a number of years. Therefore the demonstration doll had limited value.

4.2.3 Written Communication

The parents who participated in the research had been exposed to a wide variety of written communications concerning their child's nasogastric or gastrostomy tube feeding in the form of booklets and leaflets.

As mentioned earlier, we found that with written communications the longer the current tube-feeding regime had been in place, the patchier the recall of the content and format of information they had received at that time.

"I vaguely remember what the hospital gave me. It was such a stressful time and he was only 6 weeks old."

The main reason for sparse recall was the time gap since the initial procedure, with the majority of written information and advice they had received being during the initial phase of the new feeding regime.

Even with patchy recall however, perceptions of the format, quality, content, and tone of the written information varied considerably.

Written Communication from the Hospital

Written communication from the hospital varied across hospitals, departments and health boards with little consistency. The format ranged from something as rudimentary as one sheet of photocopied A4 paper to professionally produced booklets.

Booklets produced by hospitals tended to have more detailed information regarding what to do when specific issues and problems were encountered, how to contact the hospital if necessary and most were illustrated with diagrams and pictures – this was considered slightly more helpful than the rudimentary A4 sheets.

Overall, most of these booklets and leaflets were mostly received positively by parents, with a general attitude that *'something is better than nothing'*, although shorter 1-2 page leaflets were felt to be rather scant and thus did little to cover all scenarios. Because they gave little advice regarding the myriad of potential problems and solutions they were perceived by some parents as being ineffectual, particularly in assisting parents in the first few weeks. The 'Information Hungry' parents were especially scathing regarding some of the hospital's written guidance.

The tone of these written communications also varied significantly. They ranged from friendly and simple leaflets / booklets to formal, stage-by-stage written procedures regarding cleaning and maintaining gastrostomy sites. When probed regarding preference, parental typologies were evident with the Information Hungry parents being attracted to more procedural, detailed formal communications whilst the Passive Acceptors much preferred simple clear instructions supported by clear images / pictures as for some the more complex, detailed information was simply confusing and incomprehensible.

Parents were asked how they felt these written communications had assisted overall. However what concerned parents most was that generally, leaving the hospital with a tube-fed child was a time of high anxiety for most of them and for most respondents, they felt that few written communications from the hospital neither adequately addressed their concerns and worries at this stage nor did they really attempt to reassure them. In fact, most parents felt that the majority of written communications from the hospital did little to reduce apprehension at all, focussing much more on correct procedure, problems or issues that may come up:

"I only got a sheet telling me about the checking position. It wasn't enough but what could I do?"

"They gave us a small leaflet and sent us on our way... looking back we didn't really have a clue..... we were so nervous of doing anything...."

Consequently much of the written information they received was considered to be lacking in substance and ineffectual. Many felt that no one piece of written guidance had satisfied their need for information on their child's condition, feeding procedures or their desire for reassurance.

Written Communication from Manufacturer

The written information received from the manufacturer concerning either the feeding equipment and/or the food, tended to be more consistent as did parental attitudes towards it.

Mainly, this type of information had been provided in a booklet style format. The quality differed from that received from NHSS and was much more professional, colourful and polished. The tone however – in most cases – was described as being rather technical and lacking empathy or understanding of parents' emotions and concerns at this time. Consequently, parents tended to feel that the information and guidance from the manufacturer was rather impersonal.

The majority of parents agreed that the content of manufacturers' communications was extremely detailed. However a number of parents spoken to during the research commented that such booklets from the manufacturers usually contained information and guidance on a number of different feeding tubes developed by the manufacturer. This could cause problems as parents had to identify which advice and guidance related to their equipment. This meant trawling through a great deal of information before finding facts relevant to their specific piece of equipment – at a time when there may be an emergency feeding problem. Consequently, some parents would rather such 'equipment-related' information could be relayed in a more user-friendly way.

It would appear however that for some parents, information from manufacturers would only be the first source of guidance for many parents if they were having problems with the feeding equipment.

4.2.4 Verbal Communication from Manufacturer

In addition to written advice and guidance, some manufacturers of tube feeding equipment also provide a Patient Information Service that can be accessed if necessary.

Only a minority of parents we spoke to had called the service, however, and this tended to largely relate to technical issues regarding equipment. The service was not perceived by many to be a significant source of information and guidance regarding tube feeding. The lack of face-to-face contact with the advisor caused difficulty for some parents - especially if demonstrative information is necessary.

In addition, some parents felt that the Patient Information Service had no real knowledge or understanding of the family, the child and the issues they faced and so the service appeared somewhat impersonal. There was also uncertainty regarding the experience of the person on the other end of the line. They feared their experience may not extend beyond technical issues rather than medical.

The majority of parents however did say that they were contacted frequently by the manufacturers to record any issues and demand for equipment and food. In this area they were satisfied and appreciated the service.

4.2.5 Hospital Nursing Staff

We found that - in most cases – an extremely good relationship had been established between parents and hospital staff, mainly due to the length of time their child had been in hospital. Having such a relationship meant that parents had a great deal of confidence in the hospital nursing staff and in turn confidence in the information and advice they gave them.

For parents spoken to during the research - whilst their child was in hospital - nursing staff tended to be the first source of training and advice with regards to both nasogastric and gastrostomy feeding in these early stages:

“Training was very comprehensive. We were given the information together to relieve any extra stress and confusion”.

In addition, hospital nursing staff were the main source of any informal training taking place regarding equipment or feeding. Advice or guidance regarding feeding could easily be illustrated on the child at the time, with parents observing the implementation of the regime. In addition it meant that parents could voice any concerns and queries during such training. This was all highly appreciated by parents spoken to during the research.

Over and above the advice, guidance and training given in the hospital, many of the parents had specific contact details of children’s wards within the hospital that they could call for ad hoc advice and guidance after returning home – again parents had nothing but praise for the staff they spoke to on such occasions.

Nonetheless, there was one important issue where some parents were unhappy with information and advice from hospital nursing staff and this concerned inconsistencies in training.

We had anecdotal feedback from two parents who had experienced such inconsistencies in training regarding feeding techniques between hospital nursing staff and Community Nurses. These contradictions in hospital and Community Nurse advice led to some consternation amongst parents and also prolonged the time it took them to become confident in carrying out feeding procedures. Clearly training given by all health professionals should be consistent, and where such training differs, these differences and the reasons for them should be clearly and simply communicated to the parents concerned.

4.2.6 Community Nurses

Although all the above sources of information and advice were mentioned, for all parents interviewed during the research the Community Nurse was their main source of information, advice and guidance. Regardless of parental typology (as discussed earlier), throughout the research the Community Nurse was praised extremely highly by all respondents:

“I don’t know what we’d do without her. She made up a folder so we can put all the wee ones information from the hospital in it.”

All parents spontaneously cited the Community Nurse as being their first port of call whenever they needed guidance on their child's feeding regime:

"She just takes the pressure off. She knows before I do when things are getting to me"

The Community Nurse's advice took priority and surpassed all other forms of information and advice in terms of reliability, accuracy and sensitivity.

All the parents who participated in the research felt that their Community Nurse understood the physical, emotional, financial and family issues specific to their family and was able to tailor their services accordingly and could therefore advice on a number of issues:

"You just know that whatever it is, once you've told her you'll know it will get done."

With regard to specific tube feeding issues, the Community Nurse was able to physically demonstrate any aspect of the feeding regime on the child and could observe as parents then conducted the procedure. Parents preferred this as it ensured quality training was given in a relaxed environment. Overall the service they provide for these families is a personal one and this closeness and reliability is extremely important to parents.

This close relationship also develops due to the continuity provided by the Community Nurse. Many parents we spoke to commented on their Community Nurse coming to the hospital, keeping in touch with parents throughout treatment and assisting with queries and discussions with consultants. During the transition from hospital to home, they had ensured that everything ran smoothly and comfortably and in most cases they had then visited the family on a daily basis - in the initial stages - to assist with feeding and ensure that any problems encountered were resolved. Consequently this helped increase parents' own confidence when dealing with the feeding procedure. And of course they had continued to provide the parents with invaluable on-going support. They keep in constant contact with the parents and are perceived to be the vital link between them and other health services. They assist with tube feeding training issues regarding schools, home carers and other members of the family.

As such, the wholehearted support and guidance parents received from the Community Nurse meant that most parents were confident about contacting them regardless of the issue and are more likely to do so than consult a GP or refer to any written material. Consequently parents are liberated from a great deal of unnecessary pressure – this was deeply appreciated by all.

4.3 Potential Improvements

When parents were asked to consider the weaknesses in the provision of information and advice that they had been exposed to, and where they would like to see improvements, there was a consensus that the Community Nurse provided them with all the guidance and advice they required. However, when further probed, a minority of suggestions were voiced.

There was a definite call for more consistent information – especially between the hospital nursing staff and the Community Nurse - and a sense that the advice and guidance provided by the Community Nurse should be adequately backed up by the hospital.

Respondents would also like to see the production and issuing of a detailed manual which details and addresses all potential tube-feeding problems, rather than what was described as a *'piecemeal approach to written information'*.

One parent also suggested that there should be a detailed explanation as to the reasons behind each aspect of the training provided, for example, why cleanliness is important and why checking the position of the tubes is paramount rather than just detailing the procedures themselves.

Finally, it was suggested that a video illustrating how to set up feed and tubes and instruct on cleaning routines should be distributed to all parents prior to returning home with their child.

5. Key Conclusions and Recommendations

The key conclusions from the research can be detailed under five main headings:

Range of Tools

Information and advice was found to be delivered to parents in a number of forms with visual information being deemed particularly helpful – parents were reassured by being able to observe correct procedure or problem-solving. In addition, there was a clear need for simply worded, comprehensible written information, preferably a detailed manual consistently produced across all Health Boards.

However technical information – mainly from manufacturers of nasogastric and gastrostomy equipment - was not perceived to be as beneficial, largely due to its formal tone and volume. This reduced its usability – unless experiencing specific mechanical problems.

Consistency

Consistency of advice and training was of great concern to many, specifically training and advice from the hospital and that provided by Community Nurses. This caused unnecessary stress for some parents as re-training by Community Nurse was required – causing confusion. Consequently reasons for these differences in training need to be communicated to parents to diminish underlying worries regarding quality and accuracy of hospital advice.

Value Attached to Nurses

Amongst the parents, there was a huge groundswell of respect and admiration for Community Nurses. In most cases the parents of the tube-fed child perceived their Nurse as the main provider of advice, information and guidance in all situations relating to tube-feeding their child. All other sources are regarded as secondary – and consequently are perceived as of lesser value. This ongoing personal support and guidance must continue.

Parent Typologies

Three parent types were evident: The “Information Hungry”, The “Get on With Its”, The “Passive Acceptors”. As the typology impacted upon how they viewed advice and information provided, these should be noted when developing other communication resources or when identifying the level of guidance and support necessary.

Opportunities for Parental Support

It was clear from the research that the better equipped parents felt they were in dealing with potential problems and issues that may arise, the more confident they were with the feeding regime. Consequently a significant amount of adequate and accurate information is required prior to initiation of feeding regime – and in the early days.

When parents have become well acquainted with the regime, less information appears to be required – although ongoing visits and enquiries – as always – are still required.

It would appear that written advice and guidance with the most appeal contained specific elements. Parent's appreciation of written advice was at a much higher level if it had a relevant, empathetic and detailed content. Information was deemed more readable and accessible if it was written in a non-technical tone and illustrated aspects of the feeding regimes and equipment using clear associated imagery. However, an understanding of the emotional issues parents are facing is necessary to reassure them.

The lack of knowledge of parents facing similar circumstances is an issue that some parents would appreciate being resolved. It was suggested that rather than simply being bombarded with written information, parents would learn more from sharing their experiences and that perhaps the Community Nurse could help bring parents together.

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Nasogastric and Gastrostomy Feeding in Children

Appendix 1 – Topic Guide

SECTION 1: INTRODUCTION AND WARM UP

- Introduce self. Progressive; background to research (re NHS QIS etc and what they are trying to do)
- Ask respondent to explain own backgrounds; marital status; number of children
- Respondent to detail history of tube feeding child (e.g. when started; how long –graduate from NG to G?)

SECTION 2: CURRENT INFORMATION AND ADVICE PROVIDED

- From beginning – information and advice received. In particular probe on:
 - If from birth – what happened in hospital
 - When started – training given (how given – informal / formal, verbal, written, ad-hoc, specific etc)
 - Training provider – Who? Where? (hospital / home – make a difference?) Position? Adequacy and value of training given (e.g. was it in required depth?)
 - More than one trainer? If so, was training given consistent (e.g. regarding checking length of tube)? Comprehensive? If not, why not? What was missing?
 - On-going training? By whom? (If graduated from NG to G – what training given)
- Written communication – probe in detail regarding any given (ask to see if poss):
 - Content – relevant? accurate? Covered all areas you needed info on?
PROBE HERE IN DETAIL
 - Tone: sensitive; clearly understandable; friendly?
 - Format – what did it look like? Easier to read? Hold? Design and font used (Eg was it a photocopied page or a professionally designed booklet)
 - Is there on-going written communication regarding tube feeding? That is – do you received updates from hospital regarding food or

- implements used (eg any new products on the market etc?). If not, what type of updates would they like to achieve
- Have you received any written communications that have been extremely helpful? (ie something that could be seen as 'best practice')

SECTION 3: IDEAL INFORMATION: CONTENT & FORMAT

- Get parents to go through all times when information needed / requested:
 - What would be main content – what do they really need to know. If they were writing something what would be in it?
 - How would you communicate this? Leaflet? Through nurse? Ideal format

SECTION 4: SUPPORT GROUPS AND THEIR ROLE

- Have you used a support group at any time? Was it specifically set up for NG help or special needs kids? Or kids in hospital?
 - How did you find out about support group?
 - Was this good way to find out? Any other way that could have been ideal (i.e. did they need to find out themselves or info from nurse / other parent)
- If with support group – how have they helped (in general and specifically with NG)
- How helpful has been community pediatric nurse? What happens if you are unsure of a feeding tube issue outwith surgery hours (do you know who to call)

SECTION 5: GAPS

- What do you wish you had been told about tube feeding children that you had to find out for yourself?

SECTION 6: SUGGESTIONS FOR IMPROVING INFORMATION & ADVICE GIVEN

If you could speak to NHS QIS yourself what ONE thing do you think could improve the help and advice you have been given along the way?

SUMMARISE, THANK AND CLOSE

You can read and download this document from our website.
We can also provide this information:

- by email
- in large print
- on audio tape or CD
- in Braille, and
- in community languages.

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