

Parent power and choice!



infant

for neonatal and paediatric
healthcare professionals

All parents have various and diverse needs but particularly so those parents whose babies are frail and vulnerable. Parents in this group find themselves having to cope with the gamut of emotions associated with the early birth of an infant, to the situation where a previously well baby becomes ill requiring hospitalisation and maybe surgery.

In the current scenario of widespread poor hospital hygiene patients are being asked to challenge the hospital professionals if they have washed their hands before carrying out any clinical procedure! The image presented is almost 'Laurel and Hardyish' based upon good intentions, but totally unrealistic.

Maggie Redshaw¹, writing in the foreword to the BLISS Community and Health Professionals Information Guide 2004, identifies an element of commonality of need amongst these parents whose babies have been in neonatal care. When asked about the advice they would give to others in a similar situation, many of the respondents emphasised that there was a need to:

- Seek information
- Ask and....
- If you don't understand, to ASK again!

However, it takes considerable courage, nerve and confidence to challenge professional authority in any language, but particularly when a baby or young child is involved. Individual parents often feel themselves vulnerable and powerless, which can become a source of dissatisfaction. Many parents find that their most useful support and practical advice comes from other parents.

Corporate power when exerted by parents united by a shared concern can be pretty awesome, for example the influence of BLISS in the corridors of Whitehall. But, also because of their impact on clinical developments and in professional education over the past few decades. There are many other examples of active, effective and influential parent groups throughout the health service.

Politicians have woken up to the potential of the power of patients seeking to harness and utilise it within the NHS. But also 'de facto' silently implied is that those patients/parents who choose their treatment or place of hospitalisation, accept some responsibility for their care or treatment etc under the concept of choice.

Definitions of choice from the Oxford English Dictionary include 'the act of choosing, the right or ability to choose, or a range from which to choose'.

Since inception the NHS has offered a degree of choice in many of the aspects of the care that it provides. 'Choice' is now one of the most currently used words in 'NHS speak' and one of the most recent additions to the NHS lexicon. This concept aims to give patients (and parents) more choice about how, when and where they receive treatment. In addition it aims to shape local care systems, thus providing one of the cornerstones of the Government's health strategy for the new, modernised NHS. But sadly the concept of choice seems to be missing or limited in any discussion of the NHS services for children under the age of twelve months.

Even so, in order to exercise a choice parents need information and support systems in place, from which they can make an informed decision. One of the suggestions from the Kings Fund is that 'expert patients' should be recruited and used to help parents work through the choices available, based upon the best local information available². Another suggestion is that the Department of Health needs to clarify what choice implies in real terms for the young infant and its parents.

What is clear, is that in any discussion around this concept there must be a continued commitment from all health professionals to share knowledge and information with parents about treatment options, availability and the commissioning of services for them. Parents need this information in order to be able to make a treatment/care choice based upon the best detail available. The continued development of clinical networks is helping to promote and develop a shared partnership culture, with the creation of working partnerships with allied organisations to include relevant parent support groups.

In the meantime the intention of this editorial is, by raising these important issues, to further the debate to ensure that issues of choice for our client group are kept in the main frame of NHS Strategic developments.

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References

1. Redshaw M. Community Health Professionals' Information Guide. BLISS. 2004.
2. King's Fund Response to: 'Fair and Personal to you: Choice, Responsiveness and Equity in the NHS and Social Care'. 2003.