

Enjoyable meals

'Good food', I remarked argumentatively 'should be the occasion and not the topic of good conversation'. I was rounded on by my friends who berated me for such a naïve remark. From antiquity to the present day the experience of good food, the mealtime, has been a major feature of civilization and the cultural importance unimpeachable. Just so. But perhaps my view was biased by having spent time with families with children who have been hard to feed. Preparing the right food for them (good food) and helping the child consume that food over many hours can cause endless distress. When we started our first Feeding Clinic at our Child Development Centre I naïvely imagined that most of the children who came to see us would be there with social and behavioural reasons for the feeding difficulty (and there are such of course). But we soon saw children with all sorts of disabilities and it was distressing to find, as a clinician, that children referred for 'feeding difficulties' proved to have a neurological problem and we were telling parents that was the case at the same time as trying to help them with the problems that had brought them to the clinic. It is in these children that alternative feeding methods have to be considered. Already for many of them nasogastric feeding had been a feature of their early lives. Sampson-Fang and her colleagues have reviewed more than a decade of not very robust evidence of the value of gastrostomy feeding in children with cerebral palsy (CP; *DMCN* 2003, 45: 415–426). But it is important to remember that CP is not the only diagnostic category where we see feeding problems (e.g. cardiac, genetic conditions).

Earlier this year an international group met in London to review 'perinatal brain injury and nutrition'. Topics included issues such as epidemiology, what sort of feeding should be used, the content of feeds, views around surgical techniques, and ethical issues around gastrostomy. All through the workshop we were concerned about family issues and grateful for the support of a psychiatric colleague, Tony Holland, who discussed with us family decision making capacities whilst determining the best interests of child and family. In such a relatively young field perhaps it was not surprising to find that every topic we discussed was followed by a plea for more research and there are issues in my mind about getting research funding in this field of clinical research while basic health research gets the lion's share of grants.

An interesting and difficult area of discussion was the feelings of parents who did not like the notion of gastrostomy treatment and there are all sorts of issues raised here. One was the awareness of many clinicians of situations where the child's state of inanition was such that the clinician felt that it was unethical not to proceed to some intervention procedure, and the possibility of feeling that the parents were neglecting the child if they failed to take the clinical advice. While nobody had personal experience of the legal consequence of this situation, it was clear that it was a possibility in some people's minds. More often the parents simply felt that this apparently

cold and abstract way of feeding would break up what was indeed their most continuous contact with their child and believed that it was better to struggle on with the feeding difficulties than intervene in what they perceived as a very unnatural way of feeding. Our Irish colleagues represented by Dr Susan Keane reviewed outcome for those families who had refused intervention. They found the difficult situation for the families remained the same over the period when they had been resisting the clinical advice. These psychosocial issues are equally as important as the difficult technical issues such as the composition of the feed, variation of surgical techniques, and timing of such interventions, etc.

In this journal we report the impact of these factors on the quality of life of the carers of children with CP. The paper by Sullivan et al. stresses again the importance in this field, which we had recognized at our workshop, of multicentre studies. Our colleagues rightly recognized the importance of ethnicity in this study, restricting their work to 'Caucasian' families but with cooperation with two other centres they were able to study 57 families. The results are gratifying for all of us who have recommended the use of gastrostomy. The authors find significant benefits for the caregivers and conclude that the study has quantified 'a measurable improvement in the quality of life of carers after overcoming the feeding problems of children' by insertion of a gastrostomy feeding tube. Clearly the results need replicating particularly among different ethnic groups. My anecdotal evidence on that is that some of the ethnic groups we see in the UK find the notion of such intervention very distressing and therefore may have difficulties in managing it, and its outcome for them as caregivers may not be as satisfactory as it is for the Caucasian sample.

With that piece of work successfully done, we are left with all the other hosts of problems that artificial feeding involves. In order to help with these problems the participating group hope to carry out some multicentre studies and those who visit the Castang Foundation website (www.castangfoundation.net) and are interested in this procedure can contact those involved in running the site (Martin Bax and Peter Sullivan) and see whether they can usefully participate in our activities which we hope will be ongoing.

What one also hopes is that the retorts my friends gave me and with which I started this Editorial will be replicated in families with children with disabilities so that meal times become an occasion when 'the good food' is discussed. More importantly a social event occurs for the family when they come together in a relaxed atmosphere and perhaps see their way forward with other problems of the young person with a disability.

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