A touch of cerebral palsy

A mother came into my clinic with her ex-premature baby who had been through the mill of neonatal intensive care but appeared to be doing very well. After we had finished the consultation and I had praised her and her baby for the excellent progress they both were making, she asked me what I thought of another doctor’s opinion, that her daughter had “a touch of cerebral palsy”. The physiotherapist and I agreed that her daughter did not have cerebral palsy, and I reassured her, but asked whether she hadn’t been distressed at the diagnosis. “No” she replied “because you had always warned me of the risk”. Oh that breaking the news of cerebral palsy and explaining it to parents was so simple!

In a paper in last month’s *Archives of Disease in Childhood*, Baird and colleagues discuss the thorny problem of how to disclose the diagnosis of cerebral palsy and how we might improve practice.1 In their study, dissatisfaction with the structure and manner of disclosure of diagnosis was reported by 20% and 23% of 107 mothers, respectively and 43% expressed dissatisfaction with the information given at that time. In particular, lower satisfaction was found among the mothers of more premature children, mothers with more severely disabled children and worse depression scores, and not surprisingly, those taking legal action.

Does this study have implications for neonatologists and what are they?

**Improving current practice**

Baird and colleagues develop guidelines for disclosure of diagnosis which are sensible and to a large extent derived from the work of Cunningham and colleagues over the disclosure of a diagnosis of Down’s syndrome:2 tell both parents together with their child and a third party if possible, in a private place without interruptions; offer parents a chance to be alone; be clear, direct, and honest; and give accurate information with structured rapid follow up. These principles are difficult to fault and are often practised well in the neonatal intensive care setting where breaking difficult news to parents is part of routine practice, contrary to the assumption of Baird et al. The use of tape recordings of discussions may be of value to the practice, contrary to the assumption of Baird et al.

In a busy outpatient clinic, where you are unexpectedly looking after them, and a way of ensuring that everyone knows what is said to a couple. These practices are well described and can be audited.

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common in the most immature. Prediction is complicated by the fact that a proportion of infants will develop transient patterns of neurological abnormality that may require intervention but resolve over the second year.19

Parents use hope and denial as defence mechanisms in the unexpected crisis following premature birth; leading them through to realistic expectations is an important function of the counselling that occurs in neonatal intensive care. National data are now available for disability rates at 30 months of age in extremely preterm infants.3 Many regions also collect data on disability that can be used to inform parents. Hospitals providing neonatal intensive care should collect information on outcomes to inform their practice.11 Using data such as these, the neonatologist has a duty to inform and explain outcomes to parents as part of the counselling process that accompanies intensive care. Parents deserve to be aware of the potential outcomes for their child using contemporary and unbiased information. Many will explore internet sites relating to outcomes for their child using contemporary and unbiased intensive care. Parents deserve to be aware of the potential outcomes for their child using contemporary and unbiased information. Many will explore internet sites relating to prematurity and they need to be able to put the information they access into a proper context and also feel free to discuss it with their child’s carers.

Yes, we should all now get disclosure right, difficult though it may be on occasions. We should, however, start to think about preparing parents by explaining risk. The later detection of cerebral palsy and disclosure of diagnosis will come as less of a surprise, and concerns and worries may be openly discussed in the follow up clinic. We need to train ourselves in this area and equip trainees for the task. In the year 2000 a “touch of cerebral palsy” should be a thing of the past.

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