Home ventilation of a child with motor and sensory neuropathy

Life does have a price, and the rest of us have to pay it

EDITOR,—The article debating whether a child with motor and sensory neuropathy should have been ventilated at home raises many wider issues, besides illustrating how hopelessly unevolved our grasp of moral issues remains.¹ R H Davies does not believe that a person's misery can be measured (though this claim is neatly countered by Ian Harvey), but Davies nevertheless needs to arrive at some system of measurement because other people have clearly paid a price for the expenditure on this child.

The high moral tone of the mother's contribution to the article evaporates when you realise that the price that she claims one cannot put on a child's life will nevertheless be paid—and from someone else's money. Her statement expressly concerns a child's life, but one might ask why a child's life should be more valuable than that of a person outside childhood. The mother's attitude is not unique: pressure groups (currently those for patients with multiple sclerosis and patients receiving renal replacement treatment are prominent) clamour for more resources to be voted to their cause, either unaware or uncaring that the advancement of their cause means the retarding of another group's cause.

Hugh Newton-John describes the phenomenon of "entrapment" in the context of this and similar cases. Are we as a nation now entrapped by the concept of the NHS? Many health authorities, my own included, limit in vitro fertilisation. Couples thus find themselves having contributed through their taxes to a system that

then fails to meet their immediate and pressing need—perhaps the only need they have expressed in their adult life. They are then in the anomalous position that they cannot afford private in vitro fertilisation because they do not have sufficient funds after they have made their contribution, through tax, to the care of people they do not even know.

Finally, is there, to borrow Harvey's term, another "point of indifference"—that at which the morality of providing care for those who cannot afford it is exactly balanced by the immorality of taxing people so hard that they cannot afford to arrange for themselves a service superior to that provided by the state? Are we now at or beyond this point?

FRASER M HADDEN

Consultant in communicable disease control

Suffolk Health Authority,
PO Box 55,
Ipswich IP3 8NN

1 Davies RH, Harvey I, Newton-John H, Ward TA. Home ventilation of a child with motor and sensory neuropathy. *BMJ* 1996;313:153-5. (20 July.)

Central funding and a central resource providing information are needed

EDITOR,—R H Davies is to be praised for the sensitive approach taken in striving to obtain the most appropriate care for a ventilated patient.¹ Undoubtedly those readers who have been in a similar situation will have been reminded of their own experiences and the seemingly endless round of meetings that took place.

In 1993 I undertook a postal survey of members of the Paediatric Intensive Care Society asking about children ventilated at home in Britain. I hoped, forlornly, to organise a meeting of interested parties. I assumed that most children ventilated at home would be known to members. The survey discovered 31 children aged 1-16, living as far apart as Aberdeen and Bodmin, receiving some sort of ventilatory support at home. Sixteen were ventilated only at night. The 15 receiving full time ventilation had suffered inflammatory disease of the central nervous system, cord trauma, or myopathy. The geographical scatter of these children meant that no one centre had great experience of establishing long term, full time domiciliary ventilation.

In 1992 I coordinated the multidisciplinary team that successfully established home ventilation of a 2 year old boy who was apnoeic after transverse myelitis. The child survived for two years before dying of pneumonia secondary to infection with respiratory syncytial virus. Before his discharge, the family home had to be modified, equipment bought, and a team of nurses (care assistants) employed and trained. The capital costs were met by a joint funding arrangement between the health authority and local authority. The nurses were employed by the community trust. These costs were considerably less than those of a paediatric intensive care bed, as Trudy A Ward points out in her article about Davies's case.¹ Discharging this child released what was at the time a quarter of our complement of paediatric intensive care beds.

We went through many stages in achieving our patient's discharge. The idea that he should go home was initially suggested by the parents and

was then supported by all concerned. The drawing up of plans and lists of equipment lists and the training of staff were not unduly delayed: the team was well motivated. Unsurprisingly, funding took months to arrange.

I support Ward's move towards establishing a nationally consistent approach. I believe that the local clinicians should look at the individual requirements of each child, but central funding and a central resource providing information and experience would help us to expedite these children's discharge when appropriate.

IAN BARKER

Consultant anaesthetist

Sheffield Children's Hospital NHS Trust,
Sheffield S10 2TH

1 Davies RH, Harvey I, Newton-John H, Ward TA. Home ventilation of a child with motor and sensory neuropathy. *BMJ* 1996;313:153-5. (20 July.)

Study aims to set up national database of children receiving ventilatory support

EDITOR,—Arranging for children who are dependent on technology to be treated at home is often fraught with difficulties before and after discharge. The decision taken by R H Davies's team to transfer the care of a girl who was dependent on a ventilator from an adult intensive care unit to her own home was one that required a great deal of insight and planning.¹ In many instances, home care for such children is increasingly recognised as best for the child and family.² The comment made by this child's mother leaves little doubt that the decision taken was the right one for this family despite the poor prognosis.¹

A survey of members of the British Paediatric Respiratory Society in 1995 estimated that about 100 children were receiving long term ventilation in Britain, two thirds of whom were cared for in their own home. This is a substantial increase from the number reported by Robinson in 1990.³ The cost of home care, despite Ian Harvey's assertion,¹ is often less than the cost of a prolonged stay in hospital.⁴ Increasingly, purchasers are employing trained carers to deliver individual care at home. No national database of children receiving ventilatory support in Britain is available for reference. A study funded by the Department of Health and orchestrated by a team of interested parties is currently aiming to develop such a database. We also plan to quantify and assess the needs of children currently ventilated long term in NHS institutions who could receive domiciliary ventilation and to formulate guidelines for the provision and coordination of a domiciliary paediatric ventilation service.

France already has a national system for patients ventilated at home and those dependent on oxygen; this is centrally funded by the public health service and provides a uniform, comprehensive standard of care accessible to all. Perhaps this is what Britain should aim for.⁵

We would welcome correspondence from readers who have gained experience in this work or could contribute.

E JARDINE

Research sister

C WALLIS

Consultant paediatrician

Respiratory Unit,
Great Ormond Street Hospital for Children NHS Trust,
London WC1N 3JH

Advice to authors

We receive more letters than we can publish: we can currently accept only about one third. We prefer short letters that relate to articles published within the past four weeks. Letters received after this deadline stand less chance of acceptance. We also publish some "out of the blue" letters, which usually relate to matters of public policy.

When deciding which letters to publish we favour originality, assertions supported by data or by citation, and a clear prose style. Wit, passion, and personal experience also have their place.

Letters should have fewer than 400 words (please give a word count) and no more than five references (including one to the *BMJ* article to which they relate); references should be in the Vancouver style. We welcome pictures.

Letters should be typed and signed by each author, and each author's current appointment and address should be stated. We encourage you to declare any conflict of interest.

Please enclose a stamped addressed envelope if you would like to know whether your letter has been accepted or rejected.

Letters will be edited and may be shortened.