Editorial

Ventilator dependence and high tetraplegia

In October 1991 a two day conference* on domiciliary ventilation and high spinal cord injury was held in Southport, England, with the purpose of reviewing professionals' and patients' experiences of the problems and priorities in long term ventilation after spinal cord injury both in this country and in Europe and North America. The first presentations were comparative reviews of service provisions in different countries. Then, focusing on the quality of life, two papers dealt with the matter of speech and tracheostomy ventilation and one paper with the place of advanced assistive technology. The subsequent papers collectively looked at some consequences of domiciliary ventilation to the patients, to the families and to society, while there was added a note of optimism in a discussion on air travel by the participation in the conference of two patients who had both been able to fly abroad, one using diaphragmatic pacing.

Whereas assisted ventilation has been undertaken for many years in the acute phase of spinal cord injury for a period of a few days or weeks, it is mainly within the last decade that the patient with high tetraplegia who will remain ventilator dependent has survived long enough to reach hospital. The rate of increase in new cases and their long term survival means that it has been difficult to respond to the new demands with the appropriate level and distribution of service. To illustrate the changes, the rates of acute ventilation have risen in the 35 bed unit at Southport from an average of 4 per annum in the last decade to 18 in 1992, 9 of whom will not be weaned; and in addition ventilated patients are readmitted at any time either for respite or because of an intercurrent illness.

It is ideal to combine the continuum of acute and rehabilitative care under the same roof with the same team since the two stages are not separate and it should prove possible

to achieve a shorter overall hospital stay by virtue of early discharge planning. Thorough knowledge of the patient from the early stages allows for a streamlined and simplified subsequent management appropriate to a domiciliary setting. Initially trained in the hospital, the family members have become the experts in domiciliary ventilation and tetraplegia care and deserve much credit for the good survival rate. It is also true that the integrated and ongoing care which all spinal cord injury patients have been able to receive through spinal units has been crucial to their improved survival in the past few years. The concentration of medical and other expertise, such as assistive technology programmes in spinal units, is another reason for maintaining the high tetraplegia domiciliary ventilation service linked to these units. The annual incidence may not nevertheless warrant that every spinal unit should provide such a facility and we urgently need hard data in the form of a national if not international database for future agreement on the location of centres caring for highly dependent patients with chronic respiratory insufficiency. We also need to decide what our relationship would be with the network of respiratory units run by thoracic physicians offering an assisted ventilation service for over 600 patients, the majority of whom are less dependent.

There is a considerable onus upon the professions, having intervened to save life by means of assisted ventilation, to do everything possible to maximise the quality of life, and this includes the objective of discharge from hospital to home as well as harnessing the latest technological advances in the name of greater independence, even if this requires the purchase of electrophrenic respiration systems in addition to conventional backup ventilatory systems.

In these times of financial stringency we were grateful to hear Dr Pat Walsh's well argued case for equity in distribution of resources and it was heartening for everyone at the conference to listen to two tetraplegic people relating how they had

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managed to reshape their lives despite such devastating disability. These things gave one fresh impetus and encouragement in the care of these patients.

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