



Roger Goldstein, MBChB, FCCP, when presented with the Margaret Pfrommer Memorial Award in Long-term Mechanical Ventilation.

Ventilator-Assisted Individuals; Integrating Across the Spectrum of Care

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Between 1850 and 1950, negative pressure ventilators, rocking beds, cuirass shells and iron lungs were developed. The latter proved lifesaving during the polio epidemics in the mid-1950s. Subsequently positive pressure ventilators (invasive and noninvasive) as well as interfaces (tracheostomy, face mask, nasal pillows) came into being. The growing prevalence of long-term mechanical ventilation (LTMV) is associated with increased survival following a life-threatening episode, increased technology in the intensive care unit (ICU) and greater awareness of individuals whose underlying condition progresses naturally to cardiorespiratory failure so that elective ventilatory support may be initiated.

The spectrum of care for ventilator-assisted individuals (VAI) varies from the ICU (highest acuity of illness and highest intensity of care), to home (lowest acuity and lowest intensity of care). Between these two points there are non-acute assisted ventilatory care units, in-patient rehabilitation units, skilled nursing facilities and assisted living centers, each of which is designed to offer a safe setting for the VAI, preferably with a rehabilitative environment to promote autonomy and self-directed care.

It is now appreciated that the best chance of successful rehabilitation begins in the ICU, with a series of steps to enable those who cannot be fully weaned from the ventilator to be **successfully fully weaned from the ICU**. Of these steps, perhaps the most difficult for some is the psychological separation to a less intense environment.

Long-Term Assisted-Ventilatory Care Units (LTAVCU), either free standing or attached to a hospital, require a multi-

dimensional continuum of service by an interdisciplinary team. The preferred patient is medically stable, mentally alert, understands that ventilatory assistance is long term, is prepared to participate in comprehensive training and is prepared to relocate with appropriate support. Assisted-living units have a lower staffing ratio and skill level than do the LTAVCU. The VAI is encouraged to be more autonomous and so the setting is much less like a hospital and closer to the community.

In 1995, we interviewed 100 VAIs ventilated for almost five years¹. Two points in particular stood out: the first was that the ability to cope with ventilation changed with time. Whereas 52% of respondents indicated initial difficulty coping, only 11% felt this way five years later. Although only 5% indicated that overall they had no difficulty coping, this had increased to 37% after five years. The second point was that when asked if they had made an informed choice when starting ventilation or when long term ventilation was being considered, the group responded yes (37%), no (54%) and unclear (7%). Being more attentive to these points requires ongoing education of the healthcare professionals, patient and family, when ventilation is being initiated or identified as becoming prolonged. We have also developed a more **formal training regimen for VAIs and their caregivers**, in order to reduce the issues and concerns that arise regarding care of the VAI especially in the first few weeks.

It is possible to have an accelerated transition from the ICU to a more appropriate environment if the host and rehabilitation teams jointly identify the discharge setting and support

requirements early in the process of ongoing ventilation. They also need to introduce the idea of leaving the ICU after a training program as well as facilitating discharge plans that link institutional with community care, primary care, homecare and housing. The extent of caregiver training will vary with the mix of family care, private care and community support.

The importance of follow-up, especially with a measure of transcutaneous carbon dioxide tension, has become more apparent. VAIs stable for many years will sometimes require adjustments to their ventilator in response to changes in their medical condition. Age transition from the pediatric to the adult age group also requires a regular reassessment of ventilation, interface, mode of ventilation and the ventilator settings.

A few years ago we undertook semi-structured interviews with VAIs who had neuromuscular conditions (NMD), to learn which things they considered impacted on their health-related quality of life². They spoke about the physical and psychological adjustment to ventilation and the positive effect that a physician, who believes in the effectiveness of their treatment, had on their sense of well-being. They also spoke of the support they received from other VAIs. Their situation was made more difficult by the trauma of the ICU, especially if they had been unable to communicate, and made easier when they were able to share in the decision making. They spoke of the frustration of requiring personal attendants, the public stigma of using equipment, the need for legislation to regulate who could suction, manually ventilate and perform tracheostomy care as well as the energy spent scheduling multiple inter-related healthcare and social services. When asked for recommendations that might improve their lives, they made many, [summarized here](#).

Family members are essential to achieving a sustainable environment for the VAI to live safely at home. Informal caregivers underestimate the care burden especially the combination of underlying NMD and invasive ventilation. Prompted by having encountered several episodes of caregiver burnout, we recently interviewed 21 informal caregivers of 12 VAI with neuromuscular disease³. We were humbled by their tremendous sense of duty.

Many did not regret their decision seeing the satisfaction of their loved one (“If he wasn’t at home, he would not be here today.”). All had been deprived of leisure time (“I am a prisoner in my home, of my own will. I don’t regret it, but this is the way I feel.”).

Those receiving direct funding commented on its positive impact on their lives. The physical and emotional burdens were keenly felt, especially when they could not speak fluently with their loved ones (“Even at night when you sleep, you are sleeping with one eye open.”).

As far as training and education were concerned many caregivers did not know who to turn to for unexpected issues, especially in the first few months (“It was hard to come home even though we got trained. You don’t know what to expect.”). The importance of paid support was linked to the development of burnout.

In summary: There is a broad spectrum of care for the VAI, from ICU to home. The best chances of success occur when training is started early in the ICU. The VAI and caregivers’ ability to cope requires a formal training program that also includes follow-up, as well as early coordination among the various healthcare professionals, home support services, VAI and family. Support from other VAIs and a physician who confidently believes in long-term ventilation has a positive impact. Caregivers are essential to the success of home ventilation. It requires a substantial commitment from family caregivers even in the presence of outside supports. An awareness of the potential for caregiver burnout means that attention needs to be paid to their needs and to the opportunities for respite care for the VAI as well as close integration between the hospital and the community. ■

References:

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