

IVUN's New Medical Advisory Committee Shares Its Views

When IVUN was establishing its new Medical Advisory Committee, it looked for qualified health care professionals who supported the philosophy of independent living for users of home mechanical ventilation. Fifteen critically-thinking individuals, representing a wide range of specialization and experience in treating neuromuscular disorders, accepted the invitation.

For their first assignment, they were asked to respond to this question: **What are the major issues facing you as a health professional in treating/managing your patients who are users of home mechanical ventilation?** Here is a compilation of their responses.

Bach thought, “The answer is very simple ... it is the ignorance of the medical community. I get 5-10 calls and 20 emails a day to explain how to save ... patients I have never seen.”

Benditt stated that, “For me, the predominant issue is obtaining the funding for patients to receive appropriate care in the home. Insurers and the government are unaware that for ventilator-assisted individuals an ‘ounce of prevention’ is truly worth a ‘pound of (ICU) care.’ We have the technologies available to help people live longer and with better quality of life but appropriate coverage is shrinking, not growing.”

Boitano listed many challenges. “(1) The Medicare guidelines for timely initiation of noninvasive bilevel pressure ventilation are restrictive. (2) Payer support for mechanical ventilation and cough augmentation therapy is often difficult to obtain. The development of neuromuscular respiratory care guidelines, such as the ATS (American Thoracic Society) consensus statement on the respiratory care of DMD, should alleviate part of this problem. (3) Payer support for backup ventilators and backup power supply systems is poor. (4) Patients,

in general, are more mobile and require compact portable ventilators and power wheelchairs, but insurers are often resistant to supporting the newer generation of compact ventilators. (5) There is a disconnect between wheelchair suppliers and homecare companies who supply ventilators, making the development of the complete setup both difficult and slow.”

Butka reported that, “I have patients who need CoughAssist® units who cannot get coverage and inpatient respiratory therapists who just don’t seem to ‘get it’ with regard to its benefits. The manufacturer and distributors of the CoughAssist® need to help get the message out by advertising, sponsoring meetings and educating homecare companies. Congress needs to pass Medicare guidelines that will allow separate billing for respiratory therapy visits to the home, just like for nursing and PT/OT visits. Lastly, I talk to many medical directors whose general attitude is, ‘You want to do WHAT?’ and ‘Show me the literature’—of which there is not a lot that is not merely descriptive.”

Dikeman reported that, “It is frustrating to see the lack of good homecare services. Insurance coverage is

so variable and patients really struggle to obtain the services they need.”

Gay saw the biggest issues ... “from the reimbursement standpoint—as competitive bidding and how to devise homecare service to vent users when there is no provision to do so. It would be nice to have a template for standards of care to deliver home ventilator care that is updated and accepted for reimbursement.”

Hill cited several major problems. “(1) Helping patients who seem to be under a constant onslaught from many sides get the services they need; getting services from homecare providers who are under severe financial pressure; and obtaining services from nursing agencies. (2) Lack of a coordinated system, standards of care and caregiver education. (3) Our current health care environment sees patients at home with chronic illnesses requiring labor intensive and expensive care as cost-cutting opportunities rather than as individuals deserving of adequate support provided through well-organized networks. Much of the battle will have to be fought at the political level.”

Preutthipan explained that, “In Thailand, there is no federal system to financially support ventilator-assisted patients. If the patients need ventilators, they have to be admitted to the hospital and stay forever.”

Schwartz felt “... the voice of big business loud and clear. The ability to gain access to the equipment and care has outdistanced the knowledge base of how to treat specific ‘off-the-beaten-path’ disorders.”

Simonds relayed these barriers from England: “A negative view of the outlook and prognosis in individuals with

IVUN’s Medical Advisory Committee

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severe neuromuscular disease held by the public and health care professionals who are not routinely involved in their care, an assumption that one plan of medical management suits all, and a constant struggle to get funding—for research and ventilatory equipment.”

Widder identified many challenges. “(1) Getting insurance companies to understand that we no longer use 1990s technology. (2) Dealing with discharge planners who want the patient to go home ‘tomorrow’. (3) Getting paid appropriately for the services we provide, such as training which is paramount to living in the home. (5) Providing the correct amount of humidity. (6) Explaining that battery life is dependent on the type of ventilation used, the rate, the pressure, etc., and the number of alarms that may occur, and that a ‘nine-hour battery’ is an advertisement, not a reality.” ▲