Improving Long-term Respiratory Care in Ontario, Canada

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In 2006, the Ontario Ministry of Health and Long-Term Care designated a $6 million Ventilation Strategy. Driven by the need to free up ICU beds by moving medically stable ventilator-assisted individuals elsewhere, the Ministry established a hospital-based ventilator weaning program and funded additional chronic care beds at Westpark Healthcare Centre. The Ventilation Strategy acknowledged that community living was preferable to hospitalization and institutionalization, and far less costly and essential to quality of life, yet neither money nor Ministry commitment was allocated to support community living.

The Canadian Paraplegic Association Ontario (CPAO) and the Ontario SCI Solutions Alliance intend to change that by pushing the focus of effort where it belongs – in the community – where people such as Khadijah *(See box on page 7)*, who require long-term ventilator support have the right to live safely and fully.

These advocates know there are comprehensive programs in other countries and even in Canada.

Contact Peter Athanasopoulos (petera@cpaont.org) for a copy of the CPAO's revised position paper, "Living Fully in Ontario Communities: People with Spinal Cord Injuries and Disease Who Use Respiratory Supports."

British Columbia's Provincial Outreach Respiratory Program (PROP) is an excellent model for providing long-term respiratory care and support that enables ventilator users to remain in their homes and in their communities.

Through PROP, solutions and expertise are available in areas relating to equipment, new equipment trials, individualized respiratory solutions, specific disability-related expertise, innovations in mobility and portability, peer-inspired services, and developing home ventilation standards.

Respiratory therapists visit clients in their homes at least once a year and more frequently as needed. In the year 2007-2008, for example, 856 home visits were made and 700 phone calls received.

An education program provides workshops to clients, families and caregivers as well as healthcare professionals working with PROP clients. Biomechanical technicians maintain and repair all respiratory equipment, including mounting ventilators on wheelchairs. The team also works with acute care units in transitioning ventilator-assisted clients into the community.

Many educational materials have been developed, including a newsletter published three times a year, a website, booklets, program and service brochures as well as manuals. PROP maintains a detailed client database to ensure accurate information such as equipment settings, service records and inventory.

In an external review of the PROP program in 2008, Douglas McKim, MD, an Ottawa-based respiratory specialist, concluded, *"The advent of smaller, user friendly ventilators and the sheer cost of a life-supported patient in a critical care hospital bed has fueled the process of home mechanical ventilation. A very emphatic position has been taken on proper preparation and education of clients with recognition of their free-*

Khadijah, a 24/7 ventilator-assisted mother of two, is grateful for life and quick to acknowledge the support she receives. But she is frustrated. Before she became a 24/7 vent user, her physicians would not approve her to fly with a BiPAP®. When she became more vent-dependent, she was institutionalized. While there and worried about her children at home, she was told that The Children's Aid would look after her children.

"The biggest challenge to going home was to find five people with ventilator training to be with me 24/7. With help from others I escaped long-term care. If our healthcare system improved its provisions for people like me to live in the community, it would not have to bear the cost of keeping us in long-term care."

"Attendant care and the CCAC (Community Care Access Center) in total only provide six hours of the day — so you live in fear — the slightest thing gone wrong with your ventilator can risk your life."

"Ontario's Ventilator Equipment Pool (VEP) provides my ventilator, but I know there are smaller portable ventilators."

dom to evaluate their personal needs and values and maintain their own choices. The PROP program enables ventilator-assisted individuals to live outside of institutions and in the community where health-related costs are far less, and the quality of life and independence is recognized to be much greater. Home mechanical ventilation therefore provides a win-win situation for clients and ministerial budgets."

In Ontario, ventilator equipment and support is provided by the Ventilator Equipment Pool (VEP) under the auspices of the Ministry of Health and Long-Term Care's Assistive Devices Program. However, VEP does not provide clinical support, training, education or peer support. These services must be individually sought.

Ventilator-assisted individuals desiring to live in the community and able to direct their own care can spend up to 18 months living at Toronto's Gage Transition to Independent Living where they learn how to manage their disability needs, direct their attendant care, and acquire daily life skills in order to live safely and successfully in the community.

Transitioning to "what" then becomes the dilemma. Community resources are scarce indeed. Vacancies in 24/7 attendant-supported apartments are few, and the waiting lists long. Most projects lack adequate staff or are reluctant to accept "heavy care" individuals with specialized needs and equipment. Ontario's Direct Individualized Funding Program allows six hours per day with additional hours for 24/7 ventilator users, but the provincial waiting list is more than 400, with no increased provincial funding on the horizon. Discouraged, many ventilator-assisted individuals do not even apply.

The Canadian Paraplegic Association Ontario and the Ontario SCI Solutions Alliance have identified the critical prohibitive issues as:

- Insufficient attendant care hours;
- Lack of direct funding and supportive housing opportunities;
- Insufficient education for consumers, attendants and health care providers;
- Need for more appropriate ventilator equipment and evaluation (through the VEP);
- Nonexistent clinical support in the home (no access to RTs);
- Lack of community hotline for ventilator emergencies; and
- Lack of emergency preparedness planning.

Over the summer, the groups have met with Ontario ventilator users, agency staff and healthcare professionals involved in various hospital-based specialized facilities and community programs such as the Gage Transition to Independent Living Program. Their 2008 Position Paper, "Living Fully in Ontario Communities: People with Spinal Cord injuries and Disease who use Respiratory Supports," has been updated to incorporate their recommendations and advice. ▲

References for this article are online at www.ventusers.org/edu/valnews/VAL23-3ref.html