

## Home Mechanical Ventilation: obstacles to living at home

I shall focus on **seven critical points** in the process, which are frequent obstacles to living at home. This discussion will start at a time before mechanical ventilation is actually necessary for life support.

There are people with conditions that may lead to chronic respiratory failure and death unless long-term mechanical ventilation is used. Who are these people? They are mainly people with progressive neuromuscular disease, kyphoscoliosis, and those with progressive chronic pulmonary diseases. This is the "at risk" group.

People "at risk" of chronic respiratory failure and death, unless long-term mechanical ventilation is used... need careful evaluation and counseling by a physician experienced with long-term care and home mechanical ventilation (HMV). Whenever the term "physician" is used here, this means a "team approach" with other professionals including a social worker, respiratory therapist, physical and occupational therapist, etc... This evaluation and counseling usually requires a number of visits, and may need to include family members. Whenever mechanical ventilation should seriously be considered, peer counseling and networking is advised. This careful evaluation and counseling is the **first critical point**, and often is lacking.

If the person at risk is *appropriate* for long term mechanical ventilation after evaluation by the physician, and if the person is seriously interested, then the next step is to evaluate the resources to see if this option could be worked out in terms of funding and personal caregiver assistance. This is the **second critical point**: responsible advance planning; and this often does not occur.

When the patient and family and physician agree on long-term mechanical ventilation, if and when it becomes necessary, and if resources are available (making it feasible), then **noninvasive mechanical ventilation (NIV)** should be considered whenever possible. A trial using NIV should be considered before ventilator assistance

becomes necessary for life support. This provides the patient and family with hands-on experience, prepares them, and assists with decision making. This is the **third critical point**; but due to lack of planning and experience, it often does not occur.

In contrast, most people who use long-term mechanical ventilation in the United States have had an unexpected (unplanned) medical emergency, with respiratory failure and often with infection, requiring hospital mechanical ventilation and intensive care.

Most hospital emergency areas start mechanical ventilation by intubation without trying NIV. When the patient cannot be weaned in the Intensive Care Unit, usually a tracheostomy is performed without considering NIV. This is the **fourth critical point**: tracheostomy is often used when NIV might have worked as well or better. The consequence is mechanical ventilation that is more complicated, has more risk, and involves greater costs. Most people prefer NIV to tracheostomy if they have a choice. In some cases tracheostomy is needed and appropriate.

During the hospital stay the patient and family should learn to do all the needed care, including care related to the ventilator and other equipment. A team approach is needed for hospital discharge preparation, and familiarity with home mechanical ventilation. This is the **fifth critical point**: many hospitals do not have experience with HMV. The result may be a long hospital stay, transfer to a long-term care institution, or discharge home with inadequate training and arrangements. Most community hospitals can do this properly if they have a few key experienced professional staff members, including an experienced pulmonary physician.

The first six to twelve months of home mechanical ventilation usually requires professional assistance to help coordinate care, solve problems, and monitor the home care; to help with the transition to independence. The home care medical equipment company also needs to be well-versed with HMV.

A seasoned home care professional team includes: a physician, home health nurse, social worker, and respiratory therapist. This is the **sixth critical point**: home follow-up support often is inadequate. As time goes on the patient and family should learn the care process, and care coordination, and become increasingly self-sufficient. If the person is not very disabled in other respects, the major cost is for equipment, which can usually be worked out.

The **seventh critical point** occurs with the very disabled ventilator user who needs help with all aspects of personal care, and may need the ventilator for 20 to 24 hours per day. In this situation the ventilator user needs someone else to help up to 24 hours a day, which is often more hours that can be provided by family alone. It is often difficult to find community support for personal assistance services to help with activities of daily living, home making, and also with medical aspects of care. If the patient hires someone to assist as a personal attendant, this might cost \$6-8 per hour. However if this is provided by a practical nurse through a private duty agency, in California this often costs \$18-20 per hour. When 10 to 16 hours are required daily, the logistics are difficult, and a health plan or insurer often finds institutional placement more cost effective. The resources to support paid personal assistance in the home are a continuing challenge at the interface of medical care, community social services, and personal responsibility. The issue is further complicated by controversy as to whether it should be provided by personal assistance services (PAS) *vs.* a licensed nurse. Caregiver assistance may be the most difficult problem to solve. We hope there will be a change in health care in the United States resulting in better support for community-based long-term care. Related issues include often inadequate support for sophisticated communication devices, mobility devices and special transportation, and respite.

**In summary:           The seven obstacles to living at home with mechanical ventilation  
                                  that frequently occur are:**

1. Inadequate initial evaluation, counseling, and advance planning.
2. Inadequate resource evaluation to see whether home mechanical ventilation is feasible.
3. Noninvasive ventilation is often not considered, not used as a trial, and not used when appropriate.
4. Tracheostomy is over-used as the interface for mechanical ventilation.
5. Lack of the experienced team of professional staff needed to prepare the patient and family.
6. Lack of an experienced home care team to provide support particularly during the first 6 to 12 months of HMV.
7. Lack of resources for personal assistance services when the ventilator user is very disabled.

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