Invasive Mechanical Ventilation: Information for people with ALS
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Invasive Mechanical Ventilation, or IMV, is method of breathing by way of a plastic tube inserted permanently through an opening into the trachea (the windpipe), called a tracheostomy, in the lower front part of a person’s throat. It is called “invasive” because it requires surgery to access the windpipe. The invasive mechanical ventilator machine does all the work of the respiratory muscles, so it is considered a form of artificial life support. Some ALS patients choose this form of respiratory support when bi-PAP can no longer support their breathing adequately.

Most ALS patients using IMV need to be connected to the ventilator 24 hours a day, although in rare cases the person can come off the ventilator for periods of time during the day. Invasive ventilation does not slow down the weakness and eventual loss of voluntary muscles affected by ALS. The disease continues to progress despite IMV.

*For a more thorough discussion of the IMV option:


4) Contact your ALS health care team nurse, social worker, or mental health nurse for individualized attention and support to you and your family in thinking through this decision.

What are the advantages of IMV?

- For people who have little independent ability to breathe, IMV has been found to provide much longer survival for ALS patients than BiPAP; often years longer.

- It leaves the face free and avoids headgear, straps, and skin pressure problems on the face.

- It provides a secure connection directly to the airway for suctioning secretions.
- Many patients are satisfied with their quality of life on IMV

- The potential to continue to engage in life, loved ones, pleasurable activities, and to work toward personal goals as physically able.

**What are the disadvantages of IMV?**

- The person on IMV must have specially-trained individuals (reliable family/friends) able to handle advanced life support equipment, or skilled nurses (LPN or RN-level), in very close attendance, at all times: 24 hours a day, 7 days a week.

- Secretions that can block off the tracheostomy tube and airflow/breathing require suctioning, often at night as well as during the day.

- Most insurances do not cover this kind of very expensive nursing care at home

- Patients on IMV often lose the ability to eat or drink, and require a feeding tube inserted in the stomach for their nutrition and hydration.

- Patients on IMV often lose the ability to speak, using assistive technology to communicate.

- Patients usually require a motorized wheelchair with a special tray to hold their respiratory equipment, and require a wheelchair-accessible van to travel.

- Weakness continues to progress in the rest of the body, with eventual paralysis of all voluntary muscles. At some point (rates of progression differ for each person), people with ALS will progress to a totally “locked-in” state, unable to communicate with the outside world in any way.

- Family members/friend’s lives can become disrupted and deferred. Quality of life for caregivers may decline significantly.

- Personal and family financial resources can be consumed.

- Choosing IMV may mean changing your living situation to receive care in a nursing home.

**In Summary:**

**You may want to consider invasive mechanical ventilation if:**

- You are highly motivated and engaged in living.

- Your medical problems, including ALS, are stable and progressing slowly.

- Your level of independent functioning allows some ADL (activities of daily living).
- Your ability to communicate is good (e.g., using a communication device), and you can help direct the care needed.
- You and your family understand the options, both the pros and cons.
- Your family is able and wants to participate, if needed.

You may choose **not** to use invasive mechanical ventilation if:
- Your disability is advanced.
- Your ability to communicate effectively is very limited.
- Your interest in or motivation for living is low.
- You are not mentally alert or self-directed.
- You do not have intense, round-the-clock, awake caregiver support available from family or friends to remain at home, and do not want to live in a nursing home.

The decision to choose invasive mechanical ventilation is a very personal one. You will not live as long without a ventilator, but **people with ALS who choose not to use IMV can arrange for the at-home care and support they need to remain comfortable as the illness progresses.** This is usually provided through hospice, which becomes another “arm” of your ALS Care Team. Your current ALS Care Team continues to provide support and expertise to you throughout the course of the illness.

People with ALS who choose IMV can live for years. Some ALS patients utilizing IMV are cared for in nursing homes, while others are able to remain at home. Your family and friends must determine whether or not they can be available to devote the amount of time needed, over months and possibly years, to be sure that someone is always with you. Those who support your care at home must be comfortable with technologically advanced equipment, medical procedures such as suctioning mucous, as well as your routine daily care needs. Often they must put off many other personal plans. Family members generally need to make their own decision to assist with care, especially since the burdens are heavy. **Caring about someone doesn’t always mean they’re suited to caring for someone’s physical needs!** Home care should be arranged so that excess responsibilities are not carried by any one person. *As a general rule, it takes 4 to 5 people committing to “full-time” (40+ hours/week) to provide care to someone on IMV at home.*

People using IMV may elect to discontinue this medical intervention, going back to their natural state as if they had not used IMV. This is done in a supported (usually hospital) environment to keep them comfortable. Reducing and discontinuing IMV support means the person will pass away, due to the effects of ALS on the body, usually within hours.

It is important for you to decide what is best for you; **do not let an emergency decide for you.** No decision *is* a decision! If you have not documented your choices, or if your family is unsure of your wishes, the medical system will choose for you. Stay in control so you can choose what is best for you. **Speak with your neurologist, social worker and mental health nurse regarding this issue and others related to your Advanced Directives.**