

Breathing support facts - what you should know

This guide is for those whose advanced illness is getting worse despite treatment. The time may come when simply breathing in and out is hard work. Your stress and symptoms could prompt your health care team to suggest you get breathing support from a machine called a ventilator. It is better to consider this treatment option before there is a crisis. In some cases, breathing support can help you live well for many years. In other cases, breathing support may lessen discomfort but not lengthen life very much. In these cases, breathing support may extend the dying process without helping improve health, function or ability to resume a normal routine. This guide can help you decide whether you want to try using machine-aided breathing soon or in the future. Your doctor or care provider can explain risks, benefits and options suited to your condition.

What situations and conditions may prompt this discussion?

- Your breathing muscles are being weakened by a progressive disease.
- A well-managed chronic condition gets worse, despite the best treatment and causes breathing failure. This can occur in severe chronic obstructive pulmonary disease (COPD), amyotrophic lateral sclerosis (ALS), otherwise known as Lou Gehrig's disease, or congestive heart failure (CHF).
- Your immune system is too frail to protect you from pneumonia or other lung infections.

• **Chances of your return to normal routine**

could be slim to none. Some forms of breathing support might ease discomfort and other symptoms caused by breathing failure.

How and when should I decide?

Choosing to use or not use a machine to help you breathe can be a challenge. It may take time to think about your goals, values and beliefs. To learn more before you decide:

- Ask your health care providers.
- Talk with loved ones and family.
- Ask other people with a condition like yours who use machine-aided breathing.
- Speak to a faith community leader who has helped others face choices like yours.

This guide provides background needed for these conversations. It is never too soon to thin[6E(s.)]TEo-2 (c)02g

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You must think about who could provide this care if you cannot learn to do it for yourself. Friends and family might not be able to care for you. You may lack the funds to pay for in-home skilled care. Options for long-term living must be addressed. Health insurance and government-funded home care policies will affect your choices. You may have to move to a nursing home or ventilator care facility.

What could happen if I decide not to try breathing support?

If your breathing starts to fail and you have decided not to have breathing support, you could experience uncomfortable symptoms.

This is caused by the increasing stress of breathing. You may feel anxious as less air gets in and out of your lungs. If your main goal is comfort, your symptoms can be relieved. In the final stages of breathing failure, you may become drowsy and at some point, unconscious.

Talk about your fears with your doctor so you get the best symptom treatment. Health care teams trained to manage symptoms can be very