When your loved one is on a Mechanical Ventilator

You’re the expert!

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INTRODUCTION

Our team of nurses, physicians, specialists, and researchers worked with former patients and their families to create this resource toolkit. Together, our goal is to make communicating and participating in care easier for patients on mechanical ventilators and their loved ones.

Patient and Family Engagement and Communication Tools

Section 1: Complication Prevention
Section 2: Family Involvement Menu
Section 3: Communication Tools
COMPLICATION PREVENTION

Mechanical ventilation saves lives, but it also carries potential complications. The following are four steps that help to reduce complications and actions family members can take to help patients on ventilators. We invite you to talk to your care team about each of these strategies for preventing complications.
Tips for Preventing Ventilator-associated Complications

Raising Head of Bed
Most patients on ventilators benefit from having the head of their bed elevated 35 to 45 degrees at all times. This helps prevent fluid from collecting in their lungs, which can cause pneumonia.

Ventilator Weaning
To see if your loved one is able to come off the ventilator, the care team checks how they do when woken and if they can breathe on their own.

• Awakening trials: the amount of sedation is reduced so they can wake up.

• Breathing trials: the ventilator is turned down or off so they can try to breathe on their own.

Breathing and awakening trials help patients get off the ventilator and leave the ICU sooner, and are most effective when done daily. Sometimes patients struggle during the trials, which is normal. Here are ways you can help:

• Touch – holding the patient’s hand or stroking their arm or hair may be soothing.

• Talk – coaching and encouragement can reduce patient anxiety and help them breathe more slowly.

You can also describe what’s happening and rephrase what the staff says in your own words.
Tips for Preventing Ventilator-associated Complications (continued)

**Delirium Prevention**

Some patients in the ICU have new difficulty focusing and abnormal thinking, called ‘delirium.’ This may include hearing and visual hallucinations. Identifying delirium can be challenging. However, by watching for and preventing it, we can help patients leave the hospital and ICU sooner, reduce their risk of cognitive problems, and promote recovery. You can use **MNOPQR** to remember steps to prevent delirium:

- **M**ental Stimulation – Speaking with a patient can make a difference, even if they are sedated. Getting out of bed (if possible) and playing familiar TV shows, the daily news and instrumental (non-vocal) music are also appropriate.

- **N**ighttime Sleep – You can promote good nighttime sleep habits by turning lights down or off at night, closing window blinds, and minimizing nighttime noise. During the day keep lights on and the window blinds open, engage the patient in activities, and help them avoid naps.

- **O**rient – Regularly tell your loved one where they are, the date and time, why they are in the ICU, and what is happening.

  • Speak calmly and simply. (See the Communication tab for more suggestions.)

  • Patients are less likely to become delirious if they wear their glasses and hearing aids.
Tips for Preventing Ventilator-associated Complications (continued)

• **Pain** – Let the nurse know if your loved one seems to be in pain.

• **Question** – Let the care team know if you have a concern or suspect delirium.

• **Routine** – Be a calming presence at their bedside while helping them have a routine and familiar activities, for example, electronic devices, mail from home, and the newspaper.

**Early Mobility**
Your loved one may benefit from early exercise and mobility, which speed separation from the ventilator, prevent bed sores, decrease time in the hospital, and quicken recovery. Often exercises can be done even if a patient is unable to leave their bed, and frequently family members can help.

• Ask the care team if there are exercises or stretches they or you (depending on your and the patient’s comfort level) can do to help with recovery. You can also ask if consulting a physical therapist would be useful. There are more ways for you to support the patient listed in the Family Involvement Menu.
You know the person that we are caring for far better than we do. We would like to invite you to participate in your loved one’s care. Listed on the following page are options you may choose.

“Getting family involved is great... it’s a great tool to help the patient want to get better quicker.”
—Former mechanically ventilated patient
If there is a particular activity that you would like to assist with, please ask the patient and the healthcare team. The team will provide instructions for each of the following according to your comfort level.

**Personal Hygiene**
- Brushing teeth
- Face washing
- Bathing
- Oral suctioning
- Shampoo
- Combing hair
- Shaving

**Skincare: Legs, Back, Hands, and Feet**
- Massage
- Makeup
- Lotion
- Nail care

**Entertainment, Distraction, and Reminders of Life Outside the Hospital**
- Personal favorites: music, television, reading, and audiobooks
- Hobbies, daily activities
- Pictures from home
- Letters, videos, and visits from friends, family, and community

**Best Practices: Getting off the Ventilator Faster** *(See the section Complication Prevention for more information.)*
- Raising head of bed
- Ventilator weaning
- Delirium Prevention
- Early mobility
When you or a loved one are mechanically ventilated, difficulty communicating is a common source of distress and preventable complications. These tips can improve communication between patients, their families, and healthcare providers.

Mechanically ventilated patients frequently cannot talk, but often have a lot they would like to say.
General Communication Strategies – For any nonverbal person on a ventilator

Provide hearing aids and eyeglasses
If your loved one uses hearing aids or glasses bring them in, tell their nurse, and help them to use them regularly. Glasses can help prevent delirium.

Face the patient, get their attention before speaking, and give them time to process their thoughts.
Patients who cannot speak have to think about what to respond and how to deliver that message. This takes much more time than verbal communication, and can make even simple communications frustrating. Don't lose heart, and keep trying patiently.

Ask clear Yes/No questions – one at a time – and wait for a response before asking another question or providing more information.

We Recommend using consistent signals for Yes/No

Here are a few examples:
• Eyes up for Yes, scrunch eyes for No
• Thumbs up for Yes, thumb in fist for No
• Smile for Yes, pucker for No
• Written words for Yes and No
• Blink once for Yes, twice for No

Add emphasis to questions and statements:
• Yes? [Voice up] … [pause] … or … No? [voice down]
• Add visual elements to your speaking like head nods, gestures, and pointing at objects
• Break up phrases… into smaller chunks… with pauses… between chunks…
• Confirm the patient’s answer by repeating it

Post your Yes/No strategy somewhere the staff, patient, and visitors can see it.
Written Communication

Memo strategy
Encourage the patient to write messages in advance in a spiral notebook, tablet, or mobile phone. This way the messages are available when needed and can be reused.
• Place the paper or notebook on a stable, flat surface.
  - Many patients find using felt-tip pens easiest.
• Block writing (printing) is often easier to read than cursive.

Whiteboards
Many patients find whiteboards extremely useful for communicating. Ask your nurse if you don’t have one or need a dry erase marker.

Communication Boards

Letter boards
(full size located on the final page of this toolkit)
Letter boards are a good option for alert patients who cannot write. Here are some strategies for using them:

Pointing out letters: Encourage the patient to point at the first letter of the word while mouthing (saying) the word. Verbally confirm each word before moving to the next.
  • If you cannot understand the word, ask the patient to spell and mouth the general topic instead.

Line-by-line approach: Works best for patients who have a good Yes/No signal but difficulty pointing. Ask if the letter falls within a particular row. Once the correct row is found, ask letter by letter.
  • If the patient prefers spelling entire words, keep track of letters by writing them down.

Continued on next page…
Word and picture board
Personalize your own boards of words and images your loved one commonly uses.
• Recommended words: TV, Music, Time, Hot/Cold, Thirsty, Suction, Pain, Scared, Sad, and I love you

Communicating with Patients who are Sedated or Confused
Written choice technique
Ask the patient a who/what/when/where question, then write possible answers and show them to the patient while saying what they are.

Here's an example conversation using the written choice technique:
1) Ask, “What would you like me to bring you from home?”
   • Write out several options: family photos, music, books, laptop, or something else
2) Hold the list where the patient can see it, and slowly say and point to each option.
3) When they choose something – for example music – verbally confirm their choice.
4) Repeat the process as needed with clarifying follow-up questions. For example, “Okay, what kind of music should I bring?”
Cited Resources


Other

Body

Things I need

Family

Pain/medicine

Topics: Business

• quit
• start over
• mistake

You didn't understand

End word/sentence

Word as I mouth it.

First letter of each

I will point to the

Whole word.

I will spell out the