

ICU

Issues &
Answers

Chronic Critical Illness in Adults Requiring Prolonged Mechanical Ventilation

Society of
Critical Care Medicine

The Intensive Care Professionals

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Who Is This Brochure For?

If an adult member of your family has been in the intensive care unit (ICU) on a breathing machine (mechanical ventilator or respirator) for many days, this brochure about **chronic critical illness** is for you. We hope that the brochure will help you understand chronic critical illness and feel more informed when you talk with the doctors and nurses about important decisions for your family member.

What Is Chronic Critical Illness?

Most patients who need care in the ICU get better quickly. After a few days in the ICU, they no longer need a breathing machine or other critical care treatments. But even with the best ICU care, some patients remain critically ill and have trouble breathing on their own, without a machine, for a much longer time. These patients have chronic critical illness.

What Causes Chronic Critical Illness?

We do not know why some ICU patients get better quickly, whereas others remain critically ill and need a breathing machine for a long time. But we are learning how to take better care of patients with chronic critical illness and their families. We are also learning more about what to expect from treatments that exist today.

How Do Doctors and Nurses Know a Person Has Chronic Critical Illness?

There is no test to diagnose chronic critical illness. Doctors and nurses know that adult patients have chronic critical illness when they still need a breathing machine even after weeks in the ICU. For most patients, chronic critical illness also involves many body systems and organs.

What Treatment Is Available for Chronic Critical Illness?

Treating chronic critical illness involves caring for the total person rather than administering a single medication or procedure. The goal of care is, if possible, to free patients from the breathing machine, from other life supports, and from the need for more help with everyday activities than they needed before this illness. Doctors, nurses, and other members of the health care team try to slowly help the patient become free of the breathing machine in small steps (often called “weaning”). They also provide feeding through a tube, skin care, and other types of care for infections. They try to prevent new infections and other problems. Unfortunately, this is often very difficult and unsuccessful.

Where Are Patients With Chronic Critical Illness Cared For?

Patients may stay in the ICU, but sometimes patients with chronic critical illness are transferred to another unit in the hospital or to another facility outside the hospital that specializes in caring for these patients. This will depend on the patient’s situation and on the hospital and city.

Do Chronically Critically Ill Patients Regain the Ability to Breathe on Their Own Without a Breathing Machine?

In time, about half of patients with chronic critical illness are able to breathe on their own without a ventilator. The rest of the patients will always need the ventilator to help with breathing. The chances of being free from the ventilator decrease as time goes by. Each patient is different, and it is not always easy to predict how things will turn out. Feel free to ask the ICU staff for their opinion about what is likely to happen to your family member in the future.

What Does It Feel Like to Be Chronically Critically Ill?

Having intensive treatment for a long time may be difficult for patients. They may feel frustrated because they cannot talk or eat regular food. Some patients report distress or discomfort caused by pain. Some have difficulty sleeping. Some are depressed. Doctors, nurses, and other members of the health care team try to keep the patient comfortable and free of distress. The illness is still difficult for many patients.

How Alert Are Patients With Chronic Critical Illness?

In the early phase of critical illness in the ICU, many patients receive medicines to make them less anxious. These medicines are called sedatives. They make patients less alert. The doses of these medicines are often lowered or stopped as time passes, so patients can be more awake. Patients with chronic critical illness can also be confused or unconscious from other illnesses or medications. You can ask the physician how alert the patient is. You can also ask how much the patient understands what is happening.

Can Patients Live on Their Own After Treatment for Chronic Critical Illness?

Patients who survive treatment for chronic critical illness are weaker after treatment than they were before they came to the ICU. Very few of these patients can return directly home from the hospital. In fact, most patients never recover their previous strength and function. The majority are unable to do basic daily activities (such as eating, using the toilet,

bathing) by themselves. Most cannot live independently and need to be in a nursing home.

What Is the Experience Like for Families of Patients With Chronic Critical Illness?

Long critical illness is hard on the family as well as the patient. You may feel stress, worry, sadness, or fatigue. Some families worry about financial burdens. They face many challenges when giving long-term care. You can ask for meetings with a social worker or other hospital staff members to get help with your concerns.

Is Chronic Critical Illness a Serious Condition?

Yes. Patients who survive initial treatment in the ICU remain at risk of dying. Doctors worry most about patients who are elderly and about those who still need life supports like the breathing machine, even after many attempts to help these patients come off life support. Most patients have trouble fighting infections. More than half of patients with chronic critical illness die within 6 months. Even if the patient is treated and slowly begins to breathe without the help of the ventilator, the effects of chronic critical illness can be severe and long-lasting.

What Are the Options?

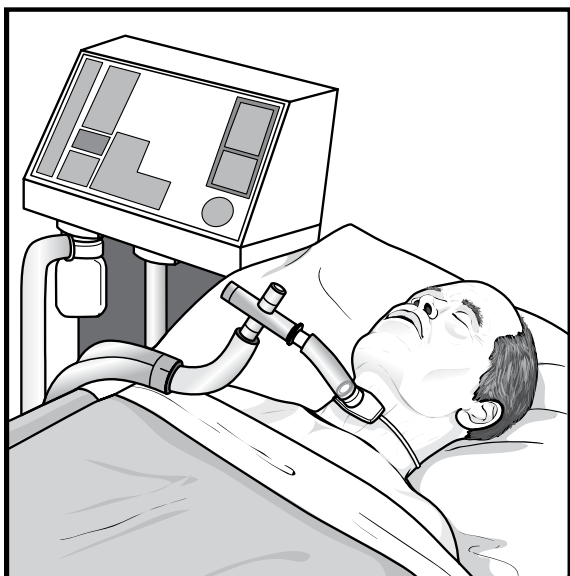
Like any patient, the patient with chronic critical illness has the right to make decisions about treatments that may be offered by the health care team. If the patient cannot make decisions, someone else who is approved to make decisions, such as a health care proxy or family decision maker, has the right to be involved in treatment decisions and help the doctors and nurses understand what the patient would want if he or she could decide personally. To make the

best decisions for your loved one, you need information about what treatment options are available. You can learn about the benefits, risks, and burdens for each option. You are encouraged to ask questions. Talk with the health care team about the patient's situation and chances of getting better. Decisions made at one point in time can be changed at a later time. You may also wish to discuss either now or later the option of stopping intensive treatments such as the breathing machine while keeping the patient comfortable. The needs and concerns of the family as well as the patient are important throughout this process.

What Is a Tracheotomy?

A breathing machine (mechanical ventilator or respirator) helps the lungs breathe and provides oxygen. When patients are first put on this machine, they are usually connected to it by a tube that goes through the mouth and vocal cords (in the larynx or voice box) into the trachea (windpipe). If the patient needs a breathing machine for a long time, the ICU team may advise that this tube be moved from the patient's mouth to the neck. A small cut called a "tracheotomy" is made in the neck, allowing the tube to be taken out of the mouth and placed directly into the trachea below the vocal cords; the patient is still connected to the breathing machine. Tracheotomy is a kind of surgery that is usually done in less than 30 minutes at the patient's bedside in the ICU. Sometimes it is done in the operating room.

If a tracheotomy is being discussed for your loved one, you can learn about the likely risks and benefits of this procedure. You can talk about the decision with the ICU team and the surgeon who would perform it. If tracheotomy



A patient who is connected to a breathing machine (mechanical ventilator or respirator) by a tracheotomy tube inserted in the patient's neck

is being discussed because the patient is still on a breathing machine with chronic critical illness (there are reasons besides chronic critical illness why a tracheotomy may be recommended—those situations can be different), you should also try to understand more about chronic critical illness and the risks and benefits of being on a breathing machine for a long time.

Who Can Help?

The doctors and nurses on the critical care team can provide facts, advice, and support. Help from a social worker or chaplain may also be valuable. Ask for information and assistance.

Glossary

Here are brief explanations of some terms you may hear:

Advance directive—Instructions from a patient (spoken or written) about treatments the patient would want or not want and about who should make medical decisions if the patient cannot do this personally. Advance directives include living will, durable power of attorney for health care, and health care proxy.

Arterial blood gas (ABG, blood gas, gas)—Blood test on a sample of blood from the artery that helps the doctors and nurses know how well a patient is breathing by measuring the amounts of oxygen and carbon dioxide.

Attending physician—Senior doctor on the health care team who oversees the patient's care.

Cardiac monitor (monitor)—Screen that shows the patient's vital signs (heart rate, blood pressure, oxygen levels, breathing rate). Various wires and cables connect the patient to this monitor.

Catheter (tube, line, drain)—Plastic tube placed in a blood vessel (vein or artery) or another part of the body (eg, bladder catheter to drain urine).

Central line (IJ, subclavian line, femoral line)—Special intravenous catheter in a large vein (usually near the neck or collar bone) to give fluids, medications, or nutrition or to measure blood pressures in and around the heart.

CPR (cardiopulmonary resuscitation)—A procedure to try to restart the heartbeat if a patient has a cardiac arrest—that is, if the patient’s heart and breathing stop. This procedure combines pressing on the chest and giving rescue breathing (in the ICU, this is done by machine) and administering medications.

Critical care team (ICU team)—Team of health care professionals who care for critically ill patients and their families; this team includes the attending intensive care doctor, critical care nurse, respiratory therapist, and critical care pharmacist. Social workers, clergy, and others may also be members of the critical care team. Some ICUs have nurse practitioners or physician assistants.

Do-not-resuscitate (DNR, do-not-attempt-resuscitation, DNAR)—A directive (order) that instructs doctors and nurses not to attempt to restart the patient’s heartbeat or breathing through CPR.

Durable power of attorney for health care—Legal document that gives another person—called a “surrogate decision maker”—the authority to make health care decisions for a patient when the patient is unable to do so personally.

ECG (EKG)—Equipment that monitors and shows the heartbeat.

Endotracheal tube (ET tube)—Breathing tube that is placed in the patient’s airway (trachea) through the mouth or nose (or through the neck after a tracheotomy). This tube is attached to a mechanical ventilator (breathing machine) to help the patient breathe.

Face mask (oxygen mask, O₂ mask)—Plastic mask that is placed over the nose and mouth. The mask is attached to a plastic hose that gives oxygen (from a tank or wall source) to help the patient breathe.

Fellow (ICU fellow)—Doctor who is training to care for critically ill patients and their families.

Health care proxy (proxy)—Similar to durable power of attorney for health care; see above.

Intensivist—Doctor or nurse with special training to care for critically ill patients and their families.

Life-supporting treatment (life support)—Treatment that can include mechanical ventilation (breathing machine), artificial nutrition (feeding by tube or through the vein), intravenous hydration (fluid given through the vein), kidney dialysis, medicines to raise blood pressure and boost the heart rate, and other treatments to attempt to prolong life.

Nasal cannula (cannula)—Plastic tube that fits around the head with two short prongs into the nostrils. It provides the patient with oxygen (from a tank or wall source).

Nasogastric tube (NGT, NG), orogastric tube (OGT, OG)—A tube placed through the nose or mouth into the stomach. It is used to give medicines and feedings or to drain stomach contents.

PEG (percutaneous endoscopic gastrostomy)—Tube placed through the skin and wall of the abdomen into the stomach to give feedings (and medicines) to patients who cannot take these by mouth.

Pulse oximeter (pulse ox, O₂ sat monitor)—Device placed on finger, toe, or earlobe to check how much oxygen is in the blood.

Suction—Removal of secretions (phlegm or mucus) or drainage from the patient's airway (trachea) or other part of the body (eg, stomach).

Tracheotomy (tracheostomy, trach)—Surgical opening in the neck for a breathing (endotracheal) tube into the patient's airway (trachea). This tube is attached to a mechanical ventilator (breathing machine) or an oxygen mask to help the patient breathe.

Vasoactive drugs (vasopressors, pressors, drips)—Medicines that are given by vein (intravenously) to raise or lower blood pressure and boost the heartbeat.

Ventilator/respirator (vent, breathing machine, mechanical ventilator)—Machine attached to the patient by a tube (in mouth, nose, or neck) to help the patient breathe.

Weaning—Process of trying to help the patient become free of the breathing machine by lessening the help from the machine step by step.

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