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 ventilator 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 always know why some ICU patients get better quickly whereas others remain critically ill and need a ventilator for a long time. Medical problems that people have before being hospitalized can be a factor. New problems that develop during the hospitalization can also hinder recovery. 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 ventilator after about 2 weeks of treatment in the ICU. For most patients, chronic critical illness also involves many body systems and organs (which can result in skin changes, weakness, confusion, and increased risk of infections).

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 ventilator, from other life-supporting treatment (life support), and from the need for more help with everyday activities than they needed before this illness. Doctors, nurses, and other members of the critical care team try to help the patient become free of the
ventilator 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 although, unfortunately, this is often very difficult and unsuccessful.

**Where are patients with chronic critical illness cared for?**
Patients will stay in the ICU initially, but often 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 patients with chronic critical illness regain the ability to breathe without a ventilator?**
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 medical team 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 healthcare team try to keep the patient comfortable and free of distress. However, 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 (sedatives) to make them less anxious or as part of the treatment for their medical condition. Sedatives 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 medical team how alert the patient is and whether there are times of day when he or she is most alert (often this fluctuates). 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 or other type of care facility where most or all of their care is provided by others.

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 or stress on family relationships. 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 higher risk of dying. Doctors worry most about patients who are elderly and about those who still need life supports like the ventilator, 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 are often permanent.

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 healthcare team. If the patient cannot make decisions, someone else who is approved to make decisions, such as a healthcare 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. In the case of a child, decisions are made based on what is in the child’s best interests. To make the best decisions for your family member, 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 healthcare 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 ventilator 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 tracheostomy?**

A ventilator 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 ventilator for a long time, the ICU team may advise that this tube be moved from the patient’s mouth to the neck. Surgery is done on the neck to make an opening and place a tube directly into the trachea below the vocal cords; the breathing tube is removed from the mouth, and the patient is still connected to the ventilator. Surgery may be done at the bedside in the ICU or in an operating room. The opening in the neck is called a tracheostomy.

![A patient is connected to a ventilator by a tracheostomy tube inserted in the patient’s neck.](image)
If a tracheostomy is being discussed for your family member, 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. Placing a tracheostomy does not make a sick patient better—it is not a treatment for a medical condition. It is a necessary procedure if a patient needs to stay on a ventilator longer than approximately 2 weeks. If tracheostomy is being discussed because the patient is still on a ventilator with chronic critical illness (there are reasons besides chronic critical illness why a tracheostomy 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 ventilator 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.