

Managing The Intensive Care Unit (ICU) Experience:

A Proactive Guide for Patients and Families

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Disclaimer

This Intensive Care Unit (ICU) guide for patients and families is intended to provide general information about adult ICUs. The guide is for informational purposes only and is not a substitute for the advice or counsel of one's personal healthcare provider.

Background

Originally developed in 2001 by members of the Assembly on Critical Care, including Constantine Manthous, MD and Martin Tobin, MD, the guide has been updated periodically for accuracy. In 2020, the guide was significantly updated and edited by members of the ATS Patient and Family Education Committee (PFEC), including Catherine Chen, MD, Vidya Krishnan, MD and Marianna Sockrider, MD, DrPH, to reflect current science and healthcare practices. Additionally, we wish to acknowledge the quotes and family directed questions provided by Drs. Carson, Curtis, Ely, Kollef, Kress, Pronovost, Schweickert, and Stapleton as part of a separate quality improvement initiative led by Dr. Manthous. Finally, we greatly appreciate the input from Drs. Akgun, Beesley and Sicilian on behalf of the ATS Ethics and Conflict of Interest Committee.

This guide is dedicated to all patients, families, and caregivers who have had an ICU experience, and the healthcare providers who cared for them.





Introduction

Each year, hundreds of thousands of patients in the U.S. and millions worldwide become critically ill. Patients who require care in the intensive care unit (ICU) have the most serious illnesses, often requiring multiple forms of life support. While the science of medicine has significantly advanced in the past 30 years, these advances sometimes create many questions, such as:

- **Will my loved one be able to live independently after this?**
- **What kind of rehabilitation will my loved one need?**
- **What will my loved one's quality of life be after this illness?**

More than ever, medical teams rely on families to help them make important decisions about their loved ones' care, and their futures.

The purpose of this series is built on the ideas that knowledge is power and that every patient needs an advocate. Here, we share some of the most important advances in ICU medicine so patients and their families can ask educated questions.



The Role of the ICU in Public Health Emergencies and Disasters:

Healthcare, including care in an Intensive Care Unit (ICU), can be in big demand when there is a public health emergency such as a pandemic infection or a disaster (natural or manmade).

The way in which an ICU provides critical care and how its staff work may change quickly in major ways.

It is possible that critical care resources may become overwhelmed. There is a risk of sudden critical shortages of specialized equipment, medications, and/or people to work. When a crisis is going on, the usual standards of care may have to change. There may be changes in the kinds of treatment you or your loved one can receive and/or in how you are able to talk with the healthcare team. These changes apply equally to all patients.

These crisis standards of care would only happen if:

- 1) the critical care capacity is, or will shortly be, overwhelmed despite the healthcare system's best efforts to increase the capacity to care for critically ill patients, and
- 2) a regional authority has declared a public health emergency (disaster).

In such a crisis, the care that you or your loved one is able to receive may be determined by what resources are available and not just by how sick you or your loved one is, or what the cause of the critical illness is. The hospital may appoint an emergency triage team to make decisions about how to best use the limited resources. This team usually does not include the physicians and staff taking direct care of you or your loved one. The medical team will keep their focus on caring for their patients as individuals.

The triage team will use accepted standards of ethics and public health as they make decisions. They have to consider how they can achieve the greatest good for the greatest number of patients. This may mean that what is best for an individual patient is not able to be done. No hospital system or critical care team ever wants to be in the position where it has to limit care based on resources. However, this could become



a reality in a dire situation such as a pandemic illness where critically ill patients outnumber critical care resources, such as ventilators.

When crisis standards of care are in place, you may notice that the operation of the ICU is different from what is outlined in this booklet. Changes may include, but not be limited to:

- **Limiting or prohibiting family from visiting in the ICU,**
- **Choosing how medications and equipment are used,**
- **Considering limits on the use of CPR or dialysis in very ill patients,**
- **Restricting tests such as bronchoscopy or certain X-rays/scans to emergency use only.**

This will no doubt raise anxiety in patients and their loved ones. Your ICU physician and all members of the care team recognize and share this anxiety with you. They remain committed to provide the best care they can to each patient. They will always advocate on their patient's behalf. Even if they are not able to speak to you in person or at the bedside, they will try to find ways to talk with you and other people who are serving as the decision makers for a sick loved one.

Since public health emergencies/disasters are uncommon events and may be local or widespread, their impact on any one ICU will vary. If you or a loved one is already receiving care in or awaiting admission to the ICU during such an event, please ask your ICU team to discuss with you the crisis standards of care at the hospital and how they could affect your care.



Structure of an ICU: Physician Roles & Procedures



Physician Roles

Unsurprisingly, many physicians and nurses are required to care for a critically ill patient. For families, it can often be confusing to figure out the roles of all these people, especially when medical jargon is used.

If you are unsure what a physician's role is in your loved one's care, please ask. Here is a quick guide to provider roles:

Primary physician/team: This is the physician or team of physicians who are overseeing all of the patient's care. They are coordinating tests, medications, and calling specialists—called consultants—for particularly difficult problems. In a team, physicians in various levels of training may be participating.

Intern: This physician has completed medical school and is in the first year of their medical training (called "internship").

Resident: This physician has completed medical school and their first year of medical training, and is now completing additional years of training (called "residency").

Fellow: This physician has completed a residency (see above) and is receiving subspecialized training.

Attending: This physician has completed all training and is practicing independently.

Consultants: This is a subspecialist physician or team of physicians who have been asked to assist in a particular medical problem. A patient can have more than one consultant. For example, patients with kidney problems will often be seen by a nephrologist—a kidney doctor.

If you are ever uncertain of a provider's role in your loved one's care, please ask.



Procedures

Patients who are in the ICU often need invasive procedures performed. These procedures usually need permission from the patient or their family members, if the patient is unable to provide permission (“consent”). Providers should always wash their hands or use hand sanitizer before starting these procedures; some procedures may be performed “sterilely,” wearing a cap, gown, face mask, and gloves. Here is a list of the most common procedures performed in the ICU:

Central line placement: An intravenous (IV) catheter that is inserted under sterile conditions to give specific and concentrated medicines and fluids. This procedure is usually performed in the patient’s room, with the IV catheter placed in a large vein in the neck or groin. This IV is intended for short term use whenever possible.

Peripherally Inserted Central Catheter (PICC Line) placement: An IV catheter that is inserted into the patient’s arm under sterile conditions and is intended for long-term use. This procedure is usually performed in the patient’s room by a specially trained individual.

Arterial line placement: A IV catheter that is inserted into an artery under sterile conditions to help measure blood pressure more accurately. This procedure is usually performed in the patient’s room, with the catheter placed in an artery in the wrist or groin.

Intubation: A breathing tube (“endotracheal tube”) that is placed into the patient’s windpipe (“trachea”) through the mouth in order to assist breathing. This is connected to a breathing machine (“ventilator”).

Transfusion: Administration of red blood cells, platelets, or other blood products in order to correct low blood counts or manage bleeding.

Cardiopulmonary Resuscitation (CPR)

CPR is a series of procedures that are intended to try to restart the heart of someone whose heart has stopped (“cardiac arrest”). This includes putting in a breathing tube if one is not already present, performing chest compressions to try to circulate blood while the heart is not beating, giving medications to try to restart the heart, and, in specific situations, shocking the heart with electricity (“defibrillation”) to try to restart the heart.



Unlike what is often shown on television, CPR is not successful in most hospitalized patients. Only about 15% of patients who have cardiac arrest while in the hospital survive to be discharged from the hospital, and a very small number of these patients are able to return home. Some patients may have brain injury due to the brain not receiving enough oxygen while the heart is not beating. It is also important to remember that CPR does not fix any of the medical problems that caused the patient's heart to stop. Patients are always sicker after undergoing CPR than they were before.

Most importantly, a choice not to have CPR will not affect your current care or result in your doctors stopping life-sustaining treatments that you are already receiving. A patient can continue to receive life support even if they decline CPR. If you choose not to have CPR, in the event your heart was to stop beating, your medical team would allow you to die naturally, without interference.

If you have any questions about how effective CPR will be for your loved one, please ask the medical team the following questions:

"If my loved one's heart were to stop, how effective do you think CPR would be?"

"What are the risks to my loved one of receiving CPR?"

"What should we do if my loved one wants CPR, or wants to decline CPR?"



Medical Decision-Making & Establishing Goals of Care



Medical Decision-Making

Many patients who are admitted to the ICU cannot make decisions for themselves because of how seriously ill they are. In these situations, family members or close friends often become involved in helping make decisions for patients. In some cases, patients have made their medical wishes known in legal documents called living wills or advance directives. Patients may have even appointed a Durable Power of Attorney (DPOA) for healthcare, an individual who has been assigned the legal responsibility of making medical decisions on their behalf if they are unable to make decisions. Often, however, patients and their families have not discussed their preferences for medical care.

If a patient has not made their preferences for medical care known, some states have laws about who can make medical decisions on the patient's behalf. Other states expect

When your loved one is in the ICU, think about his or her values. What is important to them and what do they value most about life? This can include the activities they enjoy and things they find meaningful in life. For example, some patients prioritize their independence.

Second, think about your own emotions. Try to separate what you want for your loved one and what your loved one might want for themselves. The choices your loved one might make may not be the same as the choices you would make for yourself. Your job is to help the ICU team understand the choices your loved one would make if they were able to communicate.

Finally, think about what you expect to happen to your loved one. Ask the medical team what their expectations are too. If your expectations are different, be prepared to discuss with the team why this might be.



families to come together and come to an agreement about who will participate in making medical decisions. These decisions can include whether to undergo medical procedures or to use life support machines. In order to help families make the best decision possible, the medical team may arrange a family meeting to inform and update those who are making the medical decisions.

It is important to remember during these meetings and while making medical decisions that the goal is to let the medical team know what the patient would tell us if they were able to communicate their values and preferences for care. Additionally, it is helpful to the medical team for the family to appoint one family member who can be the spokesperson and point of contact, so that the medical team knows who to notify first if the patient's status changes. It may also be beneficial for the family to ask the medical team if the team can give recommendations on what procedures and treatments to pursue.

Expect the following questions from the medical team during a family meeting:

"What is your understanding of what is happening with your loved one?"

"If your loved one could talk to us, what would they say about the current situation?"

"What is your understanding of what the future may be for your loved one?"

These questions help make sure everyone has the same understanding of what is happening.

We recommend asking the following questions during a family meeting:

"What can we expect to happen to my loved one, both during and after this ICU stay?"

"What are the 'best case' and 'worst case' scenarios that we should be thinking about?"

"What are signs that we should be looking for if my loved one is getting better? What are signs that my loved one is getting worse?"

"Please explain the treatment choices that would be reasonable to consider for my loved one."



There are some important terms that families may hear when discussing medical decision-making. Here is a brief list:

Advance directive: Refers to any number of legal documents that specify a patient's wishes in the event that they are unable to make decisions for themselves. Includes living wills and durable power of attorney for healthcare.

Living will: One form of an advance directive. A binding legal document that outlines a patient's wishes in the event of specific medical events. It is only used when a patient is unable to make their own decisions. It can cover a variety of topics, including resuscitation, being on the ventilator, dialysis, artificial nutrition, and organ donation. It may be very limited or very broad in scope.

Durable power of attorney (DPOA) for healthcare: Also referred to as a power of attorney for healthcare or healthcare proxy. A legal document that appoints an individual to make medical decisions on the patient's behalf if they are unable to make these decisions independently. A patient must appoint their own DPOA for healthcare; family members or friends cannot be granted this power by the medical team. Of note, a DPOA for healthcare is distinct from a durable power of attorney for finances, which authorizes a person to make financial decisions on your behalf.

Physician Orders for Life-Sustaining Treatment (POLST): A set of medical orders that outline a patient's wishes. The name of this form varies by state. It is completed by a patient and their physician and kept with the patient so as to be readily accessible in the event of a medical emergency.

Full code order: This is the default option for all patients who are admitted to the hospital unless otherwise stated. This means that all life-prolonging and life-sustaining measures including CPR will be performed unless specifically declined by the patient or their medical decision-maker.

Do-not-resuscitate (DNR) or Do-not-attempt-resuscitation (DNAR) order: This is a medical order that indicates that the patient does not want CPR to be performed in the event that they have cardiac arrest. This does not influence the other therapies that are offered to the patient.

Do-not-intubate (DNI) order: This is a medical order that indicates that a patient does not want to be supported with a ventilator (discussed in the "Respiratory Failure" section below) under any circumstances. This does not influence the other therapies that are offered to the patient.



Establishing Goals of Care

Throughout your loved one's stay in the ICU, it is important to be mindful of the overall goal of the care they are receiving. While the hope is to return the patient to their prior level of independence, it is important to frequently reassess the potential of achieving this goal. A patient's condition can change throughout their hospitalization, and a goal that seems realistic early on may not be later. With your loved one's values and goals of care in mind, you and the medical team can make the best decisions about the care your loved one receives.

Although advances in medicine have improved survival for critically ill patients, there are many patients who will not recover and will die in the ICU. When the medical team feels that a patient is very unlikely to achieve their goals of care or survive their illness, the team may recommend discontinuation of certain life-sustaining interventions, like the ventilator. In these cases, they may consult a team who specializes in care at the end of life. These providers are referred to as Palliative Care specialists, and their team may include physicians, advanced practice providers, nurses, social workers or chaplains.

We recommend you ask the following questions:

"How realistic are my hopes for my loved one?"

"How will this treatment help my loved one achieve their goals of returning to independence, of being less breathless, of improving their strength, of being comfortable, etc.?"



Sepsis, Severe Sepsis, and Septic Shock



Sepsis describes a syndrome that occurs when severe infection results in critical illness and affects 750,000 Americans annually. Sepsis occurs when a bacterial, viral, or fungal infection causes a significant response from the body's immune system, causing a high heart rate, fever, or fast breathing. Severe sepsis develops when the infection causes organ damage. Septic shock is the most severe form in which the infection causes low blood pressure, resulting in damage to multiple organs. About three in every 10 patients with severe sepsis, and half of those with septic shock, die in the hospital.

Antibiotics and intravenous (IV) fluids are two of the most important treatments for sepsis. Studies have shown that delays in receiving the right antibiotics can double the risk of death. Patients are usually started on antibiotics that treat many different types of bacteria—"broad-spectrum antibiotics"—until test results are available to help physicians select antibiotics that treat the specific bacteria causing the illness—"narrowing antibiotics". These tests are often referred to as "cultures", where bodily fluids such as blood, urine, and phlegm, are sent to the laboratory to identify disease-causing bacteria. Preliminary results from cultures may be available within 24 to 48 hours; final results from these tests often take several days.

Patients with sepsis often require many liters of IV fluids. In patients with septic shock, however, IV fluids may not be enough to keep their blood pressure in a safe range. In those cases, patients may need a central venous catheter in order to receive specific medicines to increase blood pressure.

Consider asking the following questions:

"Does my loved one have sepsis or septic shock?"

"Do we know what organism is causing the infection in my loved one?"

"Do we know where the infection came from?"

"How well are my loved one's organs working?"



Breathing Support for Respiratory Failure



For a variety of reasons, some patients with sepsis will need assistance with breathing. Sometimes it is because of a lung infection. Other times, it is because of excess fluid in the lungs. There are a variety of devices and machines that are used in the ICU to help with breathing.



Nasal Cannula



Face Mask



Non-rebreather Mask

Nasal Cannula, Face Mask, Venturi Mask and Non-rebreather Mask

A nasal cannula is a simple tube that directs oxygen into the nose. This is the least amount of breathing support that a patient can use.

Oxygen can be delivered with a face mask. The Venturi mask (also called a Venti mask) is a special kind of face mask that allows for more adjustment of the amount of oxygen delivered. A non-rebreather mask has a bag on one end and is used to deliver 100% oxygen.



High-Flow Nasal Cannula



A high-flow nasal cannula (HFNC) is an oxygen delivery device that can provide heated and humidified oxygen at high flow rates. HFNC can deliver up to 100% oxygen at a flow rate of up to 60 liters per minute. Patients on HFNC may be able to talk and eat while continuing to receive the oxygen support they need.

Continuous Positive Airway Pressure (CPAP) or Bilevel Positive Airway Pressure (BiPAP)

CPAP and BiPAP machines are breathing machines that deliver oxygen and breathing support through a tight-fitting face mask. The mask covers the nose or both the nose and mouth. It works by continuously pushing air into the patient's lungs through the mask. Doctors can increase or decrease the amount of oxygen and breathing support as the patient's breathing changes. While it gives more support than the other methods above, patients can find it uncomfortable as it can dry out their nose and mouth, and they are unable to eat, drink, or speak clearly while using the machine.



Ventilator



The ventilator gives the highest level of breathing support that a patient can receive, but is also the most invasive. A breathing tube ("endotracheal tube") is inserted into the patient's windpipe through their mouth and attached to a machine that can breathe for them. Because being on a ventilator may be uncomfortable, patients may need medicines to keep them calm and without pain (see next section, "Sedation and Pain Management"); these medicines make it difficult for patients to be awake. Patients will not be able to eat or drink normally or speak while on the ventilator.

Tracheostomy

Patients who require the ventilator for long periods of time are at increased risk of developing a lung infection due to the breathing tube. If the patient is still unable to breathe independently after 14 days or if the medical team thinks that the patient will need the ventilator for a long period of time, the medical team may talk to you about a procedure called a tracheostomy. A tracheostomy is a surgical procedure that creates an artificial airway in the neck, through the trachea, so that the patient can continue to receive support from the breathing machine while minimizing the risk of infection. A tracheostomy is not necessarily permanent, and if the patient improves enough to breathe independently, the tracheostomy tube can be removed and the surgical site allowed to heal.

We recommend you ask the following questions:

“What is the cause of my loved one’s respiratory failure?”

“How long do you think my loved one will need breathing support?”

“How will you know when my loved one is ready to have the breathing tube and ventilator removed?”





Sedation and Pain Management & Weaning

Sedation and Pain Management

In the ICU, there are many medications that physicians use to keep a patient calm and comfortable while they are requiring a ventilator. Each medication has different uses, some work better for anxiety while others are primarily used to treat pain and shortness of breath. These medications may be given continuously (an “infusion”) or just as needed. While keeping a patient comfortable is always a goal of the medical team, overuse of these medications has been linked to higher risk of the patient developing delirium, longer time on the ventilator, and longer ICU and hospital stays. To avoid these complications, the medical team will try to use the least amount of medication possible to achieve comfort.

The medical team uses different tools to determine how much medication a patient needs. Two different tools are commonly used: sedation scores and daily awakening trials. Sedation scales involve a nurse or physician asking the patient questions to determine wakefulness and attentiveness. Pain levels are also assessed frequently throughout the day. Based on how well the patient is waking up and answering these questions, the amount of sedation and pain medication will be adjusted. If the patient is well enough, these medications will be stopped at least once a day to allow the patient to fully awaken; this is referred to as the daily awakening trials. Daily awakening trials have been linked with a 2-day decrease in time that patients spend on the ventilator.

Patients frequently appear to be sleeping while receiving sedation. While patients may not be able to meaningfully interact with their loved ones, it may be beneficial to both patients and their family to hold the patient’s hands, talk to them, and play their favorite music at a low volume.



Weaning

If a patient is improving, the medical team will begin thinking about stopping therapies that are no longer needed, such as the ventilator. Due to risks of infection and weakening of muscles while in bed, it is always the goal of the medical team to get a patient off the ventilator as soon as it is safely possible. However, it is rarely safe for the medical team to simply disconnect the patient from the ventilator as they may be unable to breathe independently yet. The process for determining if the patient is ready to be removed from the ventilator is called “weaning.”

Weaning begins with daily awakening trials. If the medical team thinks the patient is strong enough, they will pair the daily awakening trials with a period of time during which the patient breathes with minimal assistance from the ventilator—a “spontaneous breathing trial” (SBT). The spontaneous breathing trial can last anywhere from 30 minutes to 2 hours, depending on the patient’s condition and the reason for intubation. Often, patients will require several spontaneous breathing trials before they are ready to be removed from the ventilator. Once the patient has passed a spontaneous breathing trial, they can be removed from the ventilator, called “extubation.”

We suggest asking the following questions:

“Will you try stopping the sedatives today to see if my loved one still needs them?”

“Are the sedation and pain medications being given at the lowest level possible?”

“How is my loved one’s sedation score today?”

“Has my loved one done a spontaneous breathing trial today? How did it go?”

“What still needs to happen before my loved one can get off the ventilator?”



Nutrition



One of the biggest concerns that ICU patients and their families have is nutrition. It is a natural desire to make sure that people have enough to eat while they are ill. Oftentimes, patients in the ICU are unable to eat normally for a variety of reasons: they get too short of breath, they have no appetite, or they are receiving procedures or therapies that prevent them from eating. This does not mean that patients are not receiving nutrition in other ways.

Patients are often getting some nutrition just in the medications that they are receiving. Many medications are stored in sugar solutions that help give patients a small amount of nutrition. In addition, patients may also have a feeding tube that goes through their nose or mouth into their stomachs. This allows the medical team to feed patients with a special, highly nutritious liquid called “tube feeds.” Many ICUs have specialists who help manage nutrition plans. These specialists may be called “nutritionists” or “dietitians.”

Sometimes, patients are simply too ill to receive nutrition even through a feeding tube. This could be because they are requiring high doses of medication to support their blood pressure. In these cases, it is too dangerous for the medical team to feed the patient. As soon as it is safe to do so, the medical team will start nutritional support.

We recommend you ask the following questions:

“Is my loved one able to receive nutrition today?”

“Is my loved one meeting their nutritional goals?”

“When do you anticipate my loved one being stable enough to receive tube feeds?”



Delirium



Almost two-thirds of ICU patients become confused during their ICU stay, and 7 out of 10 patients on a ventilator become confused. This is often due to a combination of how seriously ill they are and the medications they may receive to treat pain and anxiety. As a result, patients may be awake all night and sleep during the day, forget where they are, or not recognize loved ones. This confusion is known as “delirium.”

Delirium is not the same thing as dementia. While dementia steadily worsens over months and years, delirium comes and goes. Patients with delirium may have periods of time when they are fully awake, aware, and able to understand what is going on, but these are interrupted by periods when they are confused, agitated, and inattentive. While delirium can take days or even weeks to improve, dementia is permanent and irreversible. Delirium can affect both young and old patients, although older patients are at higher risk of developing delirium.

The best way to treat delirium is not with medications but rather by changing the environment. Family and friends can help by staying with the patient during the day, keeping them engaged and awake, opening blinds, reminding them where they are when they become confused, and encouraging them to participate in daily exercise and physical therapy (see next section, “Daily Exercise and Rehabilitation”). If visiting at night, family and friends can ask nurses to turn off unnecessary lights, close blinds, and minimize noise by turning off the television. They can ask if blood draws and x-rays can be rescheduled to minimize interruptions during the night. These changes in environment allowed one hospital in Denmark to stop sedation in some patients and decrease their ICU stay by almost two days.



Despite best efforts, sometimes patients will still require medications to keep them calm. The medical team's goal is to use these medications at their lowest doses.

If your loved one isn't acting like themselves, please ask the following questions:

"Has my loved one been sleeping at night?"

"My family member isn't acting normally. Do you think they are delirious?"

"How can I help my loved one with their confusion?"



Daily Exercise and Rehabilitation



Many patients in the ICU spend the majority of their time in bed; their critical illness makes them fatigued, short of breath, or uncomfortable, or they are receiving medications that make them sleepy. However, both critical illness and bedrest cause patients to lose muscle strength, and those who are sickest the longest become the weakest. Weakness can make it difficult to do basic, everyday things, such as get out of bed, get dressed, bathe, or walk to the bathroom. Daily exercise has been linked to shorter ICU stays for patients and decreased risk of delirium. For these reasons, it is important that patients participate in daily exercise and rehabilitation when they are medically stable.

Participating in rehabilitation can be challenging. Patients are often uncomfortable, with movement restricted by machines and tubes. However, even patients on ventilators can participate in rehabilitation by sitting up on the edge of the bed, sitting up in a chair, and, in some cases, walking with assistance. Family encouragement is very important to getting patients to participate in daily exercise.

We recommend asking the following questions:

“How much physical activity do you think is possible for my loved one?”

“Can my loved one get out of bed for a period of time each day?”

“Are there exercises that can be done while my loved one is in bed?”

“Is there a physical or occupational therapist for the ICU who can work with my loved one?”



After the ICU: Long-Term Care & Life After Surviving Critical Illness



Long-Term Care

Not all patients in the ICU will recover enough to return home. Some patients are left so weakened by their critical illness that they are unable to breathe on their own and must rely on a breathing machine. These patients are “ventilator-dependent” and are usually unable to live independently. If they are medically stable, patients can be transferred to a ventilator-weaning facility, called a “long-term acute care hospital” (LTACH). The goal of these hospitals is to get patients strong enough to go home, and they emphasize physical therapy and rehabilitation. About one-third of patients transferred to LTACHs improve enough to get off the breathing machine and return home. Unfortunately, many patients remain ill and debilitated in the year after being transferred to an LTACH.

Other patients are not ventilator-dependent but still too weak and debilitated to return home. Depending on the severity of their weakness, some patients may need to be transferred to a skilled nursing facility, a nursing home, or an inpatient rehabilitation center. These facilities offer different intensities of physical rehabilitation, occupational rehabilitation, and nursing care.

We recommend asking the following questions when a loved one is being considered for transfer to an LTACH:

“What are the outcomes of LTACHs in this area?”

“How many patients are alive one year after admission to this LTACH?”

“How many patients are discharged home from this LTACH one year after admission?”



Life After Surviving Critical Illness

With survival rates generally improving in critical illness, there has been an increased focus on how patients do after they leave the ICU. Many patients are still weak and debilitated after they leave the ICU despite daily exercise and rehabilitation, and it can take many days or weeks before they are strong enough to perform even simple tasks like getting out of bed or dressing themselves. Almost half of patients are still unable to function independently a year after their episode of critical illness.

Besides physical weakness, patients who survive their critical illness may have memory problems, and may have symptoms of depression, anxiety or post-traumatic stress disorder (PTSD). Family members of patients may also experience symptoms of psychological distress. While therapies to prevent and treat these symptoms are still being developed, it is important to let the patient's healthcare provider know if the patient is showing signs of depression, anxiety or PTSD. Many patients and families also find it helpful to attend support groups that focus on survivors of critical illness.

We recommend you ask the following questions:

“What level of functioning will my loved one have when they are ready to leave the ICU?”

“What signs or symptoms of depression, anxiety or PTSD should I be aware of?”

“Are you aware of any support groups in the area for ICU survivors?”



Additional Resources:

American Thoracic Society: www.thoracic.org/patients/

Get Palliative Care: <https://getpalliativecare.org/>

Making Your Wishes Known: <https://www.makingyourwishesknown.com>

Medline Plus: <https://medlineplus.gov/criticalcare.html>

Palliative Doctors: <http://palliativedoctors.org/>

Patient Provider Communication: <https://www.patientprovidercommunication.org/>

If you have a question or comment about this guide, please email
Judy Corn at jcorn@thoracic.org We welcome your input!



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