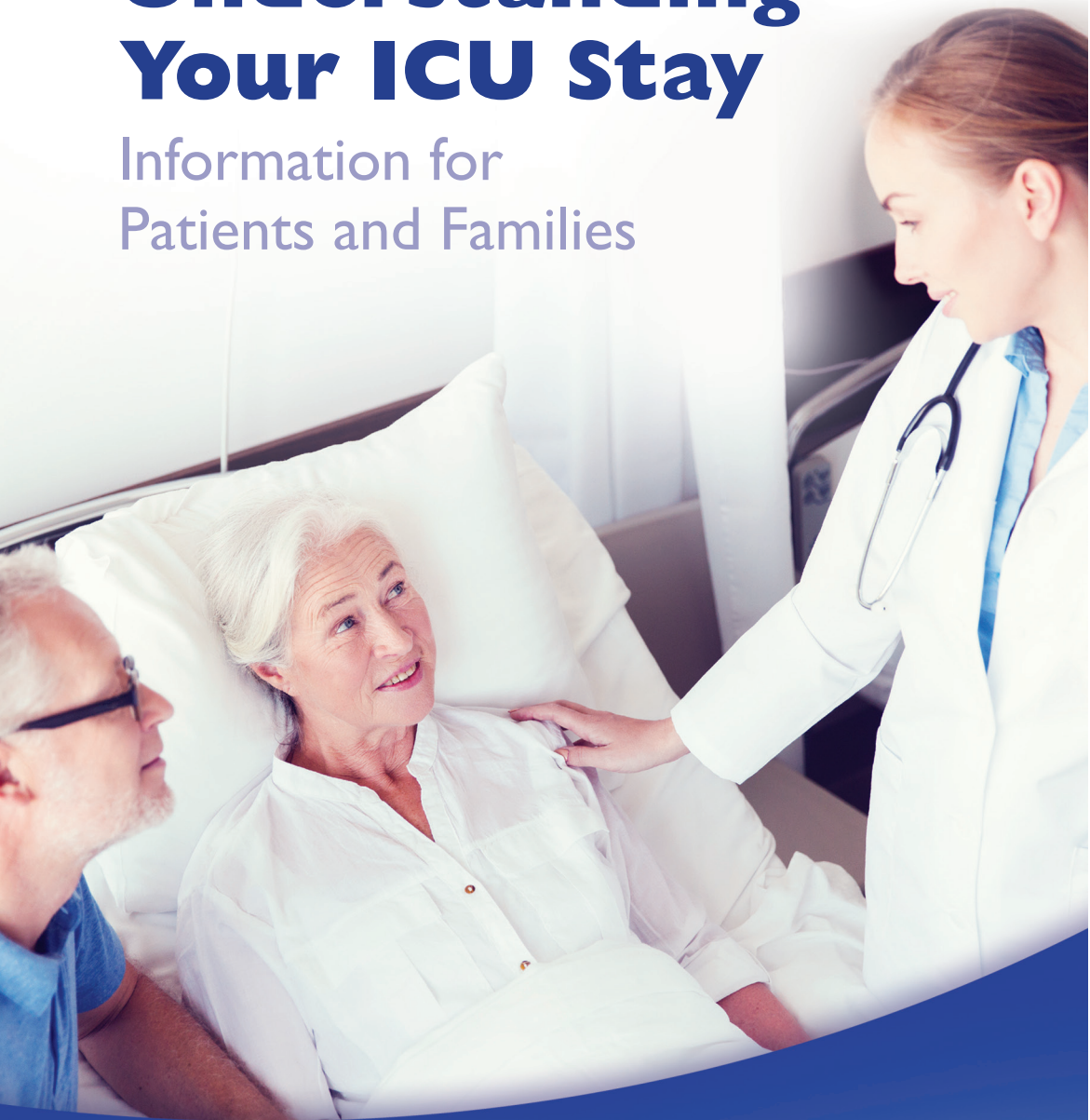


Understanding Your ICU Stay

Information for
Patients and Families



Society of
Critical Care Medicine
The Intensive Care Professionals



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Why Do ICU Patients Look and Act That Way?

How will my family member look?

Your family member may have multiple **catheters** (also called tubes, lines, and drains) in place when he or she is in the ICU. In addition, the **ICU team** (also called the **critical care team**) may use various monitors to track your family member's condition. There are many variations of the types of tubes and monitors required. A patient may have some, none, or all of the items listed below. Most of these devices are temporary and can be removed when they are no longer needed.

Tubes and monitors

Refer to the drawing on page 3. Note that many of these terms are further explained in the glossary.

1. *Heart monitor leads*: Sticky pads that are placed on the chest of almost every ICU patient in order to monitor the electrical activity of the heart.
2. *Pulse oximeter*: A small probe attached to the finger, toe, or earlobe that helps monitor the patient's pulse and oxygen in the blood.
3. *Foley catheter*: A catheter inserted into the bladder to drain the urine into a bag.
4. *Peripheral IV*: A small plastic tube placed in the vein that is used to give fluid and medications.
5. *Blood pressure cuff*: A large cuff placed on the arm or the leg, which may be automatically or manually inflated so that the amount of pressure in the arteries can be evaluated.
6. *Arterial line*: A small tube or catheter that is inserted into the artery to continuously monitor the patient's blood pressure.
7. *Central line (internal jugular line, IJ line, subclavian line, femoral line)*: A special intravenous catheter placed in a large vein (in the neck, near the collarbone, or in the groin) to give fluids, medications, or nutrition or to measure blood pressures in and around the heart.
8. *Intracranial pressure catheter and/or ventriculostomy*: A small tube or catheter inserted into the brain to monitor swelling. This tube also can be used to drain excess fluid from the brain.

9. *Endotracheal tube (ET tube or ETT)*: Breathing tube that is placed in the patient's airway (trachea) through the mouth or nose. This tube is attached to a mechanical ventilator to help the patient breathe.
10. *Tracheostomy tube*: A breathing tube inserted in the patient's neck, usually when assisted breathing (with a ventilator) is needed for a long period of time.
11. *Chest tube*: A large tube inserted between the skin on the chest and the lungs. This tube removes free air or blood that may make it difficult for the patient to breathe.
12. *Nasogastric tube*: A tube inserted into the stomach or intestines to provide nutrition and remove gastric acid or secretions.
13. *Dialysis catheter*: A catheter inserted in the groin or neck. The catheter is hooked up to external tubing and a dialysis machine, which cleans the blood and assists the kidneys.
14. *Intra-aortic balloon pump (ABP)*: A catheter inserted into the groin that helps the heart pump blood.

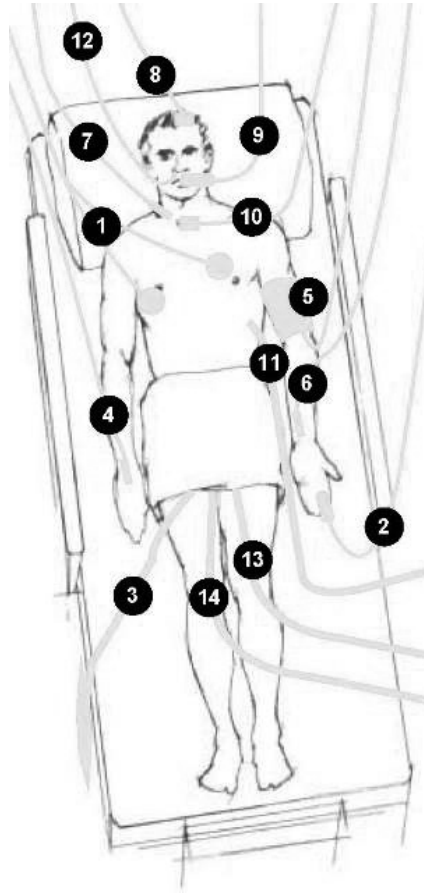
Why does my family member look that way?

Intensive care patients require a large number of blood tests. Even when the laboratory (lab) tests are drawn correctly, bruising may occur. Many critical illnesses make a person prone to bruising. Bruising may occur because the illness makes it difficult for blood to clot. Patients with liver problems, infections, or poor nutrition bruise easily. The elderly, people who have been on blood thinners, or those who drink alcohol regularly are also at high risk for bruising. The face may have bruising and swelling after a head injury or brain surgery.

In some critical illnesses, the body may ooze straw-colored fluid out of the puncture sites from lab draws and from any break or tear in the skin. The oozing is a result of swelling (the accumulation of fluid in the tissues). The straw-colored fluid is plasma that has been pushed or leaked into the tissues because of bed rest, ventilator breathing, liver failure, heart failure, or poor nutrition.

Skin tears happen when bandages and tapes are removed from the skin. The nurse will use the gentlest tape or bandage available that will still stick to the skin. Bandages are necessary over wounds as well as to keep the **intravenous (IV) lines** and other tubes in place. Skin tears may be unavoidable in people who have taken steroids, have a history of smoking, or have poor nutrition. The frail elderly are also at high risk of skin tearing.

If the patient has a tube inserted in the mouth, the ICU team may tie his or her hands down or put mitts on the hands. Although all attempts are



made to avoid this restraint, it sometimes is vital to ensure that the tube is not pulled out.

At times there appears to be a lot of mucus and even blood around the tubes. The nurse will gently clean around these areas, but sometimes some blood will remain. The patient's face may be very swollen. This is not uncommon in the ICU and should resolve as the patient recovers.

Sometimes, small pockets are made under the skin to hold internal monitors like permanent pacemakers, automatic defibrillators, or other devices.

Occasionally, an opening is made in the wall of the stomach to allow evacuation of urine or bowel movement. This is called an *ileostomy* or *colostomy*. These openings may be temporary or permanent, depending on the reason for the opening.

If the patient has a broken leg or hip, weights may be applied to keep the bones straight. This traction will prevent the patient from moving without assistance.

Frequently, the inability to move, the assisted breathing, the critical illness, and the treatments for blood pressure may cause swelling or edema. Little can be done to prevent the swelling. The nurses may try to decrease swelling by keeping the head of the bed slightly raised and the patient's hands elevated on pillows. Rings may need to be removed to protect the blood flow to the fingertips. The eyes may also swell, and the inside lining of the eyelid may stick out because of the swelling.

Why does my family member act that way?

The patient may awaken and feel confused about where he or she is and what has happened. He or she may also be anxious or in pain.

To reduce anxiety and pain, calming medication (sedatives) and pain medication (analgesics) may be needed. Sedatives relax and calm the patient, causing sleep and possibly amnesia, a partial or total loss of memory. Analgesics significantly diminish the pain. While sedated, it may be difficult for the patient to think clearly.

Sedatives may be needed to prevent the patient from fighting against the breathing machine, the catheters, and even the nurses. This is very common in the ICU. The fear that occurs in critically ill patients may be treated with sedatives. It also helps to talk to your family member in a calm and reassuring way.

Sometimes the medication that the patient receives may change his or her perception of what is happening. He or she may seem angry, combative, hostile, or just different. It is important that you tell the nurses and doctors about the difference in the patient's personality, so a decision can be made about whether a different medicine should be used or whether the change in the patient's personality is unrelated to the medication.

Your family member may act in ways that surprise and distress you. These actions may be a result of fear, frustration, or actual chemical changes in the body. Sometimes patients say and do things that they would not ordinarily do. Usually this behavior will resolve as the condition improves.

Why doesn't my family member talk to me?

There are many reasons why a critically ill person may not speak. One reason may be that the breathing tube is passed through the vocal cords and prevents speech. When artificial breathing is used, sedatives are also necessary. As well, the healthcare team may give the patient sedatives and analgesics to reduce anxiety and pain. Sedatives relax the patient, make him or her sleep, and promote amnesia. Analgesics significantly diminish the pain. When the patient is sedated and has been given pain medication, he or she may have difficulty waking up or may appear disoriented. Sometimes the amount of sedation

needed to allow the assisted breathing to take place makes the person appear to be in a coma (will not awaken).

In a person who has been brain injured by either stroke or trauma, the ability to speak or stay awake may have been affected. This is common in the first few days after these injuries. The healthcare team will have to determine whether it is likely that the brain will heal. In most cases of stroke or brain injury, it takes at least 7 days for the doctors to make an evaluation of potential recovery.

Sometimes fluids, chemicals, and toxins in the blood will make a person sleepy, disoriented, hostile, combative, or even unarousable (comatose). Nutrition, fluids, **electrolytes**, dialysis, and other therapies may be needed in order to regulate the blood.

While the person is not talking or is in a deep sleep, it is important to keep speaking to him or her. You can help by talking in soothing tones, telling stories, and supplying the patient with normal information to keep the brain active, yet calm. The voice of someone the patient knows is helpful in most cases.

Chronic Critical Illness in Adults Requiring Prolonged Mechanical Ventilation

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.

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.

Participating in Care: What Questions Should I Ask?

When your family member is in the ICU, what can you do to help?

Interacting with the intensive care team

The intensive care unit is a busy, noisy environment where there are many alarms, monitors, and devices. Watching everything that happens here may raise many questions. The doctors, nurses, therapists, and other staff are here to answer your questions. There are no wrong questions. Stress makes it difficult to understand and remember unfamiliar information. It is okay to ask questions more than once. If you are unsure of what to ask, here are some questions that may address the most common areas of concern.

What should I say to my family member?

You should speak normally. Patients are comforted by familiar faces and voices. However, keep in mind that the patient might not be able to respond to you, either because there is a breathing tube in place that does not allow the patient to speak or because of sedating medications or altered awareness. You should still speak with your family member even if he or she is in a disoriented state or coma. If the patient is alert and has a breathing tube in place, phrase questions that can be answered with nods or shakes of the head. If the patient is able, help him or her write brief answers on a pad of paper. Occasionally, overstimulation may temporarily affect vital signs unfavorably. The nursing staff will instruct you on how you can be supportive in other ways. Expect that patients in the ICU will need more time for rest than usual. Many patients have very limited memory of their ICU stay, so they may not recall your visit or conversation.

Is it okay to touch my family member?

Yes. Touching is usually comforting. Think about what your family member usually prefers when sick. Some people enjoy extra attention while others do not. The type of interaction should be suited to the patient's personality. The nursing staff will let you know if touching is interfering with rest or care.

How long should I visit?

Familiarize yourself with the visiting hours for the intensive care unit. In general, you should visit as long as it is helpful. The nursing staff can often help you with this decision. Both you and the patient need rest, quiet time, and adequate nutrition. Poor nutrition and lack of sleep will make you weak, less able to think clearly, and more sensitive to the effects of stress. When you are away from the bedside, the medical team will call you with any necessary updates.

For young children who are being treated in the ICU, having a familiar person present or near at all times may be helpful. However, one person cannot usually do this. Therefore, it's a good idea to ask relatives or close friends to take turns being with your child.

Should I bring anything from home?

Familiar things are often comforting; however, you should check with the ICU team before bringing anything into the ICU. Photographs, cards, pajamas, robes, and slippers may be helpful. Children may have a favorite stuffed animal or blanket. The ICU may have equipment you can use to play favorite music or videos. Friends and relatives who are unable to visit may send an audio recording of well wishes. Check with the ICU staff to see what items are not allowed to be brought in.

What should I ask the nurse?

The nurse has the benefit of being at the bedside for an extended period of time. Therefore, he or she may be the best person to comment on the patient's comfort and response to certain therapies. Here are some questions you can ask the nurse:

- Who are the medical team members who are caring for my family member, and what are their roles?
- Which doctor is in charge?
- What are the plans and goals for today?
- What are you checking for on your assessments?
- Is my family member having any problems with pain? How do you check for that?
- If you are not in the room, how do I call for help?
- How quickly should I expect someone to respond to the call?
- How does my family member go to the bathroom?

- Will you explain what all the lines, tubes, and equipment are and what they do?
- What can I do to help with care?
- What can I do to help my family and myself?
- Who can visit and when?
- If I am not in the hospital and something happens, how will you get in touch with me?
- What happens if something urgent happens and I am not available?

What should I ask the doctor?

When you speak with the doctor, it is often difficult to remember all your questions. Therefore, writing down questions and concerns as they arise can be helpful. Here are some commonly asked questions:

- What is wrong with my loved one? (What is his or her primary diagnosis?)
- Are there other medical issues that are important right now?
- What is the treatment plan?
- When do you expect to see a response to treatment?
- What changes will you be watching for as a response to the therapy?
- What are the risks of the therapy and/or medications?
- How do you expect things to go in the next 24 hours?
- What is the best possible outcome? Worst possible outcome?
- How will this condition affect my family member's long-term quality of life?
- What types of medications is he or she receiving?
- Is the patient in any pain?
- What is being done to ease pain and fear?
- How is nutrition provided?
- How long do you think my family member will need to be in the ICU?

How often should I get information?

In general, daily discussions with the critical care team allow for an update on the condition of your family member and the treatment plan. If an acute change or event occurs, you may need to speak with the doctor more frequently. The bedside nurse can keep you updated about events of the day as well as clarify information. In addition, it is often best to have one or two members of the family serve as the spokespersons. In case of difficult decision making or confusing information, the nurse or social worker can often arrange a family meeting to discuss the issues with the medical team.

What is the best way to share information with family and friends?

Your family and friends will probably be anxious to hear how the patient is doing. They will want to know what is wrong, how the patient is responding, and what they can do to help. Their concerns can be of comfort but sometimes seem overwhelming as you try to make contact with everyone. First of all, if there are needs at home or work that others can help you with, let them. This is helpful to you as well as to the person helping. In regard to relaying medical information, you must first decide to whom you want to relay this information and what information you want to share. Once you have decided this, it is often helpful to pick one or two relatives or friends to be in charge of getting this information to others. The person or persons that you choose must be able to understand the medical condition correctly so as to prevent miscommunication. These persons can also “filter” out all the free advice that friends and family might offer. To protect patient privacy, information from the healthcare team may be restricted to the family spokesperson.

What is meant by code status?

Code status tells the medical team what to do if a patient has a cardiac arrest (if his or her heart stops beating). All patients will have a code status designated on their chart. The default is a “full code.” Full code means doing everything possible to restart the heart and support breathing with a machine. **CPR** does not always work to restart the heart. CPR is less likely to be successful in patients who are very sick in the ICU. **DNR (do not resuscitate)** means that CPR will not be done if the heartbeat and breathing stop. As part of their illness, some people will not be able to breathe well enough on their own. Preferences should also be discussed for whether a patient would want to be on a breathing machine (ventilator). **Intubation** involves placing a breathing tube to keep the airway open. People can choose to receive other therapies and medications and also can choose to not be intubated and placed on a ventilator if things get worse. Patients may have an **advance directive** that specifies their wishes. If these wishes are known either from an advance directive or based on conversations with the patient, these wishes should be expressed to the medical team.

Physicians are not required to offer therapies that would be medically ineffective (will not increase the patient’s chances of survival), and you may be told that your family member is not a candidate for certain interventions.

If the medical condition is not curable or recovery is unlikely, what are the options?

The medical team will discuss all the options with you and the patient (if he or she is able to understand). It will be important to clarify the goals of care at that point. If the goal is to preserve life and continue to be aggressive despite the poor prognosis, the medical team may discuss tracheostomy (placing a breathing tube through the neck into the airway) or **percutaneous endoscopic gastrostomy (PEG)** (for feeding and medications). If the primary focus is on keeping the patient comfortable, options may include removal of certain therapies like mechanical ventilation, medications to support heart function, and dialysis. Certain tests and procedures that are not likely to be helpful can also be discontinued. Some questions to clarify this can include the following:

- Will CPR save the patient's life if his or her heart stops?
- How long do you think he or she will live without the breathing machine (ventilator) or other therapies?
- Will he or she be hungry if we stop the feedings?
- How will the patient be kept comfortable?
- Could the patient go home or have hospice care?
- In cases that involve children—can I hold the patient?
- Can our clergy come to the ICU?
- Can you wait to remove certain life-supporting equipment or therapies until after all relatives and friends have had a chance to say good-bye?

What if I want everything done, but the medical staff feels that stopping or not adding certain therapies is more appropriate?

This situation usually arises due to ineffective communication about the current medical condition and/or the benefits of certain therapies. If this conflict does arise, the appropriate members of the family and the medical team should hold a meeting. At this meeting, a treatment plan can usually be agreed upon. On rare occasions, the family and the medical team cannot agree on a treatment plan; most hospitals have an ethics committee that can be contacted to get involved in the decision making.

Making Decisions About ICU Care

Sharing the decision-making process among members of the family and ICU team helps provide the best care for your loved one.

When a patient is in an ICU, many people are involved in making decisions about that person's care. Doctors, nurses, and other healthcare workers make choices about how to care for patients throughout every day. These healthcare professionals see patients with conditions similar to those of your family member regularly, and they have tools to help him or her. You should talk with them regularly about goals of care for your family member and decisions such as surgery, tests, breathing help, and medications.

Kinds of decisions

Many decisions must be made for patients in the ICU. For example, if your family member has an infection while receiving life-prolonging therapy, the decision to start antibiotics, and which antibiotics to use, will likely be made by the physician. If your family member has a heart condition, the decisions about what medicines to use will also be made by the physician. In these cases, the physician will generally explain what medicines the team will be using and why these particular medications were chosen. If it is unclear which medication would be best, the doctor will try to involve you in the decision.

Some decisions are less clear. Your family member may have a condition that could benefit from surgery. If the operation is clearly necessary, the team will tell you so. Sometimes, an operation may help but could possibly cause more harm than good. Making a choice about an operation may involve one's values regarding risk and benefit. These types of decisions are best made jointly among you and the members of the healthcare team.

At times, families and ICU teams need to make decisions that are very difficult. When a patient is on life support, the goal is to help the patient get better. Life support replaces or supports a failing bodily function. In treatable or curable conditions, life support is used temporarily until the body can resume normal functioning. But, in situations where improvement is likely not possible, life support may prolong suffering and pain. If life support is prolonging the dying process without offering benefit, decisions must be made about whether to continue life support.

The ICU team always tries to improve the patient's comfort. Palliative, or comfort, care is a comprehensive approach to treating the symptoms of illness. Comfort care focuses on the physical, psychological, and spiritual needs of

patients during their illness. The goal is to provide the best quality of life available by relieving suffering, controlling pain, and providing as much independence for the patient as possible. Respect for the patient's culture, beliefs, and values is an essential component. The healthcare team continually focuses on patient comfort, even when the goals of treatment are to prolong life. However, medical machines used to keep patients alive can cause discomfort in spite of the best attempts to lessen suffering.

The decision to transition from life-saving efforts to comfort care only is among the most difficult decisions in life. Usually, the patient in the ICU is unable to participate in the decision-making process, leaving decisions to the family. For cases when a patient has not said who can make decisions for him or her, states and countries have a legal system for decision making within the family, but agreement among members of the family whenever possible is the goal of the ICU clinicians. You should never feel alone in this situation. The ICU team members are there to contribute their experience, knowledge, comfort, and compassion as they share in the decision making.

If a decision is made for comfort care only, the ICU team has the skills and technical resources to provide a comfortable death that is not painful or lonely. Team members provide both physical and psychological support for your family member. They are there to help support you, too.

How to communicate with the ICU team

Most ICUs will have a regular means of communicating with the family. Anyone can initiate a conversation with the physician regarding patient care, including end-of-life issues. Critical illness demands clear and frequent communication. A common way to share information needed for decision making is during family conferences attended by selected members of the family and the ICU team. Physicians welcome family involvement and will make time for discussions. Physicians and other members of the healthcare team can provide technical knowledge and experience, help you understand the situation, explain pain management, and describe expectations for the patient's condition and care.

The nursing staff has close knowledge of your family member's status and the treatments being provided. Nurses can arrange for a family conference with the physician and other team members at your request. Nurses can also arrange for you to meet with social workers, chaplains, or other experts. The team can help identify and address family needs related to visiting time with the patient, alternative approaches to care, gathering other opinions, and resolving conflict within the family.

Questions you may want to ask

In an effort to make the right decision for your family member, you will undoubtedly have many questions. The physicians, nurses, social workers, and other ICU team members can help address questions such as the following:

- What are reasonable goals of care?
- Will this treatment cause pain?
- What are the risks of a specific operation, treatment, or test?
- How does my family member's condition usually progress?
- If we decide to withdraw life support, how will the patient be kept free from pain? How much longer will he or she live after life support is stopped?
- What is the dying process like? How will the patient act?
- What can I do to comfort him or her?
- If this were your loved one, what would you recommend?
- The patient has communicated specifically about end-of-life care. How can I be certain his or her wishes are met?

Finding comfort in goals-of-care decisions

Decisions you make about a loved one's goals of care in the ICU are among the most private and difficult moments in life. While you may feel alone, the ICU team is there to share in the decision-making process and help you and your loved one every step of the way.

Too often, a patient arrives in the ICU without warning. Frequently, patients have never thought about, or discussed with their loved ones, their desires for the kind of care they would prefer if they were admitted to an ICU with a condition that is not expected to get better. Some individuals want very aggressive care, regardless of the outcome. In contrast, others feel that their lives lose meaning if they are unable to recognize or communicate with their family and friends and/or if they are unable to care for themselves. Open communication about a patient's wishes before ICU admission is ideal but not always possible. While advance directives can help honor the patient's wishes, they may not be specific enough to address every possible situation that could occur in an ICU. Identification of someone who knows the patient well and understands the quality of life he or she would find acceptable can help everyone in the decision-making process. Knowing that you have honored the patient's beliefs and have acted based on them will help provide comfort.

It is important for all of us to we feel that we have done everything we can for our loved ones when they are facing death. Close communication with ICU caregivers can help to make this process more comfortable. You need not feel that you bear the burden of decision making. Sometimes family members

haven't discussed the issue of critical illness, and sometimes the patient's medical condition is so complex that only ICU team members who have seen similar situations can assess the likelihood of survival and likelihood of suffering. In many cultures, the responsibility for decisions rests with the medical team. This is an acceptable alternative for anyone facing these difficult decisions. Allowing the ICU team to make decisions with input from the family may be the most compassionate and appropriate approach.

The ICU team can lessen your concerns about pain, provide support, and honor the integrity of the patient and the role of the family. They can help to explain how all appropriate care is being provided to help save the patient's life and, when that is not possible, how your loved one can be provided a pain-free, safe transition to a peaceful death.

What Are the Choices Regarding Life Support?

Understanding life support measures

Life support replaces or supports a failing bodily function. When a patient has a treatable or curable condition, life support is used temporarily until the body can resume normal functioning. But in situations where improvement is likely not possible, life support may prolong suffering.

A treatment may be helpful if it relieves suffering, restores functioning, or enhances the quality of life. The same treatment can be considered harmful if it causes pain or prolongs the dying process without offering benefit. The outcome of a treatment may diminish a person's quality of life to a point that is not acceptable.

The decision to transition from life support to comfort care only is a personal one. It is important to talk to the ICU team regarding the risks and benefits of each therapy. All life support measures are optional treatments. If you or your family members do not understand the medical options being discussed, ask questions. The ICU team wants to ensure that your decisions are based on a full awareness of the risks, benefits, and expected outcomes of treatment.

Artificial nutrition and hydration

Liquid nutrition and hydrating fluids may be given into the gut (**tube feeding**) or directly into the bloodstream (intravenous feeding) until the patient can eat and drink again. Although potentially valuable and lifesaving in some situations, artificial nutrition and **hydration** do not make dying patients more comfortable. Scientific evidence shows that patients can die comfortably without artificial nutrition or hydration.

Tube feeding

Tube feeding is a chemically balanced mix of nutrients and fluids given through a **feeding tube**. Most commonly, this tube is inserted into the stomach through the nose (nasogastric tube or NGT) or through the wall of the abdomen (gastrostomy tube or PEG) by means of a surgical procedure. Another type of feeding tube (a jejunostomy tube) is inserted surgically through the abdominal wall into the small intestine.

Intravenous feeding (parenteral nutrition)

IV feedings are given to patients who are unable to receive tube feedings. As with tube feeding, the IV feeding provides the patient with the needed amounts of protein, carbohydrate, fat, vitamins, and minerals.

Cardiopulmonary resuscitation (CPR)

CPR is used when someone's heart or breathing stops. CPR attempts to restart these functions. It may consist of artificial breathing, and it includes pressing on the patient's chest to mimic the heart's actions in an attempt to restart circulation. Electric shocks (defibrillation) and drugs may also be used to stimulate the heart. If the patient (or designated decision maker) does not want the ICU staff to perform CPR, a physician must write a do-not-resuscitate (DNR) order or do-not-attempt-resuscitation (DNAR) in the chart. This order can be changed at any time for any reason.

Comfort measures only (CMO)

If you and/or the doctors decide that prolonging a patient's life is no longer in keeping with the patient's goals of care, a patient may be transitioned to comfort measures only (CMO). CMO typically means that mechanical ventilation is stopped and a patient's breathing tube is removed. All medical interventions that do not contribute to the comfort of the patient are stopped, including blood draws, artificial tube feeding, and hydration. A patient who is CMO is allowed to pass away naturally, with pain medications given only as needed to ensure the patient's comfort. You are allowed and encouraged to spend as much time with the patient as possible. If a patient who is CMO is expected to live past a number of days, he or she may be transitioned to hospice care, which can be provided at hospice facilities or at home in certain situations.

Defibrillation

Defibrillation sends a powerful electric shock through the heart. It is used to treat certain irregular heartbeats (arrhythmias) that may cause the heart to work ineffectively. Sometimes the heart loses all of its electrical activity or is so damaged that it cannot pump blood through the body. When this happens, defibrillation may not be attempted because it will not restart the heart once the heart has stopped.

Dialysis

Dialysis does the work of the kidneys, which remove waste from the blood and manage fluid levels. This procedure requires a special type of IV that is inserted into a large central vein. Blood circulates from the body through the dialysis machine, where the blood is filtered and then returned to the body. Dialysis can be performed in the ICU or in a dialysis unit, depending on the condition of the patient. Some patients may live on dialysis for years, but dialysis for the chronically ill or dying patient may only prolong the dying process.

DNR or DNAR order

A DNR or DNAR order is written by a physician instructing healthcare providers not to attempt CPR if the heart stops beating or if the patient stops breathing. A patient with a valid DNAR order will not be given CPR. DNAR does not mean “do not treat.” Patients have the right to receive any treatments that are offered by the medical team caring for them. When cure is not possible, physicians may decide that the use of CPR is not medically appropriate. It is possible to say no to CPR but yes to all other medical treatments.

Mechanical ventilation

Mechanical ventilation is used to support or replace the function of the lungs. A machine called a ventilator (or respirator) forces air into the lungs through a tube inserted into the mouth, nose, or neck and down into the windpipe (trachea). This breathing support may be used for a short time (for example, when treating pneumonia), or it may be needed indefinitely for permanent lung disease or trauma to the brain. Some patients on long-term mechanical ventilation have a quality of life that is acceptable to them. For other patients, mechanical ventilation may only prolong the dying process.

Palliative care

Palliative care focuses on reducing the severity of disease symptoms, with the ultimate goal of relieving suffering and improving the quality of life for patients with serious illnesses. This care is often provided by a consulting group of clinicians, which may include physicians, nurses, social workers, psychologists, chaplains, and physical, occupational, and other therapists. Palliative care is not the same as comfort care only. Patients receiving palliative care have no restrictions on other forms of medical therapy, including life

support. Most patients in the ICU have severe illness and benefit from palliative care.

Pacemakers

A pacemaker is a device that produces a low electrical current that stimulates the heart muscle to beat. The heart may be paced temporarily until healing occurs. A surgical procedure to insert a permanent pacer may be required for chronic problems. Patients with incurable heart disease may choose to refuse a pacemaker.

Vasopressors

Vasopressors are powerful drugs that cause the blood pressure to rise when it is too low. This therapy is given only in the ICU and requires a special type of IV that is inserted into a large central vein.

Ethics consultants

Ethics consultants are trained experts who can help when people face certain dilemmas or choices of treatment that may go against their moral values. These experts can help mediate conflicts and facilitate communication between you, the patient, the doctors, and other providers. Ethics consultants are available at most hospitals at no charge to patients. Ethics consultants may help resolve disagreements between the patient and the family or between patients and their doctors or nurses about the patient's Living Will, about brain death, or about starting or stopping certain treatments such as blood transfusions, mechanical ventilation, dialysis, or nutrition.

Sepsis: What You Should Know

A doctor or an **intensivist** (a doctor with special expertise and training in the care of critically ill patients) in the ICU may have told you that your family member has sepsis. This condition may be the reason he or she was admitted to the ICU, or it may have developed during hospitalization. Whatever the cause, your family member is seriously ill, and you undoubtedly have questions.

What is sepsis?

Sepsis is the body's response to infection. Normally, the body's defense system can effectively fight infection. But in sepsis, as the body's defense system releases chemicals to try and fight an infection, this process triggers an overwhelming inflammation throughout the body. Unfortunately, this chemical release and the resulting inflammation occur throughout the body, in every cell, and injure internal organs. The result is that internal organs cannot function normally and begin to fail. This organ failure may first be noted in the lungs but may progress rapidly to the kidneys, liver, or any other organ. Septic shock, which is part of the progression, occurs when the cardiovascular system begins to fail. When the cardiovascular system fails, the patient's blood pressure drops and all vital organs are deprived of an adequate supply of blood and oxygen.

How does someone get sepsis?

Sepsis affects over 26 million people each year and is the largest killer of children with more than 5 million dying each year. Exposure to any kind of germ—bacterial, viral, parasitic, or fungal—anywhere in the body can trigger sepsis. Sepsis can strike anyone at any age, although very old people, very young children, hospitalized patients, and people with other medical conditions may be at increased risk. Factors that may make an individual susceptible to sepsis include these:

- An underactive or depressed immune system (such as during chemotherapy or when medications are used to prevent the rejection of an organ transplant)
- Recent surgery
- Mechanical ventilation (machine-assisted breathing)
- Genetic tendency
- Invasive procedures, including placement of IV lines to provide fluids or medicine

Signs and symptoms of sepsis

Sepsis is the body's response to an infection. The symptoms can include the following:

- Fever and shaking chills
- Reduced mental alertness, sometimes with confusion
- Increased heart rate, greater than 90 beats per minute
- Increased breathing rate
- High or low white blood cell count (determined with a blood test)
- Low blood pressure
- Altered kidney or liver function

Sepsis can develop quickly. The sooner it is diagnosed and treated, the better. The most frequent sites of infection leading to sepsis are the lung, urinary tract, abdomen, and pelvis. Sometimes however, a definite source of infection cannot be identified. For example, **blood clots** or skin breakdown may trigger the overwhelming inflammation seen in sepsis.

The course of sepsis may be unpredictable. Some patients deteriorate quickly, while others suffer from varying degrees of organ dysfunction or failure, but most will recover with treatment. Sometimes there are long-term physical or brain function consequences. This varies with the severity of the illness.

Treatment of sepsis

Sometimes it is hard to tell if someone has sepsis because this condition looks similar to other medical problems. A person with sepsis may have a fever, fast heartbeat, breathing problems, confusion, or decreased urination, but these are also signs of other illnesses.

The best way to stop sepsis is to treat it quickly. Patients should get fluids and antibiotics within one hour of the doctor's diagnosis of sepsis. There is no one treatment for sepsis. Scientists are doing research every day to find new treatments for this serious disease. If you think your family member may have sepsis, ask the doctor or nurse to evaluate for this. It's better to ask than to presume that this condition is not present.

The first line of treatment is to find the infection early. Antibiotics can help get rid of the infection. Sometimes surgery is necessary to remove the source of the infection. Some patients need other treatments, such as these:

- Fluids and drugs to raise the blood pressure
- A breathing machine
- A feeding tube
- Pain killers or sedative drugs to increase comfort
- Drugs to lower the level of stomach acid and prevent ulcers and bleeding
- Dialysis for kidney problems

Taking Care of Yourself While a Family Member Is in the ICU

To be strong for your family member in the ICU, you must first take care of yourself.

Self-care

You may experience feelings of helplessness or loss of control when a loved one is in the intensive care unit. It is difficult to wait without action, but you can do something: You can first take care of yourself.

You are as important to the healing process as the physicians, nurses, medications, and treatments are. You have been a part of the patient's life journey long before, and will be long after, this hospitalization.

Positive reinforcement and encouragement from close friends and family have a strong influence on the healing process. We are learning more and more about the benefits of family involvement in the delivery of patient care. Because of this, your well-being is important to your family member and to us. The following strategies will help you take care of yourself during this difficult time.

Take care of yourself

Proper food and sleep will help you be able to listen to and understand the significant information you will be given. Stressful situations, in addition to staying awake all night, every night, will eventually wear on you and can make you prone to illness. Try to eat healthy foods regularly. Whenever possible, get up and walk around. Exercise is very important to maintain emotional health. Do not feel you have to be available every moment. A trained medical team is caring for your loved one, and patients are closely monitored even though care providers are not directly in a patient's room at all times.

Gathering support

An important measure in taking care of yourself is to gather support from family and friends. If friends or relatives come to visit, take that opportunity for a little time to refresh yourself. Take time away from the hospital by asking a friend or relative to take over for a few hours. Make a rotational system if there are many people available to help. Remember that the time in the ICU may be the beginning of a longer recovery where your strength will be needed

as well. If friends or relatives from out of town offer to visit, encourage and welcome their support. The nurses and doctors take breaks during their shift because the continual light and noise are draining, and you should take regular breaks from the constant stimulation as well. When someone asks, “What can we do for you, we’re here to help,” give yourself permission to ask for help. A critical illness in the family is truly the time to muster support from those who care.

Identify a person to update your friends and family

Access to information is one of the most significant needs of families of ICU patients. The role of this person will be to contact all the friends and relatives who need to be reached each day to provide them with an update on the patient’s condition, relieving the patient’s spouse, parent, or significant other from that obligation during this stressful time.

Support at home

As you spend many hours in the intensive care unit supporting your family member, matters may go unattended at home. Ask someone to pick up your newspaper and mail. If people offer to cook, clean, help with child care, or any other assistance, don’t hesitate to take them up on it! Ask someone you trust to make sure all your bills are being paid.

Prepare yourself daily

Prepare yourself for setbacks. Most patients in the ICU have ups and downs: Some days are good and some are bad. Concentrate on the steps taken forward and view the steps backward as hurdles that can be overcome. Try not to become discouraged. Like the patient, family and friends also have both good and bad days.

Purchase a notebook

Divide the notebook into three sections. On the first page of the first section, write the name of the intensivist, the physicians, the social worker, and any other care provider who is involved with the care of your family member. On the second page of this section, write all the phone numbers of the various people you would like to contact each day. Don’t forget to include work and school colleagues.

In the second section, write down your questions. Anytime you think of something you are concerned about, even if you don't think it is important, write it down. As you continue through your process of waiting, you may forget what you were told or how you were supposed to follow up on the information you received. You may need to have information repeated several times before you understand it. This is normal. Don't be afraid to ask for clarification.

In the third section, start a journal. Some people find that keeping a daily journal of events, in and out of the hospital, can be very healing. It can also provide you with encouragement as you see small improvements over time.

Be positive!

Keep your faith and your hope strong. Be encouraging and hopeful while with your family member. If your family member is not alert, always begin your visit with your name. "Hi, it's _____." Talk to the patient and explain what is going on. Read cards that have been sent. All of these things can help with the patient's recovery.

Hospital resources

Ask the ICU staff what support persons are available in your hospital. A social worker, chaplain, or other support person can assist you while your loved one is in the intensive care unit. They can help you obtain resources for financial assistance and verifying credit. They can also give you grief counseling or spiritual support. Do not hesitate to contact them and request various resources.

Critical Care Medication

What should I know about medications given in the ICU?

It is important to tell the ICU team about all allergies your family member has. You should also tell the doctors and nurses about all medications and nutrition supplements the patient takes. The ICU team can use this information to ensure that they give patients the necessary medications and supplements while in the ICU.

It is also important to tell the doctors and nurses if your family member is using nonprescription drugs, alcohol, or both. This information can help the doctors and nurses adjust medications in case the patient goes through **withdrawal** or if his or her usual medications do not mix well with the ones given in the ICU.

Medications and how or when they are given may change while patients are in the ICU. Many of the medications given to patients are based on how sick they are.



By Calleamanecer (Own work) [CC BY-SA 3.0 (<http://creativecommons.org/licenses/by-sa/3.0/>)], via Wikimedia Commons.

This is an IV or catheter placed through the skin into a vein. It helps the ICU team draw blood or give medications.

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To receive these medications, your family member may need to have a catheter placed in a blood vessel or vein. This is called an IV line.

Many types of medications are given to patients in the ICU. You can speak to the pharmacist, nurse, or doctor about the specific medications your

family member is receiving. The following descriptions of medications may help you when speaking with the ICU team (see below for a summary of these descriptions).

Fluids and nutrition

Patients in the ICU need fluids and nutrition to help them heal. Patients may be given fluids with electrolytes through an IV line. Patients also need calories, protein, vitamins, and minerals. We may give this nutrition in the form of food, with the use of a feeding tube, or through a vein or IV line.

Tube feedings are like protein shakes that athletes drink to have a stronger body. Instead of drinking the nutrition, patients receive it directly into the stomach or gastrointestinal tract. This is often done by inserting a tube into the nose or mouth to reach the stomach or intestine. Sometimes a tube is placed through the skin and into the stomach (called a gastrostomy tube or G-tube) or into the intestine (called a jejunostomy tube or J-tube).

Nutrition given through a vein is called parenteral nutrition or TPN. The ICU team may use TPN depending on a patient's condition.

Analgesics, sedatives, and delirium medications

There are many reasons why your family member may feel uncomfortable in the ICU. The mechanical ventilator (or breathing machine) is a common reason.

In the ICU, the doctors and nurses may treat your family member for pain, anxiety, nervousness, confusion, or **delirium**. The most common medications used to help patients feel comfortable are analgesics (pain medicines) and sedatives.

- *Analgesics*: Analgesics may be used to help prevent and control pain. Examples include acetaminophen, ibuprofen, morphine, fentanyl, and hydromorphone.
- *Sedatives*: Sedatives may be used to help prevent anxiety, nervousness, uneasiness, or fear. Examples include propofol, lorazepam, midazolam, and dexmedetomidine.
- *Delirium medications*: Delirium medications may be used to help prevent or treat any confusion your family member may develop from being sick and in the ICU. Examples include haloperidol, quetiapine, and risperidone.

The ICU team will adjust all of these medications to try to keep your family member calm, comfortable, and somewhat awake when needed.

Your family member may be treated with continuous **sedation**. If so, the doctors and nurses may interrupt the sedation every day to check for changes in the patient's behavior and ability to breathe without as much support from a ventilator. A patient may look confused or uncomfortable when woken up, but allowing patients to wake up every day has been shown to help in weaning from the ventilator.

Blood thinners

Patients in the ICU are at risk for having blood clots in the blood vessels of their legs and arms (also called **deep vein thrombosis** or **DVT**). The doctors may use blood thinners such as heparin or enoxaparin to help prevent these blood clots from forming. These medications may cause bruising, especially on the places where catheters or IVs are inserted. The ICU team may also place special squeezing or compression sleeves on a patient's legs to help prevent blood clots.

Stomach acid-reducing medications

Patients on a mechanical ventilator are at increased risk for developing stomach ulcers that can bleed. The doctors may use medications like famotidine, ranitidine, omeprazole, or pantoprazole to decrease stomach acid. Patients usually only need these medications while they are in the ICU. Check with the patient's primary care doctor if you are not sure whether your family member should take these medications after leaving the ICU.

Insulin

Patients in the ICU often receive insulin to help control their blood sugar. A patient may need insulin even if he or she did not have diabetes or high levels of sugar in the body before being in the ICU. Insulin is given as injections under the skin or through a vein. Unless they were receiving insulin before being in the ICU, most patients do not need to be on insulin once they are better or after they leave the ICU.

Bowel regimen

Patients may have difficulty having normal bowel movements while they are in the ICU. The ICU team may give patients medications such as docusate, bisacodyl, and sennosides to help keep bowel movements regular.

Vasopressors

Some patients in the ICU may have blood pressure that is too low and may need medications to raise it. These medications are called vasopressors. They are given through a vein and are adjusted depending on the patient's blood pressure. The ICU team can turn these medications on and off as needed. Examples of vasopressors include norepinephrine, dopamine, and epinephrine.

Antibiotics

Patients in the ICU may have an infection or be at risk of getting an infection. To treat infection, the doctors will choose antibiotics based on the type of infection and the microorganism or “bug” that is or may be causing the infection. If your family member gets an infection, the team will administer antibiotics until the infection is gone. Giving antibiotics for too long may allow the bug to become immune to the antibiotics.

What is ventilator-associated pneumonia?

Ventilator-associated pneumonia (often called VAP) is an infection of the lung that happens while a patient is on the mechanical ventilator. If your family member gets pneumonia, he or she will be treated with antibiotic therapy.

How does the ICU team prevent and treat pneumonia?

Preventing pneumonia and treating it if it occurs are important. The Ventilator Bundle is a list of things that the ICU team can do to help prevent and treat pneumonia. The Ventilator Bundle was developed by the Institute for Healthcare Improvement and includes the following actions that the ICU team can take:

- Elevate the head of the bed to keep saliva from going into the patient's lungs. The doctors and nurses will do this only if the patient's condition allows it.
- Remove or **suction** saliva out of the patient's mouth and clean his or her mouth (like brushing your teeth).
- Allow the patient to wake up while on the mechanical ventilator to check if he or she can breathe without it.

- Use medications or place special squeezing or compression sleeves on the patient's arms and legs to help prevent blood clots in the legs and arms (also called deep vein thrombosis or DVT).
- Use medications to decrease stomach acid, which could cause stomach ulcers or stomach bleeding.

What is delirium?

Patients in the ICU sometimes develop delirium or confusion. This can happen even if they seem to be calm or sleeping.

Delirium is caused by an imbalance in the brain. Some of the signs and symptoms of delirium include confusion, agitation, excessive sleep or lack of sleep, restlessness, and nervousness.

Being sick and in the ICU can cause delirium. The following things can also cause delirium:

- Old age
- A history of delirium, dementia, or Alzheimer's disease
- Inability to see or hear well
- Infection or severe sickness
- Electrolyte problems, **dehydration**, and **malnutrition**
- Problems with the kidneys or liver
- Recent surgery or trauma
- Previous alcohol use
- Pain
- Sedatives or pain medicines
- Constipation

How can I help the ICU team prevent and treat delirium?

Families have an important role in helping prevent delirium from occurring in patients and, if it occurs, helping them get better. The following tips will help you be a part of treating your family member's delirium:

- Make sure the patient's hearing aids and eyeglasses are available (if he or she uses these).
- Talk to your family member; tell them who you are and that they are safe.
- Remind patients where they are and tell them the date and time.
- Tell the ICU team what time the patient normally goes to bed at night and gets up in the morning.

- Tell the team if your family member watches a television show regularly, what music he or she likes to listen to, or other favorites that would be relaxing and calming.
- Read favorite books aloud to your family member.
- Avoid too much noise or too many visitors.

If you need more information about critical care medications, feel free to ask any member of the ICU team. The team wants you and your family member to feel safe and comfortable in the ICU.

Descriptions of Medications

Type of Medication	Examples	Reason for Using
Fluids and nutrition	IV fluid	Helps keep one hydrated
	Tube feeding or IV nutrition	Provides one with calories, protein, vitamins, and minerals
Analgesics (often called pain medicines)	Morphine Fentanyl Hydromorphone	Helps prevent and control pain one may feel from sickness, a mechanical ventilator, or catheters
Sedatives	Propofol Lorazepam Midazolam Dexmedetomidine	Helps prevent one from feeling anxiety or uneasiness
Blood thinners	Heparin Enoxaparin Dalteparin	Helps prevent blood clots from forming in the blood vessels of one's legs and arms (also called deep vein thrombosis or DVT)
Stomach-acid medication	Famotidine Ranitidine Omeprazole Pantoprazole	Helps prevent stomach ulcers or stomach bleeding
Insulin	Injection under the skin or given continuously through the vein	Keeps one's blood sugar in control, even if one has no history of diabetes
Bowel regimen	Docusate Senosides Bisacodyl	Keeps one's bowel movements regular
Pressors	Norepinephrine Dopamine Epinephrine	Raises one's blood pressure if it is too low
Antibiotics	Depends on type and cause of infection	Helps prevent or treat infections if they occur

Post-Intensive Care Syndrome (PICS)

Millions of patients are admitted to intensive care units each year, one-third of whom will need a machine to help them breathe (ventilator). These critically ill patients may develop health problems related to their illness, injury, the ventilator, or other treatments. Such problems cannot be totally prevented and can continue after the patient leaves the hospital. Delirium, acute respiratory distress syndrome, and sepsis (the body's toxic response to infection) increase the chances of these problems continuing after ICU discharge. They, too, may not always be prevented.

This chapter will help you understand the health problems known as *post-intensive care syndrome*, or PICS, so you know what to look for when your family member returns home. The section also includes tips on how to minimize PICS. Many people develop PICS, and help is available. Your family member will have the best chance of recovery if his or her primary care doctor is informed of these health problems, so the primary care doctor can recommend specialists who can help.

What is PICS?

Post-intensive care syndrome, or PICS, involves a variety of health problems that remain after critical illness. They are present when the patient is in the ICU and may persist after he or she returns home. These problems can involve the patient's body, thoughts, feelings, or mind and may affect the family. PICS may show up as an easily noticed, drawn-out muscle weakness, known as ICU-acquired weakness; as problems with thinking and judgment, called cognitive (brain) dysfunction; and as other mental health problems.

ICU-acquired weakness (ICUAW)

ICUAW is muscle weakness that develops during an ICU stay. This is a common problem of being critically ill and occurs in:

- 33% of all patients on ventilators,
- 50% of all patients admitted with severe infection, which is known as sepsis, and
- Up to 50% of patients who stay in the ICU for at least one week.

People who develop ICUAW may take more than a year to recover fully. ICUAW makes it difficult to perform activities of daily living, including

grooming, dressing, feeding, bathing, and walking. ICUAW may greatly delay or even prevent people from doing activities in the way they used to.

Cognitive or brain dysfunction

This refers to problems connected with remembering, paying attention, solving problems, and organizing and working on complex tasks.

After leaving the ICU, 30% to 80% of patients may have these kinds of problems. Some people improve during the first year after discharge from the hospital; other people may never fully recover.

Cognitive dysfunction may affect whether a person can return to work, balance a checkbook, or perform other tasks that involve organization and concentration.

Other mental health problems

People who experienced a critical illness may develop problems with falling or staying asleep. They may have nightmares and unwanted memories. Reminders of their illness may produce intense feelings or strong, clear images in their mind. Their reactions to these feelings may be physical or emotional.

These people may also feel depressed and anxious and may have symptoms of posttraumatic stress disorder (PTSD). These include having nightmares and unwanted memories, feeling “keyed up,” and wanting to avoid thinking or talking about their stay in the ICU.

How does PICS affect recovery?

Up to 50% of patients may return to work within the first year, but some may not be able to return to the jobs they had before their illness. Patients may need help with activities after leaving the hospital.

What can you do to minimize PICS?

You may be able to minimize PICS by helping your critically ill family member stay “oriented” while in the ICU:

- Talk about familiar things, people, and events.
- Talk about the day, date, and time.
- Bring in favorite pictures and items from home.
- Read aloud at the bedside.

You can also keep a diary or journal and later review it with the care team and your family member. This may help your family member understand what happened, clear up some memories, and reduce stress.

Last, you can ask the care team to teach you how to help with your family member's bedside exercises. Exercises prevent weakness by keeping the joints and muscles active. Patients should move their body as soon as they can and work with physical therapists, even while using a ventilator. Moving is also good for the brain.

How does PICS affect the patient's family?

Critical illness is a family crisis. Feeling worried and confused about your family member can affect your own health. The ICU team may ask you to make decisions about important, sometimes overwhelming matters. Because of this, you might experience mental health problems such as depression, anxiety, and PTSD.

How can you lower your family member's chances of developing PICS?

First and foremost, take care of yourself. This cannot be stressed enough. Meeting the needs of your critically ill family member is a major part of care, but your needs are just as important. If you are well, you have the physical and emotional strength to support your family member and feel good about it. Eat well, get as much rest as possible, exercise, and seek support. The hospital has social workers, case managers, and pastoral caregivers who can help.

Take time to understand your family member's illness and treatment options. Having this information will help you make decisions, feel confident about the decisions you make, and reduce stress. Ask questions, ask to meet with the ICU team, and keep a journal. Review the journal with a member of the care team whom you trust to make sense of what has happened and how you are responding to it. These actions can help you and the care team recognize and respect your family member's wishes, values, and preferences as much as possible.

Participating in patient care is another way to support your family member and reduce stress. The bedside staff can suggest ways for you to participate, if you choose to do this.

After leaving the ICU

The ICU team may diagnose your family member with PICS or determine that he or she is at risk for developing it. The team may refer you to other caregivers for support services after your family member leaves the ICU. The following are possible warning signs of PICS:

- Muscle weakness or problems with balance
- Problems with thinking and memory
- Severe anxiety
- Depression
- Nightmares

If you notice any of these problems, ask your family member's primary care doctor or caregiver for a referral to one of the following specialists:

Occupational therapist: A caregiver who helps the patient relearn life skills, such as the activities of daily living and the use of memory (for example, grooming, feeding, dressing, balancing a checkbook).

Physiatrist: A medical doctor who is specially trained to diagnose and treat injuries to the muscles, bones, tissues, and nervous system. The physiatrist can prescribe medication. He or she teaches patients exercises to improve what they can do and gives patients devices to help them adapt to what they cannot do.

Physical therapist: A caregiver who helps restore a person's ability to function and be independent after injuries to the muscles, bones, tissues, and nervous system.

Psychiatrist: A medical doctor who is specially trained to diagnose and treat mental health problems. The psychiatrist can prescribe medication.

Psychologist: An advanced-degree professional who can diagnose and treat problems with thoughts, emotions, and coping skills. The psychologist tests and assesses behavior and mental health.

Speech therapist: A caregiver who helps people with problems related to memory, attention, and swallowing. The speech therapist also helps patients learn to speak again, if necessary.

Death by Neurological Criteria (Brain Death)

Despite the advances in medical technology and the efforts of the healthcare team, physicians and healthcare providers will not always be able to save a patient's life. This is the case when an injury to the brain makes it impossible for the patient to breathe or the heart to beat without life support equipment.

This chapter is provided to help families who have been told by an ICU doctor (known as an intensivist) that a family member has experienced brain death. Brain death, more formally called "death by neurological criteria," is a medical diagnosis and is recognized legally.

What does death by neurological criteria or brain death mean?

Breathing and heartbeats are complex functions controlled by many areas of the brain, including a tiny part about the size of the thumb called the "brain stem." Traditionally, death has been defined as the irreversible loss of vital functions, such as breathing and heartbeat. Injury to the brain stem and the diagnosis of brain death mean there is no possibility for a recovery. These patients cannot breathe and maintain a heartbeat without mechanical help. If no breathing machine is used to support the patient's breathing, or no intravenous medications are given to maintain the patient's blood pressure, the heartbeat and breathing will stop. No thinking occurs when the patient's brain stops working, even if artificial breaths are being given by the machine and the heart is still beating. Without artificial and mechanical support, the natural course in these patients is that all body functions will continue to deteriorate and stop.

Following a diagnosis of brain death, the patient's organs (the heart, lungs, kidneys, and liver, among others) can be supported by artificial interventions if the organs are to be transplanted. The only reason to continue organ-supporting measures is to determine whether the patient wanted to be an organ donor. The supportive measures are only possible in an ICU.

Preparation for organ transplant is the only reason that physicians are obliged to keep the brain-dead patient's heart beating through the use of the breathing machine. Continuing life support for other reasons is considered medically inappropriate and goes against medical ethics. Likewise, further invasive procedures, such as placement of a feeding tube, are inappropriate.

What can cause death by neurological criteria or brain death?

Causes of catastrophic and irreversible damage of the entire brain, including the brain stem, can include the following:

- Traumatic brain injuries caused by motor vehicle accidents, violence, and falls
- Lack of oxygen to the brain tissue for an extended period, usually after a prolonged stop in the actions of the heart or lungs, possibly caused by a drug overdose or shock
- Brain tumors, infections, massive strokes, or bleeding into the brain, leading to severe swelling of the brain

What is the legal definition of death in the Uniform Determination of Death Act, and why is this definition needed?

In the United States and its jurisdictions, a patient can be pronounced dead by either of two standards as defined by the Uniform Determination of Death Act (UDDA):

- On the basis of cardiac criteria, which means that the heart has stopped, or
- On the basis of neurological criteria (brain death), when irreversible loss of brain function, including brain stem activity, occurs.

Once a person is declared dead on the basis of neurological criteria, all medical interventions are discontinued. The time of death is when the physician determines death on the basis of neurological criteria, not when the heartbeat stopped after discontinuation of support; these patients are dead, even if the heart is still beating, because brain function has stopped. If the patient wished to be an organ donor, the breathing machine may be left on until the body is moved to the operating room. Otherwise, the body is transported to a morgue or to a funeral home. A licensed physician or coroner will issue a death certificate—which includes the time, place, and cause of death—at a later date.

Who determines death on the basis of neurological criteria (brain death)?

Every hospital or jurisdiction has adopted a vigorous series of actions (called a “protocol”) to determine death by neurological criteria. The brain death exam is performed by two physicians examining the patient independently on two

separate occasions. Physicians take the final determination very seriously and do not make a decision unless they are confident about it. Although it is not required by law, many hospitals require at least one of the two physicians to be a neurologist or neurosurgeon (a doctor with special expertise and training in diagnosing and treating brain disorders) or an intensivist. This illustrates the high level of care applied to ensure the determination of death is made correctly 100% of the time. To avoid all potential conflicts of interests, neither of the examining physicians can be caring for a patient who needs an organ transplant.

How do physicians determine death on the basis of neurological criteria (brain death)?

To be declared dead on the basis of neurological criteria, the patient should show clear-cut signs indicating the following:

- Irreversible coma or lack of awareness and arousal, and complete lack of responses to even the most painful stimulation. No purposeful eye opening, no withdrawal of a limb, and no signs of pain can be seen.
- Absence of reflexes arising from the brain stem, such as cough and gag. Some patients may have movements of the arms or legs in response to nerve stimulation, but these reflexes arise from the spinal cord, not from the brain or brain stem.
- Absence of natural breathing or even attempts to breathe. This is confirmed by an apnea test, in which the patient is observed closely after the breathing machine is stopped. If the patient makes no effort to breathe, the diagnosis is death on the basis of neurological criteria.

Additional tests may be required if the above tests cannot be reliably performed or evaluated. Doctors might check for circulating blood in the brain, perhaps using a brain x-ray or brain scan. A tracing of brain waves with an electroencephalogram (EEG) can be done to see if there is any electrical activity in the brain.

What does death by neurological criteria (brain death) mean for organ donation?

As mentioned earlier, a patient who has been declared dead on the basis of neurological criteria may still have a beating heart. This allows the ICU team to maintain blood flow to organs for transplantation if the patient had an advance directive for organ donation or, in the absence of a directive, if this is the family's wish.

What to Expect After Your Family Member Leaves the ICU: Post-Intensive Care Syndrome (PICS) and Other Issues

When your family member is discharged from the ICU, he or she might go to another department of the hospital, to a different hospital, to a rehabilitation center, or to a nursing home. It is unusual for patients to go directly home after leaving the ICU.

Communication

Ask the ICU team what person you should contact for information or questions after your family member leaves the ICU. Write that contact information down and keep it with the patient's discharge papers.

The ICU medical team who cared for your family member may not be on duty when your family member leaves the ICU. If your family member is being transferred to a floor in the same hospital, the ICU team probably has talked with the floor medical team about your family member's experience in the ICU. It is OK to ask your new team what they have heard from the ICU team about your family member. Also, if the patient goes to a different hospital, a rehabilitation center, or a nursing home after leaving the ICU, you should always feel free to ask that the new medical team communicate with the ICU team. After going home, your family member may follow up with his or her regular doctor. Feel free to give your family member's regular doctor the contact information for the ICU team in case the doctor has any questions about the ICU stay.

Financial and social issues

You may have had to take off work while your family member was in the hospital, and you might miss more work after she or he returns home. Often patients and families find it difficult to figure out financial issues such as bills, getting back to work, and arranging for help at home. Your medical team can have a social worker and case manager speak with you to help you with these issues. You and your family member may find that it is difficult to reconnect with your friends after an ICU stay—you may feel you do not know what to say to them or how to act. Social workers and other counselors can help in this area too.

Eating and nutrition

No doubt your family member's eating habits were affected by the ICU stay, because of dietary restrictions during treatment, medications received, or the illness itself. Even if able at this point to take food by mouth, your family member may not have the same appetite or may find that food tastes different than before. Temporary changes may include foods tasting saltier or sweeter or having an unusual metallic taste. Until the return of a normal appetite, it may be easier for the recovering patient to eat small frequent meals of foods that are enjoyable, supplemented by healthy snacks between meals. Encourage your family member to take time while eating and enjoy a variety of foods daily. Fruits, vegetables, dairy products, breads, and meats (poultry and fish) should be part of a well-balanced diet, which will help a recovering patient conserve energy, fight infection, and heal properly.

Smoking

A recently hospitalized patient probably has not been smoking for some time now, so this is a real opportunity to quit smoking all together. The single most important thing a recovering patient can do to help the lungs heal is to not smoke. In addition, smoking can interfere with such activities as wound healing and appetite. Each time a person says no to a cigarette, it adds 5 minutes to his or her life. Encourage your family member to find a substitute for smoking, such as going for a walk (if able), chewing sugar-free gum, exercising, or starting a new activity that interests him or her.

Here are some useful resources to help someone stop smoking:

- American Lung Association
Phone: 1-800-586-4872
Web site: www.lungusa.org
- American Heart Association
Phone: 1-800-242-8721
Web site: www.americanheart.org
- American Cancer Society
Phone: 1-404-320-3333
Web site: www.cancer.org
- National Cancer Institute
Phone: 1-800-422-6237
Web site: www.cancer.gov

Your family member's physician will be happy to discuss other options to help stop smoking for good.

Exercise

Exercise will help reduce stress and anxiety while helping your family member regain strength and appetite. Initially, a recovering patient may become easily tired because of the effects of illness, medications, or dietary change. Any exercise is good, and it is best to start small and gradually increase the level of activity. Your family member's doctor can help decide what exercises are appropriate.

Sex

It is normal for recovering patients and their partners to have a decrease in sex drive after a critical illness. Lack of interest and feeling too tired for sex are common responses. Partners should discuss their feelings to keep the lines of communication open. Remember that holding hands, massaging, cuddling, and comforting are all ways to be intimate.

Post-intensive care syndrome (PICS)

Millions of patients are admitted to ICUs each year, one-third of whom need a machine to help them breathe (ventilator). These critically ill patients may develop health problems related to their illness, injury, the ventilator, or other treatments. Such problems cannot be totally prevented and can continue after the patient leaves the hospital. Delirium, acute respiratory distress syndrome, and sepsis (the body's toxic response to infection) increase the chances of these problems continuing after ICU discharge. They, too, may not always be prevented.

Many people develop PICS, and help is available. Your family member will have the best chance of recovery if his or her primary care doctor is informed of these health problems, so the primary care doctor can recommend the appropriate specialists.

What is PICS?

Post-intensive care syndrome, or PICS, is made up of health problems that remain after critical illness. They are present when the patient is in the ICU and may persist after he or she returns home. These problems can involve the patient's body, thoughts, feelings, or mind and may affect the family. PICS may show up as an easily noticed, drawn-out muscle weakness, known as ICU-acquired weakness; as problems with thinking and judgment, called cognitive (brain) dysfunction; and as other mental health problems.

ICU-acquired weakness (ICUAW)

ICUAW is muscle weakness that develops during an ICU stay. This is a common problem of being critically ill and occurs in:

- 33% of all patients on ventilators,
- 50% of all patients admitted with severe infection, which is known as sepsis, and
- Up to 50% of patients who stay in the ICU for at least one week.

People who develop ICUAW may take more than a year to recover fully. ICUAW makes it difficult to perform activities of daily living, including grooming, dressing, feeding, bathing, and walking. ICUAW may greatly delay or even prevent people from doing activities in the way they used to. Talk to the medical team about what types of exercises your family member can do to try to get stronger. Also, your family member's primary care doctor or caregiver can provide a referral to one of the following specialists:

Occupational therapist: A caregiver who helps the patient relearn life skills, such as the activities of daily living and the use of memory (for example, grooming, feeding, dressing, balancing a checkbook).

Physiatrist: A medical doctor who is specially trained to diagnose and treat injuries to the muscles, bones, tissues, and nervous system. The physiatrist can prescribe medication. He or she teaches patients exercises to improve what they can do and gives patients devices to help them adapt to what they cannot do.

Physical therapist: A caregiver who helps restore a person's ability to function and be independent after injuries to the muscles, bones, tissues, and nervous system.

Cognitive or brain dysfunction

Cognitive or brain dysfunction refers to problems connected with remembering, paying attention, solving problems, and organizing and working on complex tasks.

After leaving the ICU, 30% to 80% of patients may have these kinds of problems. Some people improve during the first year after discharge from the hospital; other people may never fully recover.

Cognitive dysfunction may affect whether a person can return to work, balance a checkbook, or perform other tasks that involve organization and concentration.

If these problems occur, a primary care doctor or caregiver can refer your family member to an occupational therapist or physiatrist (see above) or to a neuropsychiatrist (a medical doctor), neuropsychologist, or similar profes-

sional who specializes in helping patients recover from cognitive problems after an ICU stay or brain injury. A patient may also be referred to a speech therapist, a caregiver who helps with problems related to memory, attention, and swallowing. The speech therapist also helps people learn to speak again, if necessary.

Other mental health problems

Sleep disturbances

People who have been critically ill may develop problems with falling or staying asleep. Your family member may stay awake during the night rather than during the day or may have nightmares that wake him or her up.

Anxiety

Feeling anxious after being critically ill is normal. Physical symptoms may include dry mouth, rapid breathing, rapid pulse or heartbeat, cold sweats, butterflies, or tightness in the stomach. A recovering patient also may have some mental issues like difficulty remembering or concentrating, problems sleeping, and lack of self-confidence. Your family member might be restless or fidgety, feel unsatisfied, have racing thoughts, be unable to listen closely, or lose his or her sense of humor. It may help to exercise or to talk about these feelings with someone he or she trusts.

Depression

Your family member's recent illness probably was a difficult time, both physically and emotionally. It is common to "feel down" after being critically ill. A recovering patient may experience such symptoms as sadness, crying, early waking or other changes in sleep patterns, poor appetite, or lack of energy. As well, your family member may lose interest in his or her appearance, in family and friends, or in activities that were once enjoyable. If you are concerned that your family member is not feeling better, his or her doctor can recommend some types of support (discussed later).

Posttraumatic stress disorder (PTSD)

Reminders of an illness may produce intense feelings or strong, clear images in the mind. Your family member's reactions to these feelings may be physical or emotional. He or she may feel irritable or "keyed up" at odd times and may want to avoid thinking or talking about the ICU. These may be signs of posttraumatic stress disorder, or PTSD. Your family member's doctor can recommend support.

If a doctor or caregiver feels that your family member needs support for anxiety or depression or that he or she has PTSD, your family member may be referred to one or both of the following:

Psychiatrist: A medical doctor who is specially trained to diagnose and treat mental health problems. The psychiatrist can prescribe medication.

Psychologist: An advanced-degree professional who can diagnose and treat problems with thoughts, emotions, and coping skills. The psychologist tests and assesses behavior and mental health.

How does PICS affect recovery?

Up to 50% of patients may return to work within the first year after their ICU stay, but some may not be able to return to the jobs they had before their illness. People may need help with activities after leaving the hospital.

What can you do to minimize PICS?

You may be able to minimize PICS by helping your critically ill family member stay “oriented” while in the ICU:

- Talk about familiar things, people, and events.
- Talk about the day, date, and time.
- Bring in favorite pictures and items from home.
- Read aloud at the bedside.

You can also keep a diary or journal and later review it with the care team and your family member. This may help your family member understand what happened, clear up some memories, and reduce stress.

Last, you can ask the care team to teach you how to help with your family member’s bedside exercises. Exercises prevent weakness by keeping the joints and muscles active. Patients should move their body as soon as they can and work with physical therapists, even while using a ventilator. Moving is also good for the brain.

How does PICS affect the patient’s family?

Critical illness is a family crisis. Feeling worried and confused about your family member can affect your own health. The ICU team may ask you to make decisions about important, sometimes overwhelming matters. Because of this, you might experience mental health problems such as depression, anxiety, and PTSD.

How can you lower your family member's chances of developing PICS?

First and foremost, take care of yourself. This cannot be stressed enough. Meeting the needs of your critically ill family member is a major part of care, but your needs are just as important. If you are well, you have the physical and emotional strength to support your family member and feel good about it. Eat well, get as much rest as possible, exercise, and seek support. The hospital has social workers, case managers, and pastoral caregivers who can help.

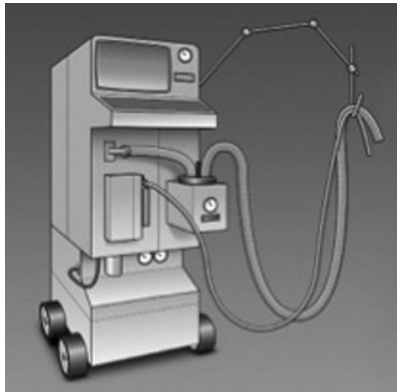
Take time to understand your family member's illness and treatment options. Having this information will help you make decisions, feel confident about the decisions you make, and reduce stress. Ask questions, ask to meet with the ICU team, and keep a journal. Review the journal with a member of the care team whom you trust to make sense of what has happened and how you are responding to it. These actions can help you and the care team recognize and respect your family member's wishes, values, and preferences as much as possible.

Participating in patient care is another way to support your family member and reduce stress. The bedside staff can suggest ways for you to participate, if you choose to do this.

Life Support Equipment

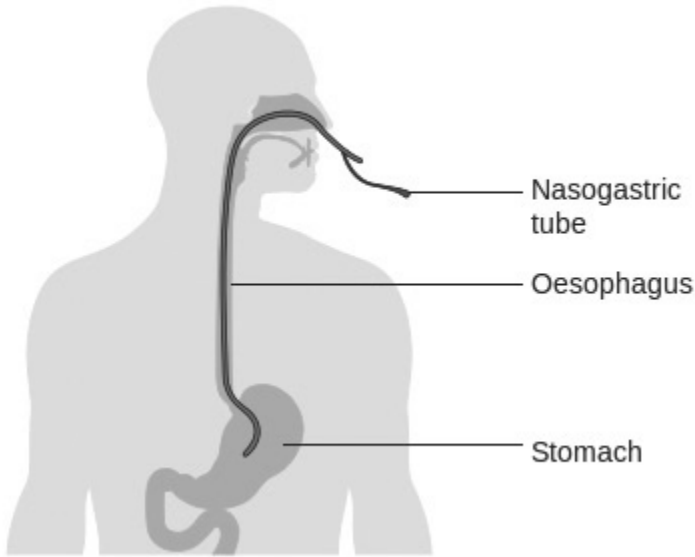
Some equipment or devices implemented in critical care are started when organs are failing and need support. These measures, intended to be temporary and allow for normal organ function to return, may conclude in dependence if organ function does not return to normal. The following are examples of frequently used devices or therapies and are by no means an exhaustive list. It is important to discuss with the healthcare team if your family member does not want these therapies started.

Mechanical ventilator



- Also known as a breathing machine or artificial ventilation.
- This machine provides supplemental oxygen and removes carbon dioxide.
- The ventilator settings are adjusted based on **arterial blood gases** and continued improvement in the condition that existed when the ventilator was started.
- Patients are usually sedated for placement of a breathing tube, which is used to deliver the artificial ventilation; once the breathing tube is placed, patients are allowed to awaken.
- The long-term option for the breathing tube is called a tracheostomy, which is a procedure to place a breathing tube in the neck to connect to a breathing machine.
- Patients with a tracheostomy and mechanical ventilation usually do not leave the hospital to go directly home but instead go to a long-term acute care facility for rehabilitation.

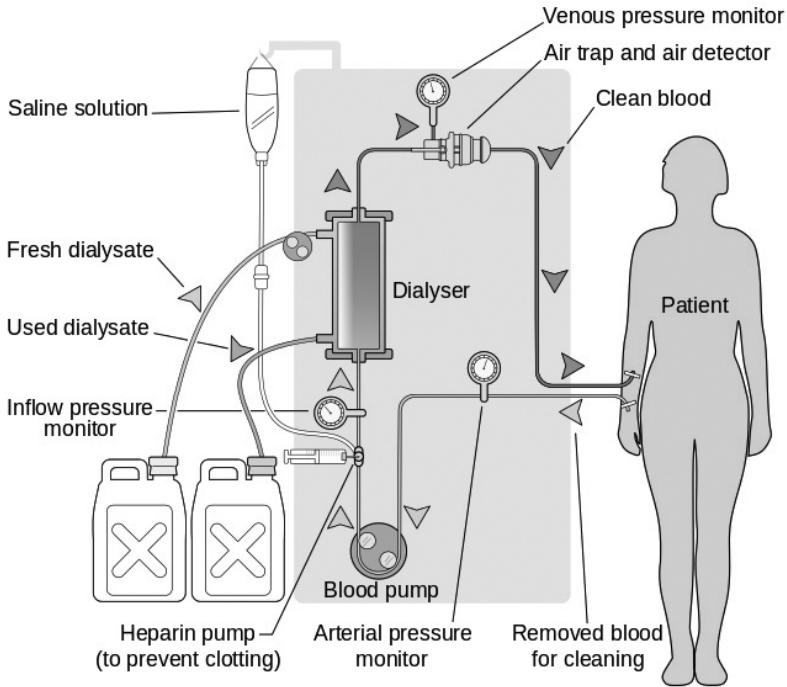
Feeding tube



By Cancer Research UK (Original email from CRUK) [CC BY-SA 4.0 (<http://creativecommons.org/licenses/by-sa/4.0>)], via Wikimedia Commons

- A patient's basic nutritional needs are met during a critical illness using liquid nutrition administered directly into the gastrointestinal tract.
- Initially the feeding can be given through a plastic tube passed through the nose into the stomach or intestine.
- This feeding may be started while the patient is on mechanical ventilation and may continue when the patient no longer needs mechanical ventilation.
- If sufficient calories cannot be taken orally when mechanical ventilation is removed or if swallowing is impaired, then a long-term option for feeding will be discussed by the care team.
- Patients usually cannot leave the hospital without a long-term permanent feeding alternative.

Hemodialysis



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- Hemodialysis, dialysis, peritoneal dialysis, HD, CRRT—all refer to the removal of body wastes and excess fluid that the kidneys can no longer remove.
- Dialysis can be temporary or permanent.
- When hemodialysis is performed as a temporary measure in critical care, a large central venous catheter is placed.
- This catheter is connected to a machine that acts as a filtration and excretion system.
- Once the patient's kidneys regain function, dialysis can be stopped.
- If the kidneys do not regain normal function, then a long-term solution for performing dialysis will be discussed with the patient and the care team.

What to Expect When Your Child Is in a Pediatric Intensive Care Unit (PICU)

What is the PICU?

In the PICU, a team of nurses, doctors, therapists, and many others who have special training and experience very closely watch and treat children who require intensive care. These children may have breathing problems, heart problems, serious infections or injuries, or other conditions that need complex tests and treatment. The specialized care in the PICU gives your child the best chance of getting better. Oftentimes, all children need is very close observation. Sometimes children can have unstable conditions and require staff intervention and support from technical equipment to do well. With modern PICU care, children can have excellent outcomes, even when their illnesses are quite serious.

Equipment in the PICU

Monitors

Children in the PICU are watched very closely, often with the use of electronic monitors that display heart rate and rhythm, breathing rate and pattern, oxygen level in the blood, blood pressure, and additional measurements. The numbers or patterns shown on monitors change frequently. Usually small changes do not mean there is a problem, even if an alarm light or sound comes on. But the nurses and doctors do use the monitors to alert themselves to these changes because some of them might be important and a sign of a problem that needs attention.

Catheters

Catheters (also called tubes, lines, or drains) are commonly used in the PICU. Medication and fluids may be given to your child through small, peripheral intravenous catheters (IVs) or through catheters that have been inserted into your child's larger veins. Central venous catheters are used to give strong medication or intravenous feedings that cannot be given through a peripheral IV. Central venous catheters can also be used to draw blood for tests. Urinary catheters are tubes that go into the bladder to collect and measure urine output. Endotracheal (breathing) tubes may be used to connect your child to a

ventilator, a machine that helps someone breathe when normal breathing is very difficult or impossible.

Many different pieces of equipment are used in the PICU. Your child's nurse and other staff will be glad to explain the reason for each piece of equipment they are using to care for your child.



A nurse critically caring for a child who needs it most. This child has an endotracheal tube connected to a ventilator that helps him breathe.

When do I meet the PICU team?

At the time of admission, members of the PICU team may be quite busy with the assessment of your child if your child is relatively stable, or they may be taking care of more urgent medical issues while stabilizing your child. As this often hectic phase slows down, the team will spend more time with you. There is often a social worker or support person available to help you while you are waiting to meet the medical team. Your child's nurse and doctor may have questions about your child's condition. They will have important information about your child's plan of care, including explanations of your child's condition as well as its likely cause. They will also be able to discuss current or planned tests and treatments.

Will the PICU team tell me what will happen to my child?

The PICU team members will do their best to tell you what to expect during your child's stay in the PICU. Predicting the course or outcome for many of the children who are more seriously ill may be impossible. Team members will make every effort to keep you up to date with the information they have, but your child's condition may change, and new or different tests or treatments may be needed.

What is my role as part of my child's PICU team?

You are one of the most important members of the PICU team. You know your child better than anyone else and can be a major help in your child's care. Please work with the team to help your child get better. Your child's nurse will be the best person to tell you what you should and should not do to help your child and the team.

The PICU team includes people with many different jobs to do to keep your child as safe and comfortable as possible while working for the best and fastest recovery. A list of these team members is included at the end of this chapter.

How safe is my child's care?

In recent years, many new safety practices have been started in intensive care units. More bar codes and stickers, arm bands, masks for your face, hand cleaners, gloves, and antiseptic procedures are being used. Members of the PICU team have many discussions among themselves to be sure they communicate all important information to one another. Please feel free to ask about the procedures or devices you see in use. If you are concerned about a safety issue, such as hand cleaning or use of certain medication, please bring it to the attention of your child's PICU team.

Usual care for children in the PICU

Because every child is different, the PICU has almost no such thing as routine care. But some kinds of care are appropriate for almost all children in the PICU.

Nutrition and medication: Most children in the PICU receive IV fluids and medicines. Some may receive oral medication and some may have oral feedings. Others may have just IV fluids or tube feedings, or IV nutrition called total parenteral nutrition (TPN).

Pain control: Your child's PICU team will do their best to keep your child comfortable. Finding the best pain medication sometimes takes more than one try. Severe pain usually requires a narcotic drug, but other choices are available to ease mild or moderate pain. Good pain control is one of the team's main goals.

Sedation: Children with or without pain may be very anxious or agitated by their condition and surroundings in the PICU. A sedative may be very important in speeding their care and recovery. Sedatives are calming medicines used to decrease the anxiety and fear that any child who is ill may have.

Pain medicines and sedatives may have to be adjusted at times to get the best balance between good effects and side effects. Your child's PICU team is specially trained to choose the best medication for your child's comfort.

What can I do?

You know your child better than anyone else and can give the PICU team helpful information about your child. Here is what you can do:

- *Participate in the care of your child.* When appropriate, wash, feed, or hold your child (always ask the nurse if this is okay).
- *Be aware of daily and long-term goals to help your child get better.* Understand what the goals are as well as the “big picture” that will help your child leave the PICU. Getting better is a process that may be unpredictable and is based on your child's progress. Every child gets better differently, even from similar illnesses.
- *Ask questions to stay informed.* Feel free to ask questions as many times as you need. The PICU team understands that you are under a great deal of stress and may not remember everything the first time you hear it. Write down the names of your child's PICU team members and what their roles are. If you think of questions when the doctors are not around, ask your child's nurse or write down the questions to ask later.
- *Bring in pictures of your child or family.* This helps the PICU team see your child the way you do and personalizes your child's care.
- *Bring in favorite toys, blankets, books, movies, and music.* Familiar objects are comforting for children. Getting your child to focus on familiar toys and objects can help him or her stay calm and recover more quickly.
- *Learn more about your child's illness.* Your child's doctor or nurse can provide you with written material and websites, and they can sit down and explain to you what is going on.
- *Ask family and friends to send mail.* Your child may enjoy receiving mail from family and friends. The nurse can give you the address of the PICU.

How can I take care of myself?

Caring for a child can be tiring and emotional. All members of the PICU team need to take breaks from the challenging work of caring for children who are ill. You will need to take breaks, too. Here are some suggestions:

- Eat healthy foods.
- Get enough sleep.
- Exercise or stretch your limbs periodically.

- Accept the help and support of family and friends.
- Keep a positive attitude.
- Use faith and spiritual support and activities, such as meditation or prayer.
- Keep a journal of thoughts and feelings about your child's progress.
- Read inspirational material.
- Ask a family member or close friend to take messages or to be a spokesperson for you.
- Make sure someone looks after your house and pets and checks your mail and phone messages.

How will this affect my other children?

The illness of a child can affect others in your family. Here are some things to look for:

- Children may feel responsible for a sibling's illness because they wished him or her ill in the past.
- Children may feel ignored or that you are favoring a sibling who is ill by spending so much time in the PICU.
- Children may act out or may regress, such as losing bladder control.
- Children may do poorly in school due to prolonged disruption in family life.
- Extended family members or close friends may need some updated and accurate information.

Addressing these issues yourself or with the help of a specially trained psychologist or child-life specialist is often helpful. Family therapy may be helpful in dealing with the stresses of serious illnesses. Take some time to be with the rest of your family and to restore balance to your own life.

When a child is extremely ill

If your child is extremely ill or injured, it is possible that he or she will not get better. Your child's PICU team will work hard to provide every chance of recovery, even when those chances may be very small.

Frequently discussing the cause and the seriousness of your child's illness with the team is very important so everyone has a realistic understanding of your child's condition and how it will affect your child.

While the course of your child's illness cannot always be predicted with certainty, members of the PICU team will share with you their best understanding of the possible and most likely outcomes of your child's illness.

Need more information?

If you need to know more about the PICU and its team's care for your child, feel free to ask questions. The members of the PICU team want you and your child to feel safe and comfortable in the PICU. They want you to have any information that will help you understand your child's illness and time in the PICU.

PICU team members

A healthcare team will be taking care of your child throughout the day and the night. This team includes any or all of the following members:

- *Parents/Guardians*: The most important member of the team is you.
- *Physicians (doctors)*: Several doctors may be caring for your child. An **attending physician** heads each team, and each team may include the following:
 - *Pediatric intensivists*: These doctors are highly skilled in treating very ill and injured children.
 - *Surgeons*: These doctors can perform an operation on your child.
 - *Heart specialists, lung specialists, infectious disease specialists, and other specialists*: These specialists work closely with the physicians and pediatric intensivists.
 - *Medical students, residents, and fellows*: These doctors are doctors in training. They work closely with the attending physician to care for your child.
- *Nurses*: These healthcare workers are specially trained to closely monitor and care for your child.
- *Pharmacists*: These specialists monitor your child's medicines and dosages during the course of your child's illness.
- *Dietitians*: These specialists help manage your child's nutrition, including IV feedings.
- *Respiratory (breathing) therapists*: These specialists help your child breathe better. They can measure how well your child's lungs are working and give your child oxygen and ventilator care.
- *Physical therapists*: These specialists help tone and strengthen weak muscles and loosen stiff joints that your child may develop during a stay in the PICU.
- *Occupational therapists*: These specialists can help your child relearn everyday skills, such as eating and dressing themselves.
- *Child-life specialists*: These specialists help your child cope with being in the PICU. They are experts in child development and can also help get siblings ready for a visit to the PICU.

- *Social workers:* These specialists support you and your family and guide you to resources as needed during your child's stay in the PICU.
- *Psychologists:* These specialists can counsel you and your child during your child's illness.
- *Chaplains:* Clergy can offer spiritual support to you and your child. They are usually nondenominational, but you can ask for denominational clergy members.
- *Unit clerks:* These desk clerks order tests, coordinate transfers, and keep the administrative aspects of the PICU running smoothly.
- *Discharge planners:* These staff members help coordinate the transfer of your child from the PICU to other hospitals or places of care. They can arrange for you to have equipment at your home that you may need to help care for your child.
- *Palliative care specialists:* These specialists are concerned with maximizing your child's comfort and quality of life during an extended illness.

Palliative Care for Children

This chapter describes how palliative care can improve your child's quality of life and reduce his or her suffering.

What is palliative care?

Palliative care is treatment given by trained specialists to improve quality of life and reduce suffering of children with life-threatening or life-limiting medical conditions. This specialized care is provided along with usual medical treatments or when these treatments cannot improve or cure your child's condition. Palliative care can also be provided for children who are suffering from severe symptoms of chronic disease. Palliative care seeks to relieve physical, social, emotional, and spiritual suffering that your child and family may have.

Palliative care aims to make your child comfortable and limit procedures and tests when desired by the family and when possible. While all of your child's doctors and nurses will try to prevent discomfort, treatments offered by the palliative care team are further designed to control as many uncomfortable symptoms as possible. New or different medications and therapies may be started to make your child more comfortable and make procedures less painful.

Palliative care includes clear and thoughtful communication with families. You can be involved as much as you like regarding treatment decisions for your child. This approach ensures that your concerns are addressed by your child's doctors and nurses. Your knowledge and expertise about your child are very valuable and will help the palliative care team develop the best treatment plan for your child.

Palliative care can help improve the quality of time with your child while he or she is in the hospital. It can also help you and your family deal with the loss of your child if death occurs.

Palliative care is about making your child and family comfortable and much more.

Who can receive palliative care?

Any child who is very ill and not responding to medical treatments can receive palliative care. Palliative care is also good for children who have complex medical problems that could result in shortened life expectancy.

When can a child receive palliative care?

- Palliative care can be given to a child whenever a life-threatening or life-limiting condition is diagnosed.
- Palliative care can be given along with usual medical treatments for any child with a life-threatening or life-limiting condition.
- Palliative care can be continued even if other medical treatment can no longer help cure your child's condition.

Who provides palliative care for my child?

The palliative care team is a specially trained group of professionals including physicians, nurses, social workers, psychologists, child life specialists, teachers, clergy, and volunteers. These professionals will help identify and treat ongoing physical, psychological, social, emotional, and spiritual needs of your child and family.

What services does a palliative care team provide?

- The palliative care team can help your child by providing new or different medicines and treatments in an attempt to relieve pain, anxiety, and other uncomfortable symptoms. This may allow your child to be more awake during the day to interact with family and friends. In some situations, your child may be moved to a different care area (possibly even home) to allow increased freedom, space, and access to family and friends.
- The palliative care team can further help you understand your child's condition, treatment options, and likely outcomes. The team can help to find specific goals that are just right for your child's care. The palliative care team can help communicate these goals to the other doctors and nurses caring for your child.
- The palliative care team can address grief and stress that families may feel when they have a very sick child by providing emotional and spiritual support.
- The palliative care team can help find resources in the community to provide support to you, your child, and your family. This may include information from local and national organizations or meetings with other families in your community through organized support groups.
- If your child is near death, the palliative care team can help you and your family spend meaningful time with your child and help you cope with the intense grief when your child dies.
- The palliative care team can help you find ways to celebrate and honor your child's life.

Does my child have to stop medical treatment to receive palliative care?

- You do not have to stop medical treatment for your child to receive palliative care services. Your child can receive various treatments aimed at curing the illness while also receiving comfort measures. The doctors, nurses, and palliative care specialists caring for your child can assist you in these decisions.
- You do not have to limit or withhold medical treatments or have a do-not-resuscitate (DNR) order for your child to receive palliative care services.

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 so. Advance directives include living will, durable power of attorney for healthcare, and healthcare proxy.

Arterial blood gas (ABG, blood gas, gas): Test of a sample of blood from the artery; it shows how well a patient is breathing by measuring the amounts of oxygen and carbon dioxide in the blood.

Arterial line (A-line): Special catheter that is placed into an artery (in the wrist, arm, or groin) to continuously monitor blood pressure and to obtain ABG readings as needed.

Attending physician: Senior doctor on the healthcare team who oversees the patient's care.

Blood clots: Scabs inside of the body within blood vessels, usually a vein; they are caused by surgery, inactivity (bedrest), the presence of catheters, and some types of drugs.

Cardiac 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) to take blood samples, give medications, or measure blood pressure; or a tube placed in another part of the body (eg, in the bladder to drain urine).

Central line (internal jugular line, IJ line, subclavian line, femoral line): Special intravenous catheter placed in a large vein (in the neck, near the collarbone, or in the groin) 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 (compressions), giving rescue breathing (in the ICU, this is done by squeezing a bag to move oxygen into the patient through a face mask or breathing tube), and administering medications.

Deep venous thrombosis (DVT): Blood clots that form in the legs or arms. This can happen in sick patients who need to remain in bed most or all of the time. The ICU team will try to prevent DVT by using sequential compression devices ("squeezers") or very low doses of blood-thinning medications like heparin or enoxaparin injected under the skin.

Dehydration: When the body does not have enough water or fluid to work normally.

Delirium: When a person feels confused or sometimes sees things that are not there.

Do not resuscitate (DNR), also called do not attempt resuscitation (DNAR): An order that instructs doctors and nurses that if the patient's heartbeat and breathing stop, they should not attempt to restart the patient's heart or breathing through CPR.

Durable power of attorney for healthcare (also known as healthcare power of attorney): Legal document that gives another person—called a “surrogate decision maker”—the authority to make healthcare decisions for a patient when the patient is unable to do so.

ECG (EKG): Equipment that monitors the heartbeat and shows the heartbeat printed on paper.

Electrolytes: Chemicals in the body such as sodium, potassium, and calcium.

Endotracheal tube (ET tube or ETT): Breathing tube that is placed in the patient's airway (trachea) through the mouth or nose. This tube is attached to a mechanical ventilator to help the patient breathe.

Face mask (oxygen mask, O₂ mask): Plastic mask that is placed over the patient's 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.

Feeding tube: A tube used to give medicines and feedings. A nasogastric tube (NG tube, NGT) is placed through the nose into the stomach. An orogastric tube (OG tube, OGT) is placed through the mouth into the stomach. A Dobhoff tube is placed through the nose into the first part of the intestine. Sometimes an NG or OG tube is used to drain stomach contents.

Fellow (ICU fellow): Doctor who has finished residency and is doing advanced training to care for critically ill patients and their families.

Hydration: The process of giving a patient fluid (usually through an IV).

ICU team (critical care team): Team of healthcare professionals who care for critically ill patients and their families. This team can include doctors, nurses, respiratory therapists, pharmacists, medical students, physicians in training (residents and fellows), nurse practitioners, physician assistants, social workers, and physical, occupational, and speech therapists.

Immune: When the body builds up strength to prevent and fight infection and repair injury (or when a bug or germ builds up strength to protect itself against antibiotics).

Intravenous or IV line: A catheter that is in a vein.

Intensivist: Doctor with special training to care for critically ill patients and their families.

Intubation: Placement of an endotracheal tube in the mouth (or less often the nose) for patients who are unable to breathe enough on their own and need to be connected to a ventilator.

Life-supporting treatment (life support): Treatment that can include mechanical ventilation, tube feeding, intravenous feeding and hydration, dialysis for kidney failure, medicines to raise blood pressure and boost the heart rate, and other treatments to support life.

Malnutrition: When a body does not have enough calories or energy to work normally.

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

Nutrition: The process of providing or obtaining the food necessary for health and growth. Calories from sugar, protein, and fat.

PEG (percutaneous endoscopic gastrostomy): Placement of a tube through the skin and wall of the abdomen into the stomach to give feedings (and medicines) to patients who cannot take these by mouth. This tube requires a surgery to be placed, and it can be removed later or left in place and used permanently if needed.

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

Sedation: The reduction of irritability or agitation by administration of sedative drugs, generally to facilitate a medical procedure or diagnostic procedure.

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

Tracheostomy (trach): Surgical opening in the neck where a breathing tube is placed that goes into the patient's airway (trachea). This tube is attached to a ventilator or an oxygen mask to help the patient breathe. This tube can be removed later or can be left in place and used permanently if needed.

Tube feeding: Nutrition that is given through a tube into the stomach or first part of the intestine in patients who are not able to eat by mouth. Different formulas are available to provide the optimal balance of nutrients to support sick patients in their recovery.

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

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

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

Withdrawal: When people feel or act sick because they are no longer taking their nonprescription drugs of abuse or drinking alcohol.

Resources

American Academy of Neurology—Guidelines

The AAN provides a set of guidelines for brain injury and brain death covering an array of topics including concussion in sports and brain death in adults.

www.aan.com/guidelines

The American Society of Health-Systems Pharmacists

The ASHP publishes a webpage for patients with helpful resources about taking and managing medications and working with pharmacists. The page includes tips on safety, prevention, traveling, and more.

www.ashp.org/menu/practicepolicy/resourcecenters/patients

City of Hope

City of Hope provides resources for patients and families affected by cancer. On their website visitors can find information on different conditions and treatments, handling cancer side effects, support groups, and much more.

www.cityofhope.org

Dying Well

The book *Dying Well* contains hospice stories and shows families how to handle end-of-life challenges from working with doctors to preparing emotionally. The book also includes helpful tips for better communication.

www.irabyock.org/books/dying-well/

ICU Delirium

The ICU Delirium website explains delirium and provides information for medical professionals and patients and families.

www.icudelirium.org/patients

ICU Steps

ICU Steps is a UK-based nonprofit dedicated to supporting patients and families through critical illness. On the website visitors can find information on different support groups and best practices for starting a support group.

www.icusteps.org

Institute for Public Informing of Research and Education in Critical Care Medicine

INSPIRE CCM is a nonprofit organization dedicated to promoting the highest standard of care to the critically ill.

www.inspireccm.org

Mayo Clinic – Disease and Conditions

The Mayo Clinic's Diseases and Conditions webpage provides information on medical conditions. Site visitors are able to look up information on individual diseases, conditions, and symptoms.

www.mayoclinic.org/diseases-conditions

My ICU Care

The Society of Critical Care Medicine's Patient and Families website provides information about critical care and the ICU. Site visitors will find information on topics including the critical care team, chronic critical illness, making decisions, and life support choices.

www.myicucare.org

The National Council on Patient Information and Education

The NCIPIE website for patients and families contains resources to educate site visitors about medications and includes a guide on the safe use of pain medications.

www.talkaboutrx.org

National Hospice and Palliative Care Organization

The NHPCO website offers resources for advance care planning, caregiving, hospice and palliative care, and grief and loss. Caring Connections is a program of the National Hospice and Palliative Care Organization, whose focus is improving end-of-life care. The organization also has a phone helpline that operates Monday through Friday, 9:00 a.m.–5:00 p.m. Eastern time.

www.caringinfo.org

+1-800-331-1620

National Self-Help Clearinghouse

The National Self-Help Clearinghouse is a not-for-profit organization that promotes the importance of self-help groups. Visitors to the National Self-Help Clearinghouse site can find information on self-help groups, self-help research, and tools for improving self-help programs.

www.selfhelpweb.org

212-642-2944

Sepsis Alliance

The Sepsis Alliance website provides information to help understand sepsis, the body's toxic response to infection.

www.sepsis.org

The Society of Critical Care Medicine

SCCM's homepage provides information about the society's mission, events, and resources. Site visitors can access SCCM's Critical Connections, guidelines, and links to both of the journals, *Critical Care Medicine* and *Pediatric Critical Care Medicine*.

www.sccm.org

Surviving Sepsis Campaign

The Surviving Sepsis Campaign is a joint collaboration between the Society of Critical Care Medicine and the European Society of Intensive Care Medicine. The Surviving Sepsis website is a resource for critical care doctors, nurses, and caregivers and provides recommendations on how to diagnose and treat sepsis.

www.survivingsepsis.org

Uniform Determination of Death Act

The UDAA from The National Conference of Commissioners on Uniform State Laws provides a comprehensive basis for determining death. The webpage contains a full text and summarized version of the UDAA and a legislative fact sheet.

www.uniformlaws.org/Act.aspx?title=Determination%20of%20Death%20Act

United Network for Organ Sharing

UNOS provides information on organ donation and transplantation. Site visitors can learn about current donation facts, how organ matching works, transplantation policy, and additional donation data.

www.unos.org

US Department of Health and Human Services'—Organ Donation

This site provides information on organ donation. The site enables visitors to learn about how donation works, who can donate, what can be donated, and additional donation facts.

www.organdonor.gov