

MY
ICU GUIDE



An ICU Workbook for Families

myicuguide.com



ICU Questionnaire



This workbook is an abbreviated version of an online workbook. For more details or to fill in a more comprehensive “My ICU Questionnaire”, please refer to myicuguide.com



Questions?

Please contact:

for further information.



The MyICU Guide was created by critical care physician and researcher, Dr. Daren Heyland, who has been studying communication and decision-making for seriously ill patients for more than 20 years. He and his colleagues have conducted many research projects through the Canadian Researchers at the End of Life Network (CARENET), the results of which have been used to inform the development of this planning tool.

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my ICU GUIDE

Having a family member or friend in the Intensive Care Unit (ICU) can be very stressful. A patient may be in intensive care because of an accident, an illness, or for treatment after having a major operation. Usually, a patient is admitted to ICU because they are very sick and their body is not working properly. If they do not get special help, they may have serious long-term effects to their health or they may die.

The ICU is a strange environment with lots of machines, noises and monitors. Seeing your family member there for the first time can be very distressing. They are likely to be connected to a number of machines and drips and will often look very different from how they normally look. You may have a lot of questions about the care your family member may receive.

This workbook provides you with information and support, and will help you and the ICU team better understand how to care for your family member who is critically ill. This workbook also provides you with information and support that may help you to better look after yourself.

At the end of this workbook, we provide you with a short questionnaire that will ask you a few questions about you and your family member (the patient). The answers to the questions provided in this questionnaire will help the ICU team better understand how best to care for you and your loved one. Please bring the answers to this questionnaire to the attention of the clinical team by sharing the last pages (pages 16–19) of this workbook with them.



Learn About the ICU

An Intensive Care Unit (ICU) is a department in the hospital that provides specialized care for patients. It is sometimes also called a critical care unit. The health care team in the ICU has experience treating severe and life-threatening illnesses or injuries.

While your family member is in the ICU, they will be checked often by the health care team, and may have many machines attached to them. Some of these machines are used to monitor the patient's conditions – for example, to check heart rate. Other machines provide medications, or support failing organs, such as breathing machines or a ventilator that help the person breathe. It is important that you understand the nature of life sustaining treatments or life supports used in the ICU including cardiopulmonary resuscitation (CPR).



To learn more about ICU terms and treatments, see 'Learn about ICU' at myicuguide.com



When a Loved One is in the ICU

Visiting Your Family Member

Most ICUs encourage visiting patients with a few restrictions. You may feel comfortable doing this, or you may feel frightened or unsure of what to do. The ICU health care team can help you feel more comfortable.

When a patient is first admitted to an ICU, it is normal for you to feel helpless and desperate to know everything you can about their chances of recovery. However, the patient will need time to let their body rest and get over the shock of becoming so ill. Sometimes they will be given strong pain-killing drugs or sedatives to help the healing process begin. If you have questions about what is being done, ask the staff in the ICU. They will answer your questions as well as they can, but they will not want to give you false hope. The staff will be happy to explain what they are doing and they will be able to update you as time goes on.

People often find it helpful to sit with the patient, hold their hand, talk or read to them, or just be with them. Patients often feel comforted by hearing a familiar voice and sensing your physical presence. If you are uncomfortable or unsure about whether to touch your family member or friend, ask the nurse. If you are unsure how long to stay, the ICU nurse can help you decide. Families might want to rotate family members and friends visiting at any given time, allowing the others a chance to rest.



What Can I Do to Help?

Days may go by with no change in the patient's condition. There may be nothing for you to do but sit by their bedside and wait. Nurses will often talk through what they are doing even if the patient is unconscious. This is because, even though they are heavily sedated, the patient may be aware of being touched, but they are unlikely to remember things as clearly as they would when fully conscious.

Helping the patient:

The nurses may ask you to bring in some of the patient's personal belongings to help them recover, such as their favourite photo or music. Talking to your relative or friend (the patient) may also help. Keeping up a one-sided conversation can be difficult, but talking about shared experiences of holidays and good times can make you feel better too. You could also try reading a newspaper, magazine or book to them.

Even if the patient is conscious, you may find it hard to communicate with them. If they can't speak, they may be able to write, or spell out words by pointing to some letters, numbers and common words you have written on a piece of paper.

Helping the staff:

Some relatives find it helpful to be more involved in caring for the patient when they're recovering. You may be able to help by doing things such as brushing their teeth or massaging or moisturizing their hands and feet. This will depend on how ill the patient is, and won't always be possible but if you want to help in this way, ask the staff.

You can help the intensive care staff by choosing a family member or friend to be the main contact. Staff can tell the main contact how the patient is doing and they can pass on the information to other family members. This will save time for staff and relatives.

Preventing infection:

Patients who are critically ill may have difficulty fighting infections and, because of how ill they are to begin with, this can be very serious. The staff will do all they can to make sure the patient is protected. You can help too by washing your hands and using the anti-bacterial creams, gels or sprays you'll see around the unit before you go near or touch the patient. You should also ask other visitors to do the same.

...What can I do to help?

KEEP A JOURNAL

Keeping a journal of key events and experiences will be helpful to you and your family member. When patients wake up after their critical illness, many of them have no memory of what happened in the ICU. Many patients find it very helpful to review the events that occurred during the ICU stay so a journal will be helpful in remembering what happened. It also may be helpful to you to process these events and make sense of what is happening.



ICU Questionnaire

Remember to fill in the questionnaire at the end of this workbook OR visit our website at myicuguide.com and fill out the My ICU questionnaire. Bring the answers to the questionnaire to the attention of the clinical team.

ASK QUESTIONS

You can play a role as an advocate for the best care of your family member. We encourage you to be knowledgeable about your family member's condition, to participate in their care, to participate in rounds, and to ask questions. Most people become anxious when they feel overwhelmed or unsure. We encourage you to write down your questions or thoughts so that you remember them when the healthcare team meets with you. There are no wrong questions. We know that stress makes it harder for families to understand and remember new information. It is okay to ask more questions or repeat questions if you are still unsure of the answers. We want to help you to understand what is happening while your family member is in ICU. [See next page for examples of questions you can ask.](#)



Below are examples of questions you may ask the health care team in ICU. These are meant to be examples to help you start conversations about their care and decision making.

To gain information on the current treatment, ask the bedside nurse:

- + What treatments and other care is he/she receiving?
- + Can I call to find out how he/she is doing?
- + Will I be informed regularly of changes and, if so, how?

To learn what you can do, ask the bedside nurse:

- + Is there anything I can do to make him/her more comfortable?
- + In a decision-making situation, what is expected of me?
- + Is there anything I can do to participate in their care? and Can I be present when the clinical team come to the bedside?

To prepare for the future, ask the doctor:

- + How long will he/she stay in the ICU?
- + Will he/she have any after-effects? Please note that the doctors may not be able to answer these questions accurately. There is insufficient scientific knowledge to inform doctors how to precisely answer these kinds of questions. However, they may be able to provide a range of possible outcomes, such as a 'best-case scenario', a 'worst-case scenario', and a 'best guess scenario.'
- + If you are worried your family member is not going to recover and you do not want to see them suffer any longer, you may ask, "Is it time to let go?"
- + Will he/she get better? What are the chances that he/she recovers? Be prepared to tell the doctors what your family member normally does and what some of their 'highly valued activities' were, such as maintaining their physical independence, and ask whether they will be able to return to this level of activity.

Looking After Yourself

The rest of your life does not stop when your family member is admitted to the ICU. You may still have work commitments, a mortgage to pay, a house to maintain, or other family and pets to care for. It is important that you continue to look after yourself. Here are some things to consider:

NUTRITION

It is important to take time for meals. Even if you do not feel hungry at meal times, try to have something small and nutritious, like a piece of cheese with toast or soup. The hospital is a very dry environment so remember to drink water.

SLEEP

Family and friends of a patient in the ICU can become exhausted. Sleep is important so that you can think clearly. The most restful sleep is often in your own bed or familiar environment. There may be a bed available in the hospital for families to use while your family member is critically ill in the ICU. Even if you have difficulty sleeping soundly, just lying down will provide you with rest. Remember the healthcare team is attentively caring for your family member even at night, so it is okay to leave to get some much needed rest. The health care team will monitor and care for your family member while you rest, and will keep you informed of any changes in your family member's condition.

PHYSICAL ACTIVITY

Other families have reported that exercise helps them cope with the stress of having a family member in the ICU. A short walk outside the hospital in the fresh air can help you re-charge and regain focus.

SEEK SUPPORT

Having a family member in the ICU can be a scary experience, full of uncertainty and anxiety. Families and friends should give each other time and a safe space for expressing emotions. The ICU team can let you know if there is a private quiet room available, if you need privacy. Remember you are not in this alone; there are many people who want to help. Whether it's a close friend or family member, social worker, spiritual care advisor, doctor, nurse, or volunteer, there are people you can talk to. Ask a member of the health care team if you would like to speak to one of these people. You may find it helpful to pray, cry, or reflect on the life of your family member together.

SPIRITUAL SUPPORT

When your loved one is unwell, you may experience many emotions, and may even begin to ponder life's 'big questions' or explore your own sense of spirituality. If you have a spiritual and/or religious practice or community of support, it can be helpful to continue these practices or rituals and reach out to people who can support you. Most hospitals also have a multi-faith spiritual care professional who is available to support you in your spiritual and/or religious concerns.

INFORMING FAMILY AND FRIENDS

Keeping your friends and family informed about your family member's medical condition can be very stressful. It is emotionally draining and exhausting to repeat the details of the latest treatment progress and test results every day. It may help to take notes which you can share with others. Consider asking a family member to send group updates via emails, websites (such as caringbridge.org) or a blog.



Managing the Helpers

Your friends and family may wish to help you, yet often do not know how best to do so. While this network of support can be useful, the number of phone calls and visits can also be overwhelming. Many people will ask you "what can I do?" It can be quite helpful to share with them practical ideas on how they can help (for ideas, see: <https://tinyurl.com/y36hq7jn>). Some people have had friends and family members assist with the routine activities that still need to get done while you are at the hospital (e.g. feeding the cats, walking the dog, cutting the grass or shoveling the driveway). It may be comforting to know that these things are taken care of in your absence.

Outcomes of ICU Care

Survival

Without intensive care, most seriously ill patients with organ failure will die. However, even with intensive care, some patients will

die from their serious illness. On average, about 20% of ICU patients will die and 80% will survive and leave the hospital.

Chance of survival from ICU Care



80% of ALL seriously ill patients survive to hospital discharge



60% of patients admitted with severe infection survive to hospital discharge



95% of patients admitted following elective surgery survive to hospital discharge



<80 YEARS
>90% survive to hospital discharge

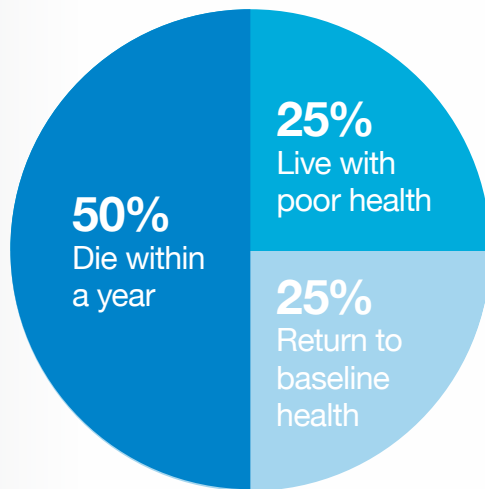


80+ YEARS
65% survive to hospital discharge

This survival rate can be higher or lower, depending on specific cases – for example, if your loved one has a severe infection, they will have a much lower survival rate. If they are in the ICU to recover from major surgery, they will have a much better survival rate. Age can also make a difference. These statistics are meant to give you an overall idea of the outcomes of ICU when considering groups of patients. It is best to talk to your family member's doctor to get a better sense of your loved one's individual probability of survival.

Quality of Life

One year after ICU, outcomes for patients 80+ years



Most patients will fully recover from a serious illness when admitted to the ICU, especially if they have had a short stay.

However, if your loved one is in the ICU for some time (more than 1-2 weeks), they may leave the hospital much weaker than they were before you became ill. They may also have problems thinking or concentrating. In addition, up to half of ICU survivors who have had a long stay will have significant depression, anxiety, or post-traumatic stress disorder in the months that follow illness.



<10% Patients with previous significant medical problems will return to their baseline health

Overall Risks and Benefits of ICU care:

Benefits:

- If your loved one is very ill, there is a greater chance of survival in the ICU than with other types of medical care
- If your loved one is in the ICU on machines for only a short period of time, they will likely fully recover and get back to their baseline health

Risks:

- Your loved one may be in more pain and discomfort because of the machines used
- Your loved one may not be able to speak or interact with you or other visitors.
- If they are in the ICU on machines for a long time, like more than one week, they might end up very weak and not as mentally aware
- Your loved one may only be delaying death and their death may not end up being very natural or dignified.

Is ICU right for your loved one ?

Most people who pick ICU care have fixable medical problems along with a reasonably high level of function or quality of life and are willing to accept the burdens or risks of ICU treatment. Because the negative consequences of ICU care happen mostly after a prolonged ICU stay more than 7-14 days, some people would be willing to undergo ICU care on the 'short-term' (less than a week in most instances).

It's like a 'trial of ICU treatments' to see if they will get better quickly and can recover back to their baseline function and quality of life. If not, if their illness turns into a prolonged ICU stay, they are unwilling to accept the risks or burdens of ICU care and prefer to have their goals of care change to focus on comfort measures only. In that instance, ICU treatments may be withdrawn or withheld.



Making Decisions in the ICU

Many decisions are made in the ICU. Some are not that important and may not be discussed with the patient and/or family member; others are really important and the doctors are required to obtain 'consent' from the patient before proceeding with the medical intervention or treatment.

See box for list of possible important treatment decisions. If you have any questions about any of these possible treatments options, ask for help understanding these treatment options from the bedside nurse or check out our website, myicuguide.com under the "Learn About the ICU" section.

Possible Treatment Decisions:

- + Undergo major surgery or invasive procedures
- + Initiation of or continuing with full ICU care
- + Initiation of or continuing with short-term trial of ICU
- + Use of cardiopulmonary resuscitation (CPR)
- + Limit or withhold further use of life-sustaining technologies.
- + Withdrawal of life-sustaining technologies and focus on comfort measures.

Who represents the patient if they can't speak for themselves?

Many patients in the ICU are unable to make their own medical decisions. The medical team will want to review with someone that can speak on behalf of the family member, to help them make clinical decisions. A person who makes decisions on behalf of a family member is called a substitute decision-maker. If your family member has a legal document naming a person to make decisions for them, then this person is the substitute decision-maker. If this was not determined in advance, the law provides a list of people who may act as the substitute decision-maker arranged in order of legal priority: often a spouse, a parent of a child,

an adult child of a parent, and so on. We are speaking to you as if you are the patient's substitute decision-maker. This is an opportunity for you to represent your loved one and help ensure they get the best care possible.

Making decisions for someone else can be a difficult and stressful time. We want to help you, the substitute decision-maker, in making decisions related to your family member's care plan. You may feel like you need more information to help you in this role. Please reach out to a member of the health care team if you do.

For more information on CPR, see our video decision aid on the resource page of myicuguide.com



What is your role as Substitute Decision-Maker?

Your role as a Substitute Decision-Maker is to help the ICU team make treatment decisions based on your family member's previously expressed wishes, values and beliefs. If you do not know what your family member's wishes are, you, the Substitute Decision-Maker, should use your best judgment to make decisions based on how your family member would want to be treated if he or she could decide for him or herself. It is important to resist the natural tendency to make decisions based on what you want to happen, but rather, you are answering questions based on what your loved one would have wanted. It would be helpful if you could think about whether your family member was the kind of person that would want to live as long as possible or focus on maintaining the quality of remaining life. Or whether your family member would want doctors to do everything possible, including the use of machines, to keep them alive for as long as possible or whether they would prefer a natural death without being attached to machines. Often times, we can not achieve both of these objectives as they compete or conflict with each other. Questions like this will be asked of you again when you go through the My ICU Questionnaire.



What is the doctor's role in decision-making?

The doctor in the ICU is a trained expert in treating critically ill people and can provide you with an explanation of the medical problems, a sense of whether your loved one is headed towards recovery or decline, and the overall chances of survival. However, doctors are often uncertain about the chances of recovery or what condition patients will be in if they survive. Nevertheless, they will try to provide you with accurate

and honest information about your family member's chances of recovering and expected long-term quality of life. They should ask you what you think your family member would have thought about their chances of recovery or what condition they will be in if they survive. The doctor may discuss starting new treatments or stopping treatments, such as life support, if they believe they are unhelpful.

What you can expect from your doctor?

Doctors should:

- + Ask you about the patient's life, life style, function and values
- + Share with you medical information about the patient's condition, chances of survival and what kind of function or quality of life they might have
- + Ask you to think about the medical information shared with you and ask you to share how you think the patient would have reacted to this information
- + Ask you for what medical treatments you think the patient would have preferred
- + Propose a treatment plan that is most consistent with the patient's values, preferences and considerations.

Please Note: If the doctor does not ask for this information, we would encourage you to share it anyway. It is important that the doctor and the clinical team have the same understanding as you do regarding the patient's function, values, and preferences.



Shared Medical Decision-making

People often find themselves overwhelmed with the thought of making a decision for a critically ill family member, particularly when there is so much uncertainty about what is the best decision. It is important to understand that you should never be asked to make a decision alone. Some people do not want to make decisions at all and prefer that the medical team makes the decisions while others prefer to be more involved. As the Substitute Decision Maker, you can also talk with other family members and friends to help with decision-making. In most circumstances, the family and the health care team will work together to make the best decision for the patient.

Your main role is to represent the wishes, beliefs and values of the patient. We have created the MY ICU Questionnaire to enable you to fulfill this role and represent your family member in a way that is useful to the health care team. The health care team's main role is to provide you with information and explore the treatment options for your family member. As a team, you and the healthcare providers can make decisions that balance your family member's wishes, beliefs and values with the treatment options available. These decisions form the foundation of the care plan moving forward.



It's important to remember that just because you want something for your family member, it doesn't mean you will always automatically get it. The medical treatments they will receive depend on their values and preferences, but also their illness, the doctor's recommendations, and your family member is responding to current treatments.

My ICU Guide Questionnaire

Help Us Get To Know You

- +** Is there anything that you would like the ICU team to know about you and your family that will help us support you through your family member's illness the best we can? There is no right or wrong answer. Just tell us what comes to your mind or if there is nothing, it is ok to leave blank.

- +** Who else would you like to be involved in making the decisions regarding the care of your family member in the ICU?

- +** Which of the following best represents the role you prefer when it comes to making the final decision about your family member's treatments in the ICU?

- ☐ I prefer to leave the medical decisions to the doctors
- ☐ I prefer that the doctors make the final decision but that they seriously consider my opinion
- ☐ I prefer that the doctor and I share responsibility for deciding about the medical decisions
- ☐ I prefer to make the final decision about the medical decisions after seriously considering the doctors' opinion
- ☐ I prefer to make the decision by myself
- ☐ Declined

(By family, we mean two or more persons who are related in any way - biologically, legally or emotionally).

Help Us Get To Know Your Family Member

- +** Tell us something special or unique about your family member, not related to his/her medical condition, that will help us get to know him/her on a more personal level. Again, there is no right or wrong answer. Just tell us what comes to your mind.

+ Consider the overall condition of your family member prior to the start of their illness that brought them to hospital. How fit or frail was she or he?

(Note: Please consider the images and read the text associated with each image to help you choose. If you are having trouble deciding between two options, pick the higher functioning level)



☐ **Very Fit (category 1)** People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



☐ **Well (category 2)** No active disease symptoms but less fit than people in category 1. Often, they exercise or are very active occasionally, e.g. seasonally. Well older adults share most attributes of the very fit, except for regular, vigorous exercise. Like them, some may complain of memory symptoms, but without objective deficits.



☐ **Managing Well (category 3)** Medical problems are well controlled, but people in this category are not regularly active beyond routine walking. Those with treated medical problems who exercise are classed in categories 1 or 2.



☐ **Vulnerable (category 4)** Not dependent on others for daily help, but often symptoms limit activities. A common complaint is being “slowed up” and/or being tired during the day. Many people in this category rate their health as no better than “fair”. Memory problems, if present, can begin to affect function (e.g. having to look up familiar recipes, misplacing documents) but usually do not meet dementia criteria. Families often note some withdrawal – e.g. needing encouragement to go to social activities.



☐ **Mildly Frail (category 5)** More evident slowing and Individuals need help in “high” activities of daily living (finances, transportation, heavy housework, medications). Mildly frail people might have difficulty with shopping or walking outside alone, meal preparation, and housework. Often, they will have several illnesses and take multiple medications. This category includes people with mild dementia. Their common symptoms include forgetting the details of a recent event, even though they remember the event itself asking the same question, or telling the same story several times a day and social



☐ **Moderately Frail (category 6)** Individuals need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing. If a memory problem causes the dependency, often recent memory will be very impaired, even though they seemingly can remember their past life events well.



☐ **Severely Frail (category 7)** Completely dependent on others for all or most personal activities of daily living, such as dressing and feeding.



☐ **Very Severely Frail (category 8)** Completely dependent, approaching the end of life. Typically, people in this category could not recover from even a minor illness.

Values Questions:

When considering the health of your loved one BEFORE they came to hospital, please answer the following questions:

Reduction in Function or Quality of life:

Q1

On a scale of 1-7, select the number to describe how willing you think your family member is to accept a significant reduction in their ability to look after themselves or a significantly lower quality of life following recovery from an ICU stay than they currently experience:

1	2	3	4	5	6	7
Very Willing		Equally important			Not willing at all	

Risks of ICU Treatments:

Q2

On a scale of 1-7, select the number to best describe how willing you think your family member is to accept the risks of ICU treatments/resuscitation:

1	2	3	4	5	6	7
Very Willing		Equally important			Not willing at all	

I choose these answers because:

Health States Worse Than Death:

Other questions or concerns I have:

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Comments and notes:

When you have finished this questionnaire, be sure to discuss the contents with your family and the health care team. You can photocopy the last four pages to share with them so they have a copy. This information will be really helpful to the doctors and will help them prescribe the treatments that are right for your family member!

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

See myicuguide.com to learn more about
how you can support your loved ones in the ICU.

