



MY

ICU GUIDE



An ICU Workbook **for Families**

myicuguide.com



ICU Questionnaire



After reading this workbook, please fill out our online “ICU Questionnaire” at myicuguide.com. Please print the report and bring to the attention of the clinical team. The answers to the questions provided in this report will help the clinical team better understand how best to care for you and your loved one.



Questions?

Please contact:

for further information.



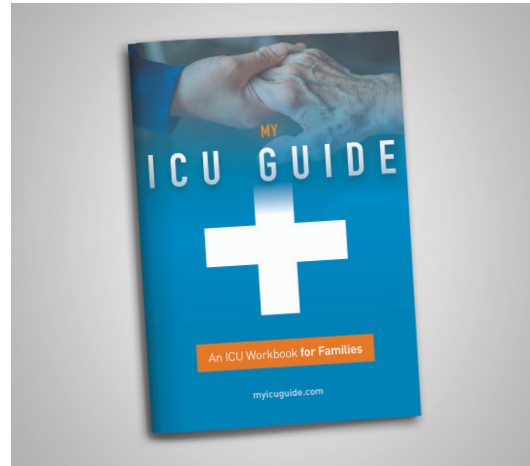
My ICU Guide

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.

Since your family member cannot communicate, we may need your help to make decisions about their care. This guide and questionnaire provides you with information and support, and will help you and the ICU team better understand how to care for your family.

This guide also provides you with information and support and will help you better look after yourself.



On our website, myicuguide.com, we have a questionnaire that will ask you questions about you and your family member (the patient). Please go to the website, answer these questions, print the report and bring to the attention of the clinical team. The answers to the questions provided in this report will help the clinical team better understand how best to care for you and your loved one. By reading this pamphlet and doing the questionnaire, it will help you to help yourself and your family member.



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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 experienced treating with 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 patients conditions – for example, to check heart rate. Other machines provide medications, or support failing organs, such as breathing machines that help the person breathe.

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 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 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.



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 these 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

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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:

- + 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 prepare for the future:

- + 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.
- + 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?"

To learn what you can do:

- + 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?"

Other Things to Expect

- + **There may be times when staff ask you to leave the patient's bedside.** This is because some of the necessary medical procedures are not pleasant and may upset you. It also gives the staff room to do their job. If the patient is ventilated (on a breathing machine), the nurses have to regularly clear the chest of mucus and fluid. They do this by putting a thinner tube into the breathing tube to suck up the mucus. This is quite noisy and may cause the patient to cough or retch.
- + **The fluids given to the patient to keep them hydrated may make them look bloated and swollen.** This is normal and will improve as the patient gets better.
- + **Some of the machines that the patient is connected to have alarms that may sound to let staff know that something needs doing,** for example if a drip needs to be changed. Usually, there is nothing to worry about – the staff will closely watch the patient at all times.
- + **Sometimes, the patient may behave out of character.** This may be because of their illness or medication. They may be agitated, confused, scared or paranoid.
- + Paranoia is a form of anxiety or fear that can make you believe people are plotting against you or trying to hurt you. **They may also have hallucinations (see things that aren't really there) and nightmares** that seem very real to them. Patients sometimes believe the staff are trying to hurt them. This can be extremely distressing for you and the patient but it will improve as they get better and begin to recover.
- + **If the patient in the ICU has been given sedatives, the sedatives will be gradually reduced as the patient gets better.** This process is called weaning. Depending on how ill they were, the drugs they needed and how long they were sedated for, the weaning process can take hours or it can take days. During the weaning process, the patient will be drowsy and confused, particularly in the early stages, but it's a necessary step and it means they're getting better.

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 sleep, eat and exercise.

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](https://www.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: <http://www.cancer.net/coping-and-emotions/communicating-loved-ones/supporting-friend-who-has-cancer>). 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.

Making Decisions in the ICU

Many patients in the ICU are unable to make their own medical decisions. In these situations, knowing if they have already communicated their wishes or written them down can be helpful in making decisions about the treatments your family may receive. The medical team will want to review with you the overall goals of care. For some ICU patients, treatment with life-sustaining therapies is time-limited.¹ One of the most important decisions that may arise is whether to continue using invasive technologies to prolong life alongside medical management and symptom control, or to focus only on medical management and symptom control. **See box for list of possible treatment decisions.**

Possible treatment decisions:

- + Continue with full ICU care including CPR
- + Continue with full ICU care excluding CPR
- + Continue with short-term trial of ICU care including CPR
- + Continue with short-term trial of ICU care excluding CPR
- + Limit or withhold further use of life-sustaining technologies but continue active medical management
- + Withdrawal life-sustaining technologies and focus on comfort measures only

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

Making decisions for someone else can be a difficult and stressful time. A person who makes decisions on behalf of a family member is called a substitute or surrogate decision maker (SDM). If your family member has a legal document naming a person to make decisions for them, then this person is the substitute decision maker (SDM). If this was not determined in advance, the law provides a list of people who may act as the

SDM 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 SDM. This is an opportunity for you to represent your loved one and help ensure they get the best care possible. We want to help you, the SDM, 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.




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 how you would want to be treated if you were critically ill.

What do you think would be most important to your family member?

It would be helpful if you could think about the answers to the following values questions. They will be asked of you again when you go through the ICU questionnaire. Think about your answers to these questions and why you chose those answers. You will be asked to record your answers to these question in the ICU questionnaire.

	On a scale of 1-7 circle the number to best describe how important you think the following would be to your family member:						
	1	2	3	4	5	6	7
	Focus on prolonging life	Equally important			Focus on maintaining the quality of remaining life		

	On a scale of 1-7 circle the number to best describe how important you think the following would be to your family member:						
	1	2	3	4	5	6	7
	My family member wants doctors to do everything possible, including the use of machines, to keep them alive for as long as possible	Equally important			My family member wants a natural death without being attached to machines		

What is the doctor's role?

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

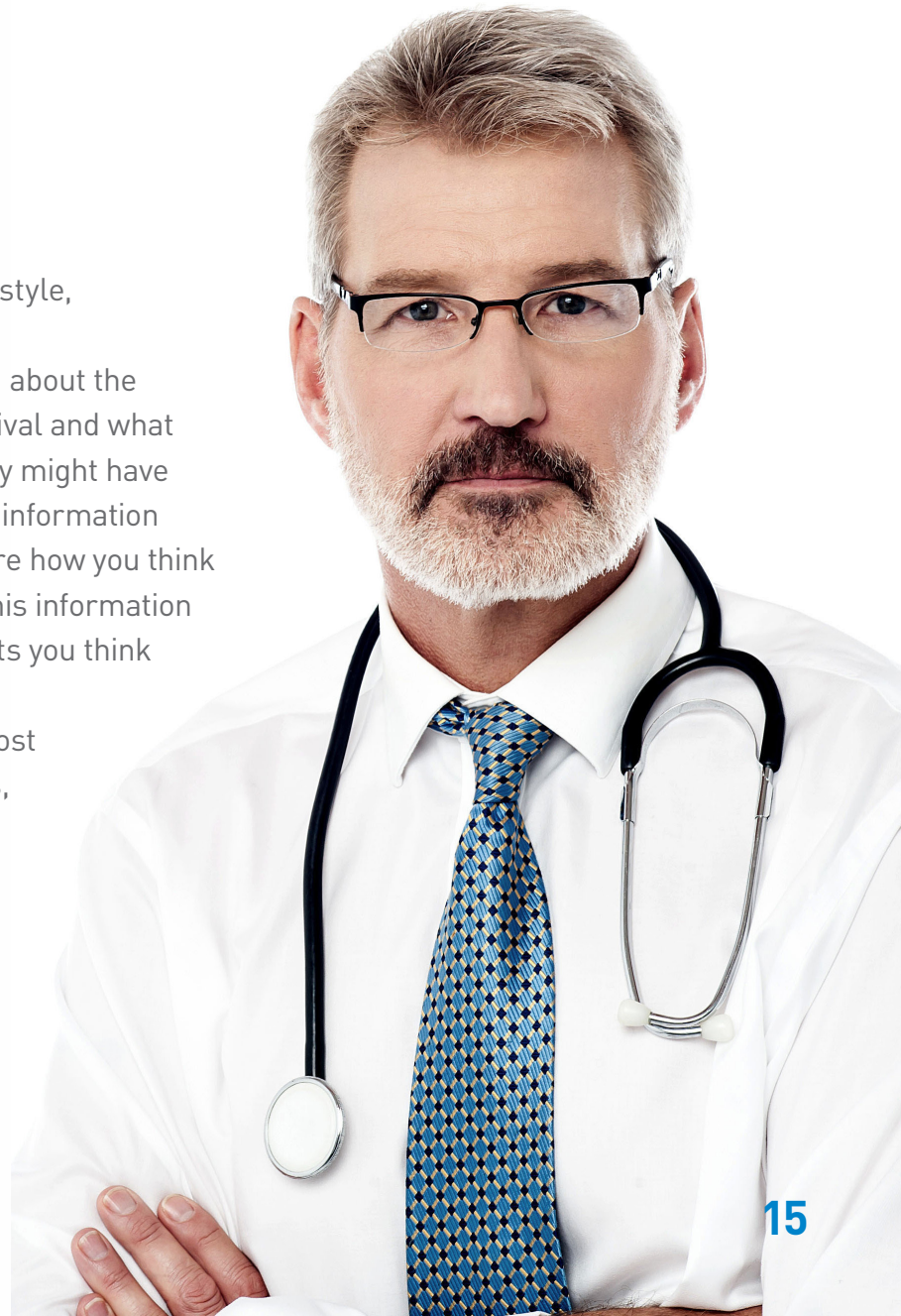
information about your family member's chances of recovering and expected long-term quality of life. They should ask you what you think your family member would have thought about their chances of recovery or what condition they will be in if they survive. The doctor may discuss starting new treatments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



Do I have to make decisions alone?

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. 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.

If the Patient Does Not Survive

Despite the best efforts of the ICU staff, sometimes patients are too ill and do not survive. A person dies when their heart stops beating or they are declared brain dead. If the doctors believe the patient is brain dead, they have a set of tests they must follow to confirm this. If the patient has died the next of kin and family members may be approached to discuss organ donation. Knowing the patient's wishes regarding organ donation can help

in making the right decision for your family. Most families who agree to donate one or more of the patient's organs find it comforting that something good will come from their loss. It may help you to talk to a bereavement counselor at this difficult time. They can offer support and understanding for adults and children. Funeral homes may be a helpful resource in connecting you with consellers and support in the community.



ICU Questionnaire



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What to Expect Following ICU Discharge

This page tells you how critical illness may be treated and what recovery may be like. Not every patient will experience all of these things, but they are more likely to if they have been in intensive care for more than a few days. Most of this page is written for patients but there is a section specifically for relatives and visitors. By reading this, relatives will learn what a patient's recovery may involve and it will give them the answers to some of the questions they may have. Recovery is often a long and slow process. To begin with,

patients may not feel up to reading this information, so if you are a relative, please keep hold of this information and pass it on when the patient is ready.


One of the scariest things about having a critical illness is not knowing what's going to happen. This information can't answer all your questions, but it will answer many of them. It will try to tell you what may happen and where you can find out more information.



Your Time In the ICU

When you've been critically ill and you have been asleep for long periods because you were unconscious or sedated, you may have difficulty remembering what happened to you. Also, you may have had vivid dreams, nightmares or hallucinations which upset you.

You may even believe that staff were trying to hurt you, because of the treatments you were given to make you better. These things are normal for someone who has been critically ill and can be caused by the illness or the drugs used to treat it. You may find it difficult, but it can help to talk to someone you trust about this and it really is nothing to be ashamed or embarrassed about.



Patients may not feel up to reading this information, so if you are a relative, please keep hold of this information and pass it on when the patient is ready.

Planning for your recovery

After being critically ill, it may take you several months to recover. The staff may carry out health checks to find any likely physical or psychological problems you may face because of your illness. If they think you are at risk of having problems later in your recovery, they may carry out more checks:

- + before you leave the ICU
- + before you're discharged from hospital
- + after you've been out of the ICU for two to three months.

Depending on the results of these checks, the intensive care staff may prepare a rehabilitation plan for you. What is in this plan will depend on how long you were in intensive care and your needs, but may include information on:

- + the difference between intensive care and ward-based care
- + the physical, dietary or medical needs you are likely to have in the future
- + who will be responsible for your care when you are in the hospital and when you leave.

When You Leave the ICU

Before you leave the ICU

As you start to get better, you will not need the machines that were helping to support your body's normal functions and monitoring your condition. The physiotherapist will probably give you exercises to help strengthen your muscles to get you moving around again. You will be very weak and get tired easily at first.

As you become able to do more for yourself, you may be moved to a different section of the ICU or transferred to another ward in the hospital with a reduced level of nursing.

Many hospitals have high dependency units (HDU) or Step-down Units, where each nurse will normally look after two or three patients. Some hospitals might send patients from the ICU to the HDU or Step-down Units as they get better, until they're well enough to go to a general ward.

Moving to a general ward in the hospital

This can be a difficult time for patients and relatives because there is no longer the one-to-one nursing that there was in the early stages, but you are still far from being well. You may need to re-learn how to do simple things such as walking, eating, drinking, or even breathing for yourself. This

can be frightening but is normal at this time in your recovery.

When you move to a ward, there may be a written plan that includes:

- + a summary of your care and treatment while you were in the ICU
- + a monitoring plan to make sure you continue to recover
- + a plan for ongoing treatment and
- + details of your physical and psychological rehabilitation needs.

From this time you will be cared for by the ward staff, but they will be able to talk to the ICU staff if they need to. If the hospital has an Outreach service, you may be visited by an ICU nurse while you're on the ward to check on your progress.

The visiting times in a general ward may not be as flexible as they are in the ICU and you may be disturbed more by other patients and visitors around you. Your normal sleep pattern may be upset due to the constant activity while you were in the ICU. This does return to normal in time. Rest when you can. You may find that a personal music player with headphones helps you to relax and pass the time.

Returning Home – What Will Life Be Like Now?

When you leave the hospital

Leaving hospital and returning home is a major step in your recovery and is likely to have been a goal you've been working towards for some time. It is a very positive step but it will take time and effort to get back to a normal life.

Before you leave hospital, your physiotherapist may give you an exercise plan to help with your recovery. If not, you (or a friend or relative) can ask them for a plan.

When you're well enough to leave hospital, you may have an assessment to find any difficulties you might face when you get home.

This would include psychological or emotional problems, as well as any care and equipment you need. Your healthcare team should discuss and agree with you what your rehabilitation goals are (what you want to achieve as you get better), and organise any referrals and any other care or rehabilitation **you will need before you leave the hospital:**

- + a letter that summarises your time and treatment in ICU (this is called an ICU discharge summary)
- + the contact details of the person co-ordinating your rehabilitation and
- + if appropriate, a copy of your rehabilitation plan.



For more information on what to expect following discharge, please visit:
icusteps.com

Notes & Questions to Ask Doctor

[illegible]



2. Symptom Management?
How well the ICU staff assessed and treated your family member's symptoms.

a. How well the ICU staff assessed and treated your family member's pain.
* must provide value

Poor 1 Fair 2 Good 3 Very Good 4 Excellent 5 N/A -

b. How well the ICU staff assessed and treated your family member's breathlessness.
* must provide value

Poor 1 Fair 2 Good 3 Very Good 4 Excellent 5 N/A -

c. How well the ICU staff assessed and treated your family member's agitation.
* must provide value

Poor 1 Fair 2 Good 3 Very Good 4 Excellent 5 N/A -

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Family Satisfaction with ICU Survey

This website houses a unique satisfaction questionnaire that allows family members to provide feedback on the quality of care delivered to them and the patients.

visit fsicu.org

PLAN

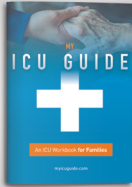
WELL

"In order to keep you ticking, we need to know what makes you tick." As you consider your future medical care, we recommend you visit planwellguide.com to...

Make a Plan



Tools and Resources

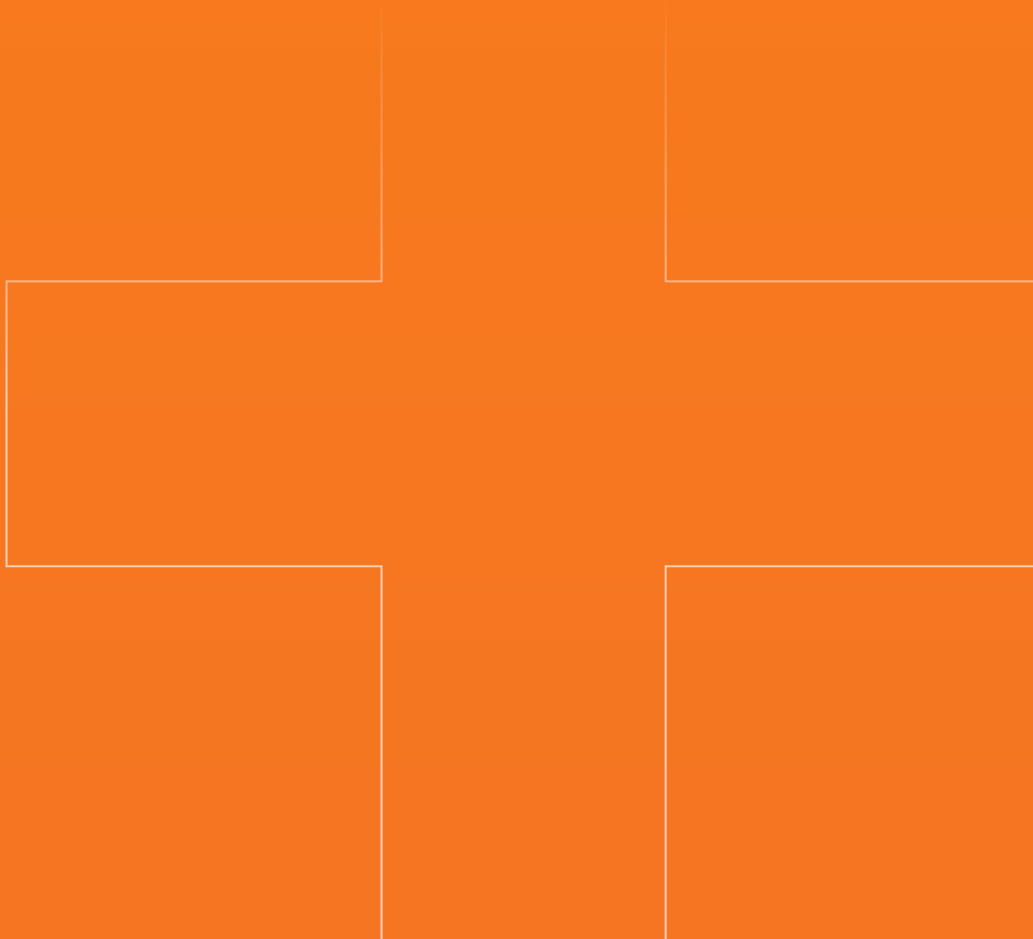


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The following tools and resources can help you support your loved one and make decisions in the ICU:

- + **CPR Decision Tool** – This video can help you learn more about CPR and whether it's appropriate for a loved one in the ICU
<http://www.myicuguide.com/tools-and-resources/>
- + **Other Decision Aids** – The Ottawa Hospital Research Institute has a website with information and tools for a number of specific conditions to help people make decisions about treatment.
<https://decisionaid.ohri.ca/index.html>
- + **Plan Well Guide** – this website can help you clarify your values and can better inform you about the different treatment options available to treat serious illness. It is more designed for patients than family members of ICU patients but the explanations and tools are applicable.
www.planwellguide.com
- + **Society of Critical Care Medicine** – this website has information for patients and families about critical care, the ICU and treatments.
<http://www.myicucare.org/Pages/default.aspx>
- + **ACP Conversations** – “Conversations” features real-life stories and thoughts from researchers, health professionals and family members about sharing our thoughts for end-of-life care.
http://www.youtube.com/watch?v=_6gFzCiMnlq
- + **When Someone Close to You is Dying**
<http://www.myicuguide.com/tools-and-resources/>
- + **Ain't the Way to Die** – by ZDoggMD, this video offers an easy way to break the ice and start conversations about end-of-life issues.
<http://www.youtube.com/watch?v=NAInRHicgWs&feature=youtu.be>
- + **Family Satisfaction with ICU** – this website houses a unique satisfaction questionnaire that allows family members to provide feedback on the quality of care delivered to them and the patients www.fsicu.org

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



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