

# Understanding *the* OPTIONS



Planning care for critically ill patients in the Intensive Care Unit



Critical illness threatens a patient's life so that they are near death. When a critically ill patient is not capable of making decisions, a family member may be asked to make decisions for them. This person is called a substitute decision maker.

This guide prepares you, as the substitute decision maker, to consider care options for your family member during critical illness. It will help you share your views with other family members and the healthcare team. The plan of care must be discussed with the doctor in charge of your family member's care in the Intensive Care Unit (ICU). The healthcare team will then work together to implement the decision.

### **Who cares for your family member in the Intensive Care Unit?**

Some critically ill patients will receive care in an Intensive Care Unit. Care here is given by a healthcare team which may include **nurses, doctors, social workers, pastoral care workers, clinical ethicists, respiratory therapists, pharmacists, physiotherapists, occupational therapists and dietitians.**

### **What types of care are given in the Intensive Care Unit?**

The members of the healthcare team work together to discover the reasons for the critical illness and provide care around the clock to treat the problem. **This guide presents two types of care that can be given in the ICU: life support and comfort care.**

## Care Options

At this time, your family member may already be using some kind of life support. Even so, your healthcare team wants to make sure that life support is a treatment you think your family member would want.

## LIFE SUPPORT

Life support aims to lengthen life while trying to cure illness. The healthcare team can explain what kinds of life support might be helpful for the patient. It can include the use of a breathing machine as well as drugs and procedures to maintain body functions and minimize suffering. The patient is usually kept asleep.

### Reasons to choose this option:

The patient has a better chance of staying alive longer. This may give family members from far away enough time to visit the patient. Some patients may get better during this time.

### Reasons to avoid this option:

The patient is attached to machines and tubes. Some patients are agitated or uncomfortable during treatments. Sometimes, despite the healthcare team's best efforts, the patient on life support may still die.



## COMFORT CARE

Comfort care aims to relieve suffering and preserve the dignity of the patient who may be dying. There are usually fewer tests, fewer tubes and no life support machines or monitors connected to the patient.

### Reasons to choose this option:

The healthcare team can concentrate on relieving the patient's pain and other symptoms with drugs and treatments.

### Reasons to avoid this option:

It is likely that, without life support, the critically ill patient's breathing and heart may stop and they may not live as long as they would on life support.



## How do I prepare to consider the care options?

Ask yourself the following questions.

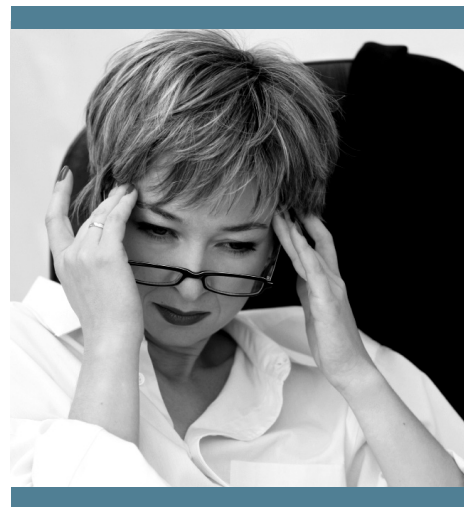
**STEP 1:** What was your family member's situation before coming to the ICU?

**STEP 2:** What is your family member's situation right now?

**STEP 3:** What matters most to your family member?

**STEP 4:** Who is involved in this decision?

**STEP 5:** What else do you need to do to prepare for decision making?



**INTRODUCE YOURSELF** to your family member's healthcare team when you meet them at the bedside, or ask the nurse to help arrange a meeting between family and healthcare team members. Use this guide to help you prepare your questions.

## STEP 1: What was your family member's situation before coming to the ICU?

Check ✓ how your family member was over the last few weeks before coming to the ICU.

Moving about	Activity	Self care	Eating & drinking	Alertness
<input type="checkbox"/> Able to move about as usual	<input type="checkbox"/> Able to do their usual activities such as job, hobbies, housework	<input type="checkbox"/> Able to do all their personal care such as washing, dressing, going to the bathroom	<input type="checkbox"/> Able to eat and drink as usual	<input type="checkbox"/> Alert as usual
<input type="checkbox"/> Moving about less than usual	<input type="checkbox"/> Able to do their usual activities <i>with effort</i>	<input type="checkbox"/> Needed occasional help with their care	<input type="checkbox"/> Ate and drank less than usual	<input type="checkbox"/> Less alert than usual
<input type="checkbox"/> Mainly sitting	<input type="checkbox"/> Unable to do their usual job	<input type="checkbox"/> Needed a lot of help with their care	<input type="checkbox"/> Ate small amounts of food and sips of fluids	<input type="checkbox"/> Drowsy most of the time
<input type="checkbox"/> Mainly in bed	<input type="checkbox"/> Unable to do their usual hobbies or housework	<input type="checkbox"/> Someone else provided most of their care	<input type="checkbox"/> Not able to eat or drink	<input type="checkbox"/> Slept all of the time
<input type="checkbox"/> In bed all of the time	<input type="checkbox"/> Unable to do any work	<input type="checkbox"/> Someone else provided all of their care		
	<input type="checkbox"/> Unable to do most activities			
	<input type="checkbox"/> Unable to do any activities			

How would you rate your family member's overall quality of life over the last few weeks before coming to the ICU?  Worst possible  Poor  Fair  Good  Best possible

## STEP 2: What is your family member's situation right now?

Some serious problems of patients in the ICU are listed below.

Check ✓ if your family member has these problems right now.

	Yes	No	I don't know
<b>Brain injury.</b> Do they have a brain injury that prevents them from waking up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Breathing with help.</b> Do they depend on a machine to breathe?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Heart problems.</b> Do they need drugs to keep their blood pressure up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Kidneys don't work.</b> Do they no longer make urine and need a dialysis machine to filter their blood?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Digestion problems.</b> Do they need to be fed by a tube into their bloodstream?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Liver problems.</b> Do they have yellow skin because their liver is not working?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Bleeding difficulties.</b> Do they have problems with bruising or bleeding, enough that they need transfusions with blood or platelets?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Severe infection.</b> Do they have a severe infection that affects their blood pressure?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>List any other problems here.</b> _____			



## What do you think might be the outcome of your family member's critical illness?

Your expectations may change as your family member's health situation changes.

Check ✓ what you expect right now.

- I think that they might be healthier than before they became critically ill.
  - I think that they might improve back to the way they were before they became critically ill.
  - I think that they might improve, but not be as well as they were before they became critically ill.
  - I think that they might improve, but live with serious health losses.
  - I think that they might die soon.
  - I don't know what might happen.
  - Other expectations
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### STEP 3: What matters most to your family member?

Does your family member have a written document (an advance directive) that includes their wishes for medical care if they are critically ill? Check  one  Yes  No  I don't know

Common reasons to choose either **life support** or **comfort care** are listed below.

Choose how much you think each reason matters to your family member. Circle your choice on a scale from 0 to 5, where 0 means it is not important to your family member and 5 means it is very important to them.

#### Reasons to choose life support

How important is it for your family member...	Not important ←————→ Very important					
...to live as long as possible?	0	1	2	3	4	5
...to have more time with family?	0	1	2	3	4	5
...to respect a belief that life should be preserved?	0	1	2	3	4	5
List other reasons your family member would want life support.						
_____	0	1	2	3	4	5
_____	0	1	2	3	4	5

## Reasons to choose comfort care

How important is it for your family member...	Not important ←————→ Very important					
...not to prolong their death?	0	1	2	3	4	5
...to be comfortable and suffer as little as possible?	0	1	2	3	4	5
...to avoid being attached to machines and tubes?	0	1	2	3	4	5
...to respect a belief that nature should take its course?	0	1	2	3	4	5
List other reasons your family member would want comfort support.						
_____	0	1	2	3	4	5
_____	0	1	2	3	4	5

**Now, think about which option has the reasons that would be most important to your family member. What do you think *your family member* would want in this situation?**

Check  one  Life support  Comfort Care  I'm not sure

### STEP 4: Who is involved in this decision?

Think about who should be involved in this decision. Your healthcare team, family and friends can provide support as you consider care options for your family member in the ICU. Ask others to share the reasons why they prefer one option.

Name	Relationship to the patient?	Which option does this person prefer? Check <input type="checkbox"/> one	How can this person help plan for care in the ICU?
Your name		<input type="checkbox"/> Life support <input type="checkbox"/> Comfort care <input type="checkbox"/> I'm not sure	
ICU doctor		<input type="checkbox"/> Life support <input type="checkbox"/> Comfort care <input type="checkbox"/> I'm not sure	
		<input type="checkbox"/> Life support <input type="checkbox"/> Comfort care <input type="checkbox"/> I'm not sure	
		<input type="checkbox"/> Life support <input type="checkbox"/> Comfort care <input type="checkbox"/> I'm not sure	
		<input type="checkbox"/> Life support <input type="checkbox"/> Comfort care <input type="checkbox"/> I'm not sure	
		<input type="checkbox"/> Life support <input type="checkbox"/> Comfort care <input type="checkbox"/> I'm not sure	

## How would you prefer to be involved in decision making?

Check ✓ one.

- I prefer to make the decision about the patient's type of care.
- I prefer that other family members and I make the decision about the patient's type of care.
- I prefer that other family members and I make the decision about the patient's type of care, after seriously considering the healthcare team's opinion.
- I prefer that the healthcare team and family share responsibility for the decision about the patient's type of care.
- I prefer that the healthcare team makes the decision about the patient's type of care, after seriously considering the family's opinion.
- I prefer that the healthcare team makes the decision about the patient's type of care.

# STEP 5: What else do you need to do to prepare for decision making?

Yes No

## Knowledge

Do you know enough about your family member’s health situation right now?

Do you know enough about how your family member is expected to recover?

Do you know enough about the benefits and risks of each option (comfort care or life support)?

## Values

Are you clear about what matters most to your family member?

## Support

Do you have enough support to participate in decision making?

Do you have enough advice to participate in decision making?

## Certainty

Do you feel sure about the best decision for your family member?

## NEXT STEPS

### How can I find out more about care in the ICU?

- Make a list of your questions.
- Ask your healthcare team for answers when you are at the bedside.
- Ask to have a family meeting with your healthcare team.

### How can I decide what matters most to my family member?

- Review your answers in Step 3.
- Discuss what matters most with other family members.
- Discuss with others how documents written by the patient can be considered in decision making.

### How can I share my thoughts with others?

- Share the answers in this guide with your family and healthcare team.
- Talk to the people whose opinions matter most.
- Find someone neutral to help you talk with others. Nurses, social workers and clinical ethicists in hospital settings often help families discuss important decisions like this.

**What do you plan to do to prepare for decision making?** \_\_\_\_\_

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Since a patient's health situation often changes in the ICU, you may revisit the decision several times to make sure that your family member continues to receive the care that they would want.

**I would like to re-evaluate my family member's situation on this date.** \_\_\_\_\_

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