Chronic Critical Illness

Decision Aid
Making an Informed Decision

Review this book
We give you this information to help you understand options for your care.
We want you to take time to review this book and think about the decision that is right for you and your loved one.

- Treatment may extend my life with organ failure, but it may mean I will live the rest of my life in hospitals.
- Do I want to have everything done to keep me or my loved one alive, or not?
- Do I want to be kept comfortable until I die and not be kept alive with machines?

Ask questions of your doctor or others on your care team if there is anything that is not clear. Having difficult conversations now will help with difficult decisions in the future.

This is not an easy decision
We understand you are in a difficult position.
This decision can be scary and confusing. You may feel pressure to make a decision. All of these are normal emotions.
We want to be sure you know the details of this process, so you can make the right decision for you or your loved one.

Remember, choosing comfort care does not mean that your care team is giving up on you. It is just a different treatment path.
This book is not to replace conversations with your care team.
Use it as a guide to help you, your family, and your care team know what is important to you.
Life with Organ Failure

Ongoing or Chronic Critical Illness

Having one or more organs in your body failing or not working well enough to support your life without ongoing high level medical care is called ongoing or chronic critical illness.

While there may be enough improvement in your condition to leave the intensive care unit or the hospital, you are often too sick to be able to go home. Care may be needed in a long term acute care hospital, also called LTACH.

Care in the LTACH

The long term acute care hospital can provide support for the person who needs a ventilator, dialysis, tube feedings, wound care, and daily care. They can also provide therapy as the person is able to tolerate it. Most patients are sent to the LTACH because their care is too involved to be done at home.

It is not the same level of care as in an ICU. The nurses and support staff will be caring for more patients each shift than in an ICU.

While in the LTACH, the progress of the patient will be checked to see if there is improvement. Most often that may result in 1 of 3 outcomes:

- There is **improvement seen in the first 2 to 6 weeks** and the person is able to be moved to a skilled nursing facility (SNF) to continue rehab. A few patients may be able to go home with caregiver support.

- There is **slight improvement, but treatments are still needed to support their failing organs**. The patient care may need to continue in the LTACH, or the patient may be moved to a skilled nursing facility (SNF) or an extended care facility (ECF). Another option is to change the goals of treatment to comfort which can be done with the support of hospice. Treatments would be removed that are not helping the patient.

- There is **worsening of the organ failure or other medical problems occur**. Patients at the LTACH are more at risk for problems that require more intense care, so often you end up going back and forth between the ICU and the LTACH. Each cycle weakens your body and more damage may occur to your organs. The options are to treat the patient in the ICU as needed, or to change goals to focus on comfort until death.

Treatments

Based on the failing organ or organs, available treatment may include:

- **Breathing machine**, also called a ventilator, to support breathing. Often, this will require a tube being placed in the neck, called a tracheostomy or trach.

- **Dialysis** to filter the blood when the kidneys are not working. This may be needed every 2 to 3 days.

- **Feeding tube** that may first be in the nose to the stomach, called a nasogastric or NG tube. If a feeding tube is needed long term, it would be placed into the stomach through the belly wall, called a PEG tube.

- **Wound care** because of slow healing and risk of skin breakdown because of serious condition.

- **Daily care**, such as bathing, feeding, and turning due to weakness and inability to do own care.
Is LTACH care right for me?

Your care team has decided that your condition has stabilized and ICU care will not give any further benefit at this time. Either organ function has leveled off or more time may be needed to see if your organs are able to recover any more. Your care options are to transfer to LTACH or to consider focusing on comfort with the help of hospice care.

Options for LTACH care

The case manager or social worker will help you and your family get information about LTACH care options.

• In the Columbus area, there are 3 LTACH sites run by Select Specialty Care.
• If you are from outside the Columbus area, other options closer to home can be explored.
• The arrangements for the referral and transportation to the LTACH would be arranged by the case manager or social worker.

What if I decide on comfort care?

The focus of comfort care is the quality of your life, care, and comfort. Treatments, such as the ventilator or dialysis, are stopped. The hospice team helps to manage your pain, shortness of breath, or anxiety.

Hospice care can happen in your home, in a hospice unit or facility, or in some skilled nursing facilities.

The care provided includes medical, emotional, and spiritual support for you and your family as you near the end of your life. Even if your life cannot be extended, comfort can be provided.

Caregiver impact

Most caregivers are happy to help their loved one with their condition and care. Others may feel overwhelmed, stressed, and feel a financial strain.

Your illness and decisions for next steps impact your family and caregivers, so they need to be part of the decision with you.

Things to consider

On the next pages, there are some questions or statements that may help you and your family to guide your decision.

This may also help you to know what other questions you want to talk about with your care team.
Things to Consider

How do I want to live the rest of my life?
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

What are my hopes and fears?
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

What are my concerns?
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

Questions I have for my care team about the LTACH.
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

Questions I have for my care team about hospice.
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

What questions do I have for my family?
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
Questions I Need to Ask

For my doctor or case manager/social worker

For my family and caregiver

For me

I want to do everything I can to live as long as I can, even if it means having major surgery and being dependent on one or more machines.

Strongly agree  Agree  Neutral  Disagree  Strongly disagree

I am at peace with the life I have lived, and feel it is my time.

Strongly agree  Agree  Neutral  Disagree  Strongly disagree

The most important thing to me now is:

What are my family members thoughts and feelings?

What other information do I need to make my decision?

What are my family members thoughts and feelings?

What other information do I need to make my decision?
Chronic critically ill patient
- Little or no improvement for 7 to 10 days
- Ongoing organ support needed

Discharge to Long Term Acute Care Hospital (LTACH)
- Provides time and ongoing organ support
- Provides therapy services as patient is able

Condition improves:
- Home (Rare)
  - If family able to meet patient needs
- SNF/Rehab Hospital
  - If patient able to take part in several hours of therapy
- ECF (Nursing Home)
  - Not well enough for home

No improvement:
- Return to Hospital
  - Try to treat organ failure problems
  - Discharge to LTACH
  - Cycle repeats

Condition worsens:
- Comfort Care/Hospice
  - Focus on comfort and quality of life goals
  - Provided at home or in extended care facility (ECF), skilled nursing facility (SNF), or hospice

Need to place trach for breathing or PEG tube for feedings?