Talking about changes after an ICU stay

Bring one example from an ordinary day to your follow-up visit. What you were trying to do, when you noticed a change and how much help you needed can tell your clinician where to start.

Have you ever received care in an intensive care unit, or had a loved one who did? If so, you are likely familiar with the mixed emotions and feelings that may come afterward. On one hand, you feel relieved to be stable enough to continue your recovery, but on the other hand, care in an ICU setting can be traumatic to emotions and your body.

The Society of Critical Care Medicine recognizes how important it is to support people in this circumstance by identifying a collection of disorders common to people who experience critical illness and intensive care. Those conditions are referred to as post-intensive care syndrome, or PICS.

What is Post-Intensive Care Syndrome?

Intensive care can affect a person's body, thoughts, feelings, mind and interactions with friends or family. As a loved one transitions out of intensive care, they may not have the same abilities physically, mentally or emotionally as they did before.

This is referred to as post-intensive care syndrome, or PICS. It can be as obvious as weakened muscles, or less obvious like problems with thinking and judgment, depression or anxiety. The risk that your loved one may experience PICS increases if they:

- Were in the ICU longer than three to five days
- Have an infection or sepsis that needs daily care
- Multiple affected organs like their lungs, kidney, skin, heart, brain or others
- Need a mechanical ventilator to help them breathe
- Weakness from degenerated nerves and muscle
- Poor nutrition
- Trouble with attention, memory or reasoning
- Post-traumatic stress disorder symptoms with frightening memories or hallucinations

If your loved one is experiencing any of the above, they may need more time to recover and work on regaining key functions of their daily life.

Where Can You Receive Treatment for PICS?

PICS alone does not establish that a person needs hospital care. The referring and receiving teams assess the medical treatment still required, ability to participate in therapy and other support needs.

These LTACH hospitals offer in-depth care, like that you would receive in a traditional hospital or intensive care unit, but with access to a team of specialists who work together to guide your care when you need additional time to recover after a hospital stay.

What Can You Expect at the LTACH?

The length of an ICU or long-term acute care stay depends on the person's condition and progress. Ask which treatments still require hospital care, what would make transfer appropriate and how the team will follow changes after the move. Hospital-level support may include the following.

- Helping people wean off of a mechanical ventilator
- Providing occupational, physical and speech therapy
- Ensuring daily physician visits with a full-staff of specialists when necessary
- Assisting with pain management
- Prevention and treatment of Infection and sepsis
- Preparing people for a lower level of care through family-focused discharge planning

What If You've Never Heard of Long-term Acute Care Hospitals?

Because these hospitals are specialized to treat people experiencing critical illness or injury, many people have not heard of them. However, Congress and Medicare have acknowledged the value LTACH hospitals play in supporting the recovery of chronically, critically ill people, like those experiencing PICS.

When evaluating a recovery setting, ask how it follows the outcomes that matter to the patient and family.

- Ask how discharge destinations are defined and what support patients typically need after discharge.
- If comparing readmissions, ask about the patient group, reporting period, definition and how medical complexity is taken into account.

For questions about a possible stay, call Lakeview Admissions at (262) 534-8509. During a stay, ask the bedside nurse who can help with your question.

If you think your loved one is experiencing PICS, speak with their physician about your options or use one of the resources below:

- Read the National Library of Medicine's indexed overview of post-intensive care syndrome for background on changes in strength, thinking and emotional health. Bring observations about day-to-day activities to the follow-up visit. https://pmc.ncbi.nlm.nih.gov/articles/PMC5506407/
- Learn about local support groups emerging across the country to provide support to people and their loved ones experiencing the after-effects of the ICU

Write down a change you have noticed since intensive care and bring it to the clinician who is coordinating follow-up.