



After an ICU Stay

Staying on the Road to Feeling Better

Pulmonary & Critical Care Medicine
Post ICU Longitudinal Survivor Experience (PULSE) clinic



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Suzanne's Story

Following my hospitalization, my previous very active and athletic lifestyle became a distant memory. Finances took a big hit, due to my inability to quickly get back to work. Socially, I became a different person, less able to engage and interact. And the impact on my thinking and concentration levels was huge. Although everything about me continues to recover and improve, the rate of improvement has been frighteningly slow.

I was determined to make a comeback, to make good out of this fall from good health. I was so tired most of the time. I had lost most of my strength and much of my muscle mass. Following the advice of my health care team, I focused on taking care of myself through much needed rest, counseling, and a slow return to regular activities. I found that a huge part of self-care is in listening to and respecting my body and its new limitations, and in having empathy and compassion for myself.

I have learned to appreciate that the new me is not a failure, but is instead, a person with new strengths, priorities and perspectives. This self-acceptance is so important to healing, particularly since the recovery process is difficult for family, friends and many health professionals to understand.

I am indeed, a different person than I was, and am finally realizing that this is really okay, in some ways probably better.



Critical illness is a life-changing experience, and recovery does not stop when you leave the hospital.

The information on the next few pages is intended to help you understand and be attentive to the possible ongoing symptoms you may experience from a stay in the ICU. These symptoms are normal. We share the stories of other survivors to help you know that you are not alone and that there is a way forward. Tips for minimizing ongoing challenges and for accessing care for symptoms are also included. It is our hope that additional knowledge and awareness will help you stay on the road to a full recovery!

Physical Symptoms:

What should I be on the lookout for?

Weakness

Muscle weakness often occurs during and after an ICU stay. This weakness makes it harder to bathe, dress, fix/eat meals, and walk. It may make it difficult to do the things you did before your hospital stay.

"No one understands what happened to me. They think I should just snap back. I feel so worthless, like I have nothing left to offer my family."

Being tired

Roughly 50 out of 100 individuals who have a long stay in an ICU experience feeling:

- Emotional and physical exhaustion
- Having little or no energy
- Like they are unable to get anything done

Difficulty sleeping

- Not able to fall asleep
- Waking up frequently
- Nightmares
- Pain

Shortness of breath

Breathing problems after a stay in the ICU are not uncommon. The muscles that help you breathe have been weakened, making it harder to do things such as walking, standing, bathing, or housekeeping without becoming short of breath.

Thinking, Memory & Concentration Symptoms:

Changes in short term memory, the ability to concentrate, think clearly, and follow directions often happen after an ICU stay. These changes can be very scary, both to patients and family members.

"Feeling like I am not getting better almost 7 months after hospitalization is very scary."

What should I be on the lookout for?

Signs of short term memory problems:

- Asking the same question over and over again
- Difficulty remembering words
- Forgetting what you went into another room to get

Decision making:

- Unable to process all of the details needed to make a decision
- Becoming overwhelmed when asked to make a choice or decision
- Easily frustrated when asked to decide something

Difficulty concentrating:

- Difficulty reading; re-reading the same page several times
- Unable to follow a conversation
- Struggling to follow the plot in a television show

Difficulty getting things done:

- Having trouble following a recipe or doing something that you have done many times before
- Difficulty following instructions
- Difficulty paying bills, managing finances

Mental Health Symptoms:

What should I be on the lookout for?

Anxiety:

- Worrying a lot
- Irritability
- Being very tired
- Feelings of panic
- Restlessness

"I keep waiting for the other shoe to drop; always worrying that I am going to get sick again. It just happened so fast."

Signs of depression:

- Loss of pleasure: inability to find joy or pleasure in activities
- Feelings of extreme sadness
- Feelings of worthlessness, hopelessness or helplessness
- Being tired all the time, inability to sleep, or sleeping all the time
- Irritability

Signs of Post-traumatic Stress reactions:

- Nightmares
- Unwanted thoughts of ICU experiences (flashbacks)
- Feeling on edge; thinking something bad is going to happen without any reason
- Fear or anxiety about being in places/situations that remind you of your ICU stay
- Unexplained sense of horror, anger, guilt
- Numbness; difficulty connecting with others

What can I do to continue getting stronger?



In the hospital:

- Understand what is happening and why
- Communicate with your care team
- Look for changes in yourself
- Engage in physical and occupational rehab
- Early walking and physical movement
- Talk with your friends and family
- Friends and family should look for changes in your thinking and memory
- Ask friends and family to explain the care being provided
- Use your ICU diary
- Share your fears and worries with your care team



At home:

- Get support in place at home (canes, walkers, shower chairs, etc)
- Do physical and occupational therapy
- Get up and move about as able; exercise
- Have a pharmacist review your medications
- Ask a dietitian about healthy food
- Look for changes in how you feel
- Be alert to changes in thinking
- Ask to be screened for problems with thinking and concentrating
- Consider seeing a counselor
- Talk to your physician about possible needs for anti-depressant/anti-anxiety meds
- Schedule an appointment for a thorough check-up with a doctor
- Be patient. Push yourself, but don't overdo it
- Know that you are not alone and that you are not crazy

Impact of The ICU On Family Members:

Family members of critically ill people can be affected physically and emotionally during and after a family member's hospital stay. Your family may be affected in some of these ways:

- Inability to sleep
- Anxiety
- Depression
- A sense of loss
- Symptoms of post-traumatic stress

Encourage your family to:

- Accept help from friends and other family
- Get enough sleep and eat healthy
- Ask questions of the health care team
- Consider talking to a counselor
- See their physician



Additional Resources

Websites:

- My ICU Care: <https://sccm.org/MyICUCare/THRIVE/Post-intensive-Care-Syndrome>
- ICU Steps: <http://www.icusteps.org/patients/patient-experiences>
- Sepsis Alliance- Patient and Family Education: <https://www.sepsis.org>

Helpful video links:

The Society of Critical Care Medicine has several videos featuring interviews with caregivers and ICU survivors. These videos are available at www.youtube.com/SCCM500. Some videos that might be useful are.

- ***What advice would you give ICU staff?:***
<https://tinyurl.com/y3x3a44y>
- ***What advice do you have for other survivors?:***
<https://tinyurl.com/y4udw2v9>
- ***How could your care after ICU discharge have been improved?:***
<https://tinyurl.com/y5b6wtu8>
- ***What was your experience in the ICU?:***
<https://tinyurl.com/yxzu8q7w>

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