

New Feature: Our Advisory Board bring a world of experience to our Early Mobility Team.

In our recent bi-annual advisory board meeting, our team of advisors gave great input about important early mobility considerations. One of the foremost discussion points especially with the COVID-19 environment was around humanizing the patient in the ICU and including the family. This is the “F” portion of the ABCDEF bundle.

One of our advisory team, Eileen Ruben brings us the unique perspective of having personal experience with having had Acute Respiratory Distress Syndrome (ARDS) herself. TODAY marks her 25th anniversary of her admission. Eileen is a strong advocate for patient survivors. She founded and is president and CEO of the ARDS Foundation (<https://ardsglobal.org/>) and supports work that helps improve patient outcomes and helps improve the human dignity and experience as patients and their families navigate the complex medical system throughout their journey from survival to recovery.

We are honored for Eileen Ruben to share her personal story with us today, and recommend you visit the ARDS Foundation website to see what Eileen and her team are doing to support and advocate for those who are affected by Acute Respiratory Distress Syndrome.

Twenty-five years ago, on June 2, 1995, my world changed forever. When I was 33 years old, I was suddenly admitted to with hospital in septic shock and later diagnosed with Acute Respiratory Distress Syndrome (ARDS).

Less than two days later, I was on a ventilator, fighting for my life. Acute respiratory distress syndrome (ARDS) occurs when fluid builds up in the tiny, elastic air sacs (alveoli) in your lungs. The fluid keeps your lungs from filling with enough air, which means less oxygen reaches your bloodstream. This deprives your organs of the oxygen they need to function. It is like you are drowning from within. Patients with ARDS need life support to survive. Many have heard of ARDS recently because CoVID-19 can also be a precipitating cause that leads to ARDS.

I spent the next 4 harrowing weeks in the hospital in a medically induced coma, for a total of 8 weeks, on a ventilator. After only 2 weeks, doctors suggested ‘pulling the plug’ because they said that they had done all they could do medically; they said that that I would never breathe

Corporate Office: 12051 NW 4th Court, Plantation, FL.

Phone: 989.751.2891

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on my own again, I would never get off the ventilator, that I likely suffered brain damage and it was a 'quality of life' issue. My family declined; they told the hospital to try to save my life.

During my 8 weeks on a ventilator, I suffered fluid overload, my weight fell to 82 pounds, my spleen died away by 90% almost requiring surgery, both my lungs collapsed twice, requiring 5 chest tubes, I received 8 units of blood, suffered a hospital acquired infection in my tracheostomy, a hospital psychosis, delirium and complete narcotic withdrawal. Further, I was vent dependent, suffered anxiety, depression and many panic attacks.

To say this was the fight of my life would be an understatement. Therefore, I mark this anniversary as I would any significant event that occurred in my life. It is of such a magnitude that to do otherwise would be unforgivable.

This monumental event is not just about me. It is about my devoted and dedicated family, who were at my bedside each of the 63 days in the hospital. My parents spent everyday at Lutheran General Hospital in Illinois. My brothers, and their wives, and my sister, were there everyday as well, asking questions, doing research, and letting people know I had a family that cared about me, that they needed to answer to.

It is also about those nurses, who held my hand, who comforted me, calmed me, cared for me. I would not have made it without day nurse, Lisa, and never would have survived those nights without Lilia. I cannot underestimate the connection with my nurses that lifted me, both physically and metaphorically, when I could not life myself. It is about my devoted doctors who were always certain they were on call during my worst crises... And they were right, they all were, saving my life at those critical times because I was in crisis so often. Still, those doctors did more than their 'jobs' because in me, they saw their wives, sisters, or children and within them, I felt they would not let me die on their watch. And thankfully, they did not. It is about those physical, and speech therapists who made sure I kept moving, thinking, remaining motivated. And it is about my angel, my dedicated occupational therapist who entered my room with tremendous determination and motivation; yes, I could actually see it... love... love... every Monday, she brought her dedication to work me hard all week, forcefully, but gently, and gave me goals to achieve every Friday for the weekend. If I disappointed Nancy, I felt I had failed. She helped me hold my head high. She was a gift I did not deserve, but so appreciated.

Of course, I was so lucky to also have many people who supported me aside from family after I was discharged after nine weeks in the hospital. And I turn to what worries me to much now, with CoVID-19 as a precipitating cause of ARDS. While I am so thankful that our medical professionals are saving so many CoVID-19-ARDS patients, I am so worried for these survivors who are leaving countless hospitals without the appropriate information to not only survive, but to thrive, through this diagnosis.

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When I left the hospital in 1995 after surviving ARDS, I was told, by a medical world that was just not information, that yes, recovery would be difficult, but after about a year, I would be fine and back to 'normal.' Nothing could be further from the truth.

As President of ARDS Foundation for twenty years, I realize that ARDS survivors do not go back to 'normal.' That is not to say that they do not achieve a life worth living, but that this process is very slow, very arduous, and while some survivors may feel closer to the way they felt before getting ARDS, they many have a different sense of what normal is.

Many feel a larger amount of stress, depressions and Post Traumatic Stress Disorder (PTSD) after surviving ARDS. Often this is due to delirium that they suffered while in the intensive care until. Sometimes this is combined with cognitive impairment. Because many ARDS patients do not receive the benefits of early mobility, those patients suffer from severe de-conditioning. This can cause them delay in returning to work, or a reduced work load, or worse, the inability to do the work they loved, enjoyed and from which they gained satisfaction. Other patients, post ARDS, just do not 'feel' like themselves. This causes them distance themselves socially from others, as family and friends continue to ask why they are not 'themselves' anymore. They may find themselves withdrawing further into themselves because they continue to disappoint the expectations of their loved ones who stood by them.

So while in a 'normal' year, over 200,000 Americans are diagnosed with ARDS, with a survival rate of a little over 50%, with CoVID-19 leading to ARDS, we will have so many more patients diagnosed with ARDS. And as a nation, it is our responsibility to ensure that these poor souls receive the resources that they NEED post ARDS to have not just a life, but a life worth living. I hope that you will join me, and ARDS Foundation, on my 25th anniversary of surviving ARDS, to make sure that our nation provides not just CoVID-19-ARDS survivors but also all ARDS survivors a life worth living.

Thank you Eileen for sharing your journey, and we at EarlyMobility.com challenge every clinician to "HEAR" every one of their patients through Eileen's testimony. We can support your efforts with tools, education and consulting if needed. Together, we can implement the best evidence-based practice to improve outcomes for every patient in our care.

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