

Chapter 1

The New Normal

***“Life changes in the instant.
You sit down to dinner and life as you know it ends.”
Joan Didion***

Jeff paced in the ICU waiting room, anxious to see his mother and to find out what was happening medically. His mother, a socially vibrant and physically active 65-year-old, had been admitted to the ICU with pneumonia. Her voice had sounded so raspy and breathless on the phone, Jeff hadn't recognized her. As he drove to the hospital, he felt a sense of dread. Hospitals made him uncomfortable and he had never been to the ICU before. He imagined how frightened and alone his mom must feel. What if his mom needed to go on a ventilator? What if he lost her?

Like Jeff, many people have little prior exposure to the hospital Intensive Care Unit (ICU). Usually people are thrust into the ICU environment when they or someone they know is admitted following a medical crisis. The ICU is the hospital unit reserved for the most medically compromised patients. Just mentioning a possible admission to the ICU can invoke dread for anyone. We worry about the patient's wellbeing and survival. We may be uncertain about what the future might hold. We may even fear visiting the ICU patient and disrupting life-saving interventions. Even when an ICU stay is anticipated and planned (such as

following scheduled heart surgery), we can still find ourselves feeling intimidated by the ICU environment and anxious about the medical outcome for our loved one.

The mission of the ICU is to save even the most critically ill and injured patients. More than 5 million patients are admitted to ICUs in the US each year. Medical interventions transform heal and transform many of those treated in the ICU. Even so, %40 (Check this) of patients die in the ICU each year.

Everyone hopes for a miracle in the ICU. While a patient is in the ICU, the future may be disrupted and uncertain at best. Some individuals may be caught in a dire struggle to survive. Family hold vigil while waiting for urgent updates about patients. People may refer to this time as their new normal, even though there is nothing that feels remotely normal about it. Things may indeed be forever changed for some individuals going forward after an ICU stay, as one-third to one-half of ICU patients will develop chronic physical, cognitive, and emotional difficulties following their ICU treatment.

If you are struggling to support a patient in the ICU, my heart goes out to you. No one ever wants to be in the ICU. It is awful to watch those we love suffer and to fear that we may lose them. Many may feel powerless or uncomfortable in the ICU, and may assume that they need to stay away while the patient is treated in the ICU. But there is much that family can do to support healing and recovery for ICU patients.

Family is a broad, encompassing term to include any people who love the patient and have close relationships with the patient. These can include people related to the patient by blood or marriage as well as friends or romantic partners. Across the board, ICU patients with family support heal better medically and emotionally than those who do not have this support. Family can offer essential information to the ICU medical team about a patient's prior medical history, current medications, lifestyle habits, and recent life events. Family can ask vital questions and advocate for a patient's preferences. Family are often the best cheerleaders as patients cope with physical therapy, surgeries, and life-changing medical conditions. Even when patients are unconscious in the ICU, family can offer important reassurance at the patient's bedside and lessen the potential for a patient to feel traumatized by the ICU experience. ICU patients with active family support have more favorable medical outcomes during their ICU stay and following discharge compared to patients without family support. And when a patient is transferred to a less intensive hospital unit or back home, family support is vital for continued healing and recovery for many patients.

Physicians, nurses, and other hospital staff increasingly recognize the role of family in supporting ICU patients. The recent COVID pandemic has only magnified the vital role that family can play in nurturing critically ill patients while in the ICU and beyond. Ensuring that family members are given the support they

need during an ICU experience has never been more essential. To best support someone in the ICU, it is crucial that family members receive 1) accurate information about the ICU and how to navigate this specialized unit, 2) timely and accurate information about the patient's unique medical condition; and 3) expert guidance to support effective coping for themselves and for the ICU patient.

The United States is unfortunately behind the curve compared to other countries with educating patients and family about the ICU. While some countries routinely offer detailed informational websites about the ICU as well as highly trained emotional support to patients and family members, US ICUs typically rely upon the medical staff to offer information and support to patients and family. This expectation is heaped upon critical care medical staff who are already tasked with delivering life-sustaining treatment to ICU patients. Expecting the ICU physicians, nurses, and other hospital staff to emotionally support patients and families in addition to their existing duties creates an unrealistic overload. The recent COVID pandemic has worsened this burden on our critical care professionals with high ICU admission rates and increased staffing shortages. Though ICU staff are highly medically knowledgeable, many US ICU staff also report low confidence about their training to offer effective emotional support to ICU patients and family members. Though US hospitals are beginning to shift these practices, both ICU

professionals and their families consistently endorse the need for more effective resources to provide informational and emotional support to patients and families.

In a concerted effort to address the needs of family, there are four self-help books for patients and their families published in the last four years. These books focus largely on detailed medical and practical information about navigating an ICU stay. While these books provide valuable medical guidance, no prior self-help book combines practical, in-depth information about the ICU with detailed knowledge involving the emotional impact of the ICU environment and how to effectively cope with this distress. This self-help book addresses these needs for families and combines these resources in an easy-to-use reference.

Within this book, we will cover:

- Accurate, detailed information about the ICU setting, including typical rules and routines in the ICU, the staff you may encounter in the ICU, and common ICU procedures, tests, and treatments.
- Effective guidance to understand staff roles and interact with ICU staff during a patient's care in the ICU.
- How to successfully communicate with staff, ask questions, and advocate on behalf of yourself or a patient while in the ICU.
- Practical suggestions about being present for a patient during their ICU stay while also caring for yourself in the process as well.

- Information to better understand the potential traumatic impact of the ICU experience on you, the patient in the ICU, and other family.
- Practical crisis strategies for both you and the ICU patient to effectively cope with elevated distress levels during an ICU stay.
- Longer term coping strategies to reduce and eliminate distress to optimize healing while moving forward out of the ICU and beyond.
- Strategies to cope with grieving changes in function, death, and dying.

This book is intended for anyone seeking to better understand the ICU with written information. Patients and their family are the main focus of this book. The term patient will be used to refer to the person admitted to the ICU unit of the hospital. The term family is used broadly and may include anyone who cares about a patient admitted to the ICU. This includes immediate or extended family, significant others and spouses, romantic partners, friends, and acquaintances. Medical, nursing, allied health, and mental health professionals may additionally want to read this book to better understand and support families and patients who are facing an ICU admission or have been in the ICU recently. Finally, anyone who knows someone supporting a patient in the ICU may want to read this source to offer support to these families as well.

How to read this book:

Practical and medical information about the ICU

Information about the emotional impact of the ICU, the nature of psychological trauma, and effective ways to emotionally cope with the ICU both when in crisis mode and longer term.

Each chapter will offer factual information as well as specific recommendations to help family best support patients in the ICU.