

A Family's Guide to the ICU

What to Expect in the ICU and Your Strategy for Navigating the Unexpected



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Introduction

Even the air in the waiting room of a hospital feels uncertain. When you first arrive you hesitate at each word, not knowing what is appropriate, who to ask for help, and how or if to break the ice with the others waiting to hear the fate of their loved ones. Each step into the critical care setting creates more questions -- entering the ICU, sitting in your loved one's room, watching as machines are hooked up to her, eavesdropping on discussion about her prognosis and care plan. It feels like you are walking in a foreign land without a guide.

The hospital's care team rightly centers on caring for the patient. Yet in complex and lengthy scenarios, caregivers can play an important part in a patient's care and recovery. After all, it's their lives that will be most affected by the outcome of the decisions made in the hospital. It's their emotional turmoil that is most palpable in those waiting rooms.

This guide tries to bring light to what can be a confusing and emotional journey for caregivers. It's based on my family's own personal experiences over nearly eleven weeks at UCSF (almost entirely in the ICU), from my mom's admission to the hospital, across multiple surgeries, through to her bilateral lung transplant and her eventual (successful) recovery. It incorporates what we learned and experienced through sharing, crying, and praying with the families and friends of other patients we encountered; and conversations with providers and patients at other hospitals about how care is delivered.

This guide barely touches on the emotional rollercoaster of watching a loved one fighting for their life. There is a special uniqueness to each of us and the circumstances we face. I can only offer that it will almost certainly be hard, and caring for yourself is critical to being the best support system you can be.

With this guide I hope to provide you with insight into the written and unwritten rules of critical care -- and help you navigate them through the experience. There is no single best path to handling such a unique journey. This document is one source of information -- and could be too much information or too hands on for your situation. Your context and own perspectives should guide you in how it fits (or doesn't) in your story.

A Caregiver's Journey

Navigating the Chaos

Everyone's story for how they get introduced to the critical care unit is different. Some know they are heading there, while for others, it is a surprise. In our case my mom entered the hospital for a medium to high risk procedure -- a lung biopsy to try to diagnose her Interstitial Lung Disease. After what appeared to be a smooth procedure and initial recovery, she developed ARDS (Acute Respiratory Distress Syndrome). Within three days of her initial procedure she was on a ventilator and unable to speak for nearly her entire stay at the hospital.

It soon became clear she would require a lung transplant in order to recover. Luckily, we were at UCSF which has an excellent transplant program. Others started at different hospitals and came to UCSF when it became clear a transplant was their only hope.

Where you are provides some context for how you should engage - and what kind of additional help or support you might need. For example, the quality of the hospital you are in and its expertise in what is happening to your loved one may impact how often you decide to be at the hospital or the level of detail in the questions you ask. While everyone's situation is unique, one of the first things anyone can do upon entering a critical care setting is to try and understand the structure and surroundings in which you and your loved one are now entrenched.

Who's Who in the ICU - An Overview

Each hospital will have its own structure of doctors, nurses, and specialists - and several types within each of these categories. This is particularly true once you are taken into an ICU.

Medical - General	Medical - Specialists
<ul style="list-style-type: none"> ● Doctors (Intensivists, Hospitalists) ● Nurse Practitioner (NP) ● Physician Assistant (PA) ● Nurses ● Residents ● Fellows 	<ul style="list-style-type: none"> ● Doctors (pulmonologists, cardiologists, etc.) ● Doctors - Surgeons (transplant, plastic, cardio-thoracic) ● NP, PA, Nurses, Fellows ● Nutritionists ● Fellows (MDs undergoing advanced training)
Therapists	Support / Other
<ul style="list-style-type: none"> ● Physical ● Occupational ● Speech ● Respiratory 	<ul style="list-style-type: none"> ● Social Workers ● Case Managers (Financial) ● Religious Care

At UCSF we interacted with nearly all of the roles above, and it became quite overwhelming at times. We had our medical specialists (cardiothoracic surgeons, pulmonologists, transplant surgeons) who were technically in charge of my mom, but they would coordinate with or even defer to the ICU team (intensivists etc.). There were also many at various stages of training (fellows, residents, medical students) supporting or learning from these groups.

The team outside of the doctors was larger and as essential to care. Therapists had specialized responsibilities related to key elements of care. A small group of nurse practitioners acted as the central point of continuity. The nursing team spent the most time in the room caring for my mom.

To make it even more confusing, each of these roles will have rotating schedules. Some work a standard week, others three shifts per week (which are usually 12-13 hours). In certain roles, each person is on call/service for a week, then won't be back for 4-8 weeks.

Nurses and the Nurse Practitioner - The Front Lines

In most ICUs nurses will cover one or two patients at a time. They are the front line of care for your loved one and the ones you will most interact with if you are spending significant time in the room. They have a lengthy set of responsibilities. These can include:

- Administering medications
- Responding to alerts (i.e. alarms going off in the room)
- Performing regular checks of a patient's medical systems
- Caring for wounds
- Cleansing
- Drawing blood
- Managing the IVs that administer nutrients or medicines
- Understanding what the patient is feeling and experiencing
- Coordinating with doctors and specialists
- Responding to the patient (e.g. call button)

Depending on whether it's the day or night shift, what is occurring and how many patients a nurse is managing, the ICU nurse might be in the room with your loved one from 3-8 hours over the course of a 12 hour shift. For caregivers, these nurses are important people to establish a relationship with even though there will be many of them throughout the patient's stay. In an average week, nurses work three twelve hour shifts. So a patient might see between 5-10 nurses during the week. Over the course of about three months we had ~50 different nurses.

In my family's experience, the greatest continuity across the weeks came from Nurse Practitioners (NP) who were associated with the transplant team. Nurse Practitioners would visit my mom 2-3 times per day during their shift and they connected with the rest of the medical team. They also could make decisions regarding changes to medications and other normal procedures.

The Elusive Doctor

By comparison, doctors are fewer in number and seldom available directly to you. Every morning after the first shift starts, the doctors and some combination of nurse

practitioners, residents, fellows, and nurses “round” on each patient to discuss their situation and plan. Sometimes multiple groups will round on the patient. During our most extreme times we would see the pulmonologists, ICU team and surgeons separately. In times of stability, this can be the only time you see “the doctor” during a shift or even the day. Rounding at night was a smaller ordeal with sometimes only a single resident, attending physician or nurse practitioner stepping in to review the patient.

Often the rounding group gathers outside of the room to talk about the patient; reviewing test results (i.e. labs), charts and images and discussing their care and plan. Some doctors welcome the patient’s caregiver to sit in on rounds, others seem more resistant to it. Then the group walks into the room to talk to the patient (if possible) about how she/he is feeling and what is happening, review questions and communicate key procedures, changes to plan, etc. In some settings rounding and the patient interaction are done together in the room. While we likely saw more than 20 doctors during my mother’s time in the hospital, the majority of care decisions were made by between 5-7 doctors.

A wide range of specialists will likely visit your loved one during the day as well -- guided by the care plan of the doctors and coordinated with the nurses. My mom saw a respiratory therapist twice a day for breathing treatments; and often saw a speech, occupational and physical therapists as well as a nutritionist. In her context much of this therapy was critical in keeping her strength up -- first so she would be eligible for a transplant, and then during the most important recovery phase after the procedure. Most specialists are only available during the day Monday through Friday. If you miss a session -- whether due to a procedure or scheduling challenge -- it can feel like a massive missed opportunity for continued improvement.

Tips to Navigating the ICU Staff Structure

1. Try to identify who is on your team and their roles/responsibilities. Who is your primary contact for care questions?
2. Understand the schedule of your primary contact(s) and team as well as when and to whom they will transition those responsibilities.
3. Keep a journal and track who is caring for your loved one to remember names and help with continuity.

Communicating with these different providers can be challenging. Communication is normally restricted to in-person discussions or through a nurse's page. Phone calls are typically one way - they call you for when something is needed. Email, text and other messaging is not normally an option. If you want to speak with a doctor, you will likely need to be there when she stops by or explicitly request a meeting or call. With some research you may be able to discover their email addresses, but direct contact information is rarely provided to you.

Understanding these different roles and how and when they work together helps ease the frustration limits on communication can create at a time of enormous stress.

Getting To Know Your Surroundings

It's shocking to walk into an ICU room for the first time. You're in a place with serious consequences and your loved one is hooked up to machines that look like they are twenty years old. Things are constantly beeping. Patients are connected to machines that help them breathe, process their blood (e.g. dialysis, ECMO), deliver medications, closely monitor vitals, and the list goes on.

One of the most disruptive aspects of the experience is alarms constantly going off. Alarms are supposed to represent an event that requires attention from the nurse, such as an escalating or declining blood pressure, heart rate, respiratory rate, or oxygen saturation. Initially, you may feel like nurses are not reacting to problems (especially when they are not in the room). Yet studies have shown that more than 90% of alarms in an ICU setting are either not medically important or false -- so it is easy to see why they are not perceived urgently by the staff. Depending on how long a patient's stay is, you will likely become more familiar with what is monitored and what is normal for your loved one.

Tips on Navigating the ICU Environment

1. Ask if there are any end-user apps available (e.g. MyChart from Epic or equivalent for their **E**lectronic **H**ealth **R**ecord system) that can allow you to view your loved one's information remotely.
2. Respect the environment and people around you. People may be coming out of other rooms with great joy or sorrow. If an emergency occurs even in another room ask your nurse whether you should stay or leave.
3. Develop patience. Whether it is the time that doctors round, when a room or piece of equipment will become available or when a procedure will occur, expect things to be fluid and sometimes feel inefficient.

You also may notice that your loved one is not alone. Most ICUs group between eight to sixteen people to an area, often divided by curtains and/or glass dividers. While the lack of privacy might be jarring, the ICU is set up like this so that providers have more visibility to patients and can respond faster to emergencies.

Emergencies will happen that cause a dozen plus staff to assemble around a single patient to intervene. When this happens to your loved one it can feel surreal. If you are spending a significant amount of time in the room, you'll almost certainly observe such an event somewhere nearby in the ICU and it's hard to know what to do in such an event. In my experience at UCSF, expectations for caregivers varied by the nature of the emergency and based on the staff that was there. Sometimes they wanted us to stay put and not leave the room so we didn't disturb what was occurring elsewhere, and in other cases they asked us to exit the ICU so they could prepare for a procedure. The nurse in charge of your loved one during that shift is the best source of direction in most of these real-time scenarios. You'll also notice a computer that's inside and/or outside the room. The hospital staff use this to look up information about your loved one (procedure notes, imaging, lab tests, medication), to scan in medications and treatments, and capture other important insights about their progress. If the screens look like they are 20 years old, it's most likely because they are.

Some hospitals will have additional consumer apps that let you see a subset of the patient's data such as real-time lab results (see screenshot of one common one call MyChart). However, these apps are few and far between and lack much information.

Understanding the Why and the How of the ICU

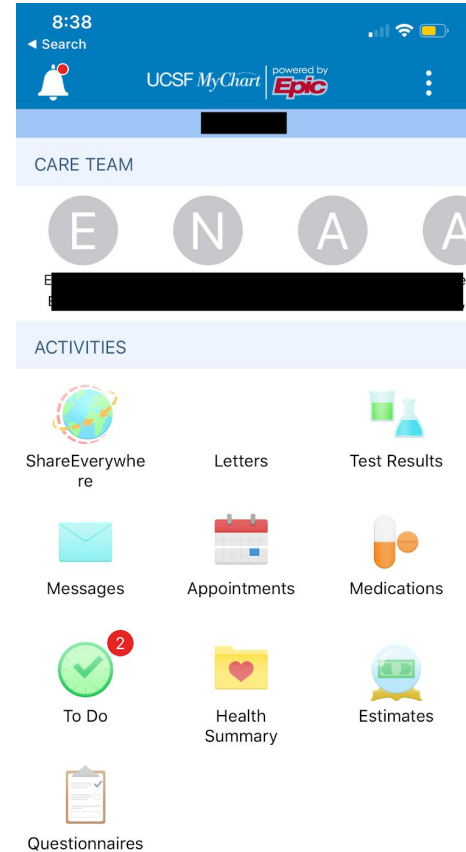
After the first few days in the ICU, your anxiety and shock might begin to morph into confusion about why things are the way they are. You will have many questions about what role you and your family should be playing in this new environment.

Your Presence

Most ICUs will have an established policy for visitation -- who can come into the ICU, how to ask if the patient can have visitors, the visitation hours, etc. Many of these rules are put into place for a reason. Most patients in the ICU are immunosuppressed, which means their immune systems are weakened and less resistant to infection. Hospitals tend to favor short visits to provide patient support, suggesting that creates more rest time for recovery.

Some ICUs have more restrictive visiting hours than others, and some discourage family from being there too often. At first glance, the rationale for such recommendations seems straightforward. In addition to the above, families get emotional and they can distract nurses from giving patients the attention they need. Yet even if this was true on average (which recent [research suggests is not the case](#)), it's not automatically true in your individual situation.

The premise that caregivers are distracting offers an incomplete, overly generalized, and slightly disingenuous view of the situation. What if the patient has difficulty communicating



because English isn't their first language, or if they don't trust strangers easily? It also fails to fully value the power of actually knowing the patient. What is their tolerance for anxiety or pain? How do they react to certain circumstances? What does their gesturing mean when they can't speak or write?

I also believe that one of the drivers for limiting visitors is related to the staff not wanting to have someone constantly looking over shoulders while they do their job. While this is understandable at a human level -- few of us would welcome that scrutiny at our own workplaces -- when the stakes are life and death of your loved one it feels irrelevant.

Hospitals have rules in place because they perceive they help to provide the best care possible to all the people in the ICU. However, as a caregiver, your objective is to advocate on behalf of one patient. You have a population of one that you are fighting to give the best chance possible. These objectives are not often in conflict and it is in your interests to maintain a respectful environment. But where the hospital perceives them to be, it is their responsibility to manage that, not yours.

Your Role in Your Loved One's Care

Depending on your life situation, time, desire, knowledge, personality, you may want to be there all the time, visit strategically, or perhaps blend the two. You might be OK simply knowing the details of your loved one's medical conditions and treatment or being there simply for emotional support, or you might want to choose to be more proactive in care and recovery.

Everyone's circumstances are unique, however, here are a few points of engagement that you need to agree upon as a family going into and during your time as a caregiver in the ICU.

Decision Making - Who's the Point Person

There are a great deal of decisions that need to take place in an ICU, and it's important to have a point person for helping a patient make important medical decisions -- especially if the patient is incapacitated.

In a perfect world, you'd have this figured out before even entering the hospital but that was not our situation. In our case, we were in the waiting room at UCSF with my mother, filling out the advanced directive information (who decides if the patient is unable to) as an afterthought. Our approach was haphazard. We barely filled out the form even though lung biopsies (the procedure she was having) had a serious complication rate of between 5-15%. We had not substantively discussed the concept of the lung transplant and spent no time discussing what to do if things went poorly.

Even though I was listed as the responsible party, it was clear I would never make such decisions without broadly consulting and having consensus from our family. Yet not speaking directly about the possibilities ahead of time with my mom created repeated stress and sometimes delayed our decision making and consent for certain medical procedures. These delays could have been costly in her outcome, so have these conversations before situations become dire if possible.

Ongoing Care and Emotional Support

Once my mom's initial complications occurred we knew we wanted someone from the family to be available to her as often as possible. We felt this was critical to support her emotionally given who she was as a person and the unexpected set of events and uncertainty of what would happen next. As we spent more time in the hospital, we also came to believe being there ensured the best chance for a positive outcome for my mom. We saw that we helped provide emotional support, pushed her to do more to help herself, and ensured the care team acted on accurate information about her conditions, progress and emotional state.

For my mom, mornings tended to be the most difficult part of the day. She had more discomfort, felt more anxiety and was generally less engaged early in the morning. We chose to be there, especially during those tough mornings, to reinforce that we loved her, even if it was at conflict with her wishes in the moment. Being there to push her to get more active and letting her be frustrated with us instead of the nurses might not have been what she wanted at the moment, but it helped her do more in enabling her recovery.

Also we observed that certain medications meant to help her ward off pain or anxiety actually made her lethargic and less motivated. Often, helping her struggle through a few minutes of pain or anxiety helped reduce her reliance on these interventions (which meant she was more awake/alert for all forms of therapy).

Providing this support can drain caregivers. You are there to be sensitive to your loved one's pain, needs, troubles, worries and concerns. Yet, it becomes clear that supporting him or her often means being insensitive - forcing them to work through pain and discomfort to participate in their own recovery. Many times patients go through actual delusions or hallucinations in the ICU. They can also develop skewed perspectives on who amongst friends and family is there for them and caring for them the "right" way. It can be hard to handle that unfair or inaccurate judgement from your ill loved one. It's important to remember they are using everything they have to fight for life and what they may be expressing in a moment is not necessarily reflective of how they feel or what is happening. Making sure you have a support system to help you manage through this.

Pushing the Patient - Sometimes Love Hurts

Years of medical research shows the correlation between medical outcomes and the amount of activity pre- and post-procedure. The days of just wanting patients to rest in bed are a distant memory. The entire team constantly reinforced to my mom and my family how important it was to maintain her strength if she wanted to remain on the transplant list and recover well from the eventual surgery. As a result, we were constantly focused on her therapy. The Physical Therapy (PT) and Occupational Therapy (OT) teams at UCSF were exceptional at pushing all of us on this front. Yet they could only come maybe once or twice in a day. That created a sense of urgency to get the most out of those sessions, to ensure we never missed their windows, and for my mom to do her 'homework exercises' as much as possible between sessions.

Our role was to help her with this so she could build her strength. We acted as the "bad cop" to make sure she did her assigned exercises, and constantly encouraged the breathing, physical, occupational and speech exercises that would make her stronger. She didn't always like it, but we believe it helped her recovery in the end.

A Day and Night Difference

There is a well known phenomenon that care levels change between night and day shifts, between weeks and weekends, and even between different times of year. Yet because of liability, no one at the hospital can directly address which times are more dangerous. The fact is, sometimes the right care decisions are wrong simply based on when they are occurring.

In our case, after a few weeks in the ICU, it seemed obvious staff members were over-medicating my mom at night. In certain cases the plan was to wean her down or off of a particular set of drugs at night and we'd return in the morning to find it at the same levels or even higher. In other cases, certain medications administered selectively at night would result in her sleeping until noon and missing important morning activities such as physical therapy or her doctors doing their rounds. We were still early enough in her journey so we were hesitant to say anything, but were increasingly contemplating doing so. Then, an abrupt experience made it clear that the quality and reliability of care at night was not as good as that during the day - and that was the deeper concern.

After some small but steady improvement to her breathing (she was on a trach collar with ventilator support at the time) she started having an elevated heart rate and her oxygen levels dropped. During the night she had more and more trouble and her oxygen level dropped dangerously low. All of a sudden doctors and nurses poured into her room. They were not her normal team but residents, nurses, and nurse practitioners from other departments. It was difficult to fully discern who was in charge and who was making the decisions. Nurses not assigned to my mom more freely offered their opinion on what should happen. Some of them were right, others just distracting. The resident who ended up being in charge nervously consulted with an attending physician from another floor, called the doctor on my mom's team who was on call, and intermittently directed the activity.

The next day through eavesdropping on conversations and reading body language it seemed like the actions taken were most likely the right ones. However, it was also clear that the decision making process, expertise available, and general control of the situation

was much more subject to error because it had happened at night. There simply wasn't the same number of people or depth of experience available during the night shift.

Seeing this recast our view of medication dosing and all other activity in terms of days vs. night. If slightly over dosing the patient resulted in a lower chance of an emergency occurring at night it was likely worth it. It's clear certain doctors and nurses had the same philosophy but it was not openly articulated. A similar phenomenon occurred between staffing levels on weekdays vs. weekends. As the weeks went by we learned to hope for steady progress in health metrics (strength, walking distance, breathing, etc.) during the week; our goal for the weekends became much more modest -- just not to lose ground.

Overall, it gives one some appreciation for how complex and subtle medicine and critical care can be. The right actions during the day can be the wrong ones at night. It's not a reason to simply give up and not pay attention, but it does reveal that it's important to understand context before making or conveying critiques. Trying to understand why certain actions would happen can help mitigate your concerns. How you perceive the correctness of actions, risk, and excellent care will certainly change over the days, weeks and months.

Tips on Caregiver Engagement

1. Ask about the ICU visiting hours and policies around visitation, but don't be afraid to respectfully push to see your loved one more if you think it will help.
2. Decide if you are there to provide emotional support or to help the patient get better. The former is helpful but not the same, and sometimes in conflict with, the latter.
3. Recognize the patient can suffer from delirium and a skewed perspective of your help. Sometimes that judgement can hurt but is neither their fault nor yours.

Over time you'll pick up on these nuances and even who on the care team is more competent or engaged than others. This is also important intelligence when determining how much attention you pay during various stages of care. For example, as we got to know the various nurses, who was covering mom greatly impacted our presence and actions. It would affect when we would be at the hospital, if we would stay overnight, what questions we would ask after a shift and more.

Being An Advocate

If you are in the hospital with your loved one for any extended period of time you will pick up some of the terms and thought process of the doctors driving care decisions. Yet after their years of education and experience caring for patients, it's highly unlikely you'll stump them with some question you looked up on Google.

There are helpful questions you can ask regardless of your medical knowledge, but before you start asking questions, think carefully about why you want such answers and how you'll process them. For some of us going to the extreme of reading medical textbooks and journal articles provides context and understanding for what is happening and what might happen next to stay more closely engaged in care decisions. For others, this kind of research would be overwhelming and would take away from being there emotionally for the patient.

Regardless of your approach, it is a smart idea to keep a running list of your questions so you are prepared when you meet with doctors on their daily rounds. Asking these questions may help you understand what might happen next and cross reference what people are saying. As mentioned above, many teams and specialists may see your loved one. Asking similar questions of these different people may help you understand how clear the situation is or how aligned the care team is on what needs to happen. Questions can also be used to nudge people towards another way of thinking, acting as a softer way of suggesting something that might otherwise be perceived as challenging a staff member's expertise.

Finally, there is no voice more powerful than the patient's. If your loved one can communicate, having them drive the discussions with the care team can be highly effective.

Just remember, regardless of how politely they answer your questions, each interaction builds or reduces credibility for other observations or thoughts you may convey regarding care. So be conscious of what questions you ask, how often, and what you do with the information.

Asking Questions to Help

Level I - Questions to track direction and consistency	Level II - Broad questions incorporating multiple concepts	Level III - Questions that require more understanding of medical concepts
<p>Doctors range from brutally blunt or pessimistic to overly concerned with how you will respond. Ultimately, we just wanted an accurate view of what was happening and to make sure everyone was on the same page.</p>	<p>A more advanced version of level 1, this line of question seldom arises from your own research. It's usually conveying the concepts one part of the medical services team has expressed to you to someone in a different area in order to nudge thought or behavior.</p>	<p>These questions can focus on factual scenarios or very specific nudging of providers to certain actions. It is important the facts / reasoning conveyed in your questions be accurate.</p>
<ul style="list-style-type: none"> ● What are you concerned with the most, has that changed since (yesterday, earlier this week, last week/month etc.)? ● What are the important decisions the team or we will likely face? What do you think is the right course of action? ● Are there procedures we may need to consent to in the coming day(s)? (Consent is required for any significant procedure.) 	<ul style="list-style-type: none"> ● X, Y, and Z (labs, vitals, imaging, etc) has happened and I'm concerned {condition, response to medicine, etc.} is happening? Is that the right way to think about this and if so what is the plan? ● Dr. T was concerned about X,Y and Z and ordered additional tests. Have those come back, what was the result, and are you still concerned about that? 	<ul style="list-style-type: none"> ● Earlier this week we changed medication X to Y because there was concern for Z. Since Z has gotten worse/ better, do we need to make another change? ● The nurse last night was worried about metric X and had proactively given her medication Y before she has to {do PT, insert a line, etc.}. Is that because of Z / will we do that again?

The Family Meeting

On occasion, it's possible to request a meeting with the care team. Usually that will bring together some combination of doctors, nurse practitioners and others to meet with you and your family in the patient's room or a conference room. These meetings nearly always needed to be requested, but they can be very helpful because they are longer and more in-depth, taking place in a room where everyone can sit and have a discussion. They can also be more detailed and be more strategic in nature. The team can walk through where things are at, what might happen, and what is most important.

Often the family meeting is as much for helping your own family navigate these scary time as it is for an exchange of information with the medical staff. For example, in the case of my mom's lung transplant, we were asked several times whether we would give consent to "experimental" trials or "high risk donors". The very wording made us lean towards "no". However, these very same procedures can often be the best chance a family member has (and clearly were in my mom's case). In these scenarios, no level of research and diligence I could do to confirm safety was completely effective in convincing members of my family something was the right course. However, for them, a doctor they knew had been caring for my mom saying "if this was my mom, I would 100% consent to this" made all the difference. The meetings helped get everyone on the same page.

Ensuring Continuity

With so many different people rotating in and out of providing care, it often feels that medical care is a game of telephone with a message passed from person to person, often being retranslated and sometimes misinterpreted along the way. Because you are tracking only one patient it's often easier for you to recall exactly what has happened than it is for the medical system. While I'm not recommending that you sit in every discussion or handoff, offering context for certain decisions isn't a bad thing. We never second guessed the major decisions my mom's medical team made, but there were a number of occasions where we provided context that changed a decision they made because they did not have the best information.

For example, at one point my mom could not eat regular food because of aspiration risk. The primary care team felt getting a feeding tube into her immediately was important to get her the nutrition needed to maintain her strength prior to a transplant. Various nurses made several unsuccessful attempts to insert the feeding tube, and eventually the staff decided to have IR (interventional radiology) place the tube.

However, before this could happen my mom was transferred to a different ICU floor tailored to pre (lung) transplant patients. The staff in the new ICU repeated the same bedside process - unaware of the previous failed attempts. The delay led to missing the window for IR to do the procedure and they said it would have to happen after the weekend, unaware of the urgency a different team had placed on regaining nutrition. After our raising the earlier team's recommendation and describing what happened, they decided to accelerate this and have IR place the feeding tube the following morning.

One of the most common challenges in continuity relates to medications and dosing. We never had the same nurse on for more than two or three consecutive days, and as a result we were often in a better position than the care team to recognize patterns in what medications and doses created lethargy or excessive sleep. A couple of months into my mom's stay a newer staff member tried increasing the frequency and dosage of an anti anxiety medication that normally didn't make people drowsy or lethargic. However it had done exactly that with my mom, who had displayed a high sensitivity to it and similar medications throughout her stay.

Limiting the medication led to her being more awake and able to participate in physical therapy. This in turn allowed the staff to see excessive fluid drainage from her wounds as she walked. As a result, they came to suspect, verify and treat an infection with an additional surgery. Being caught a few days later (or earlier) could have had a significant impact on her recovery. Less dramatic versions of this example occurred throughout her stay.

When your loved one is on a dozen medications it's hard for even the professionals to fully understand what exactly is causing lethargy, excessive sleep, anxiety or other conditions. Yet regular observations from the same person or group can provide a level of continuity

that staffing situations in critical care make difficult. No hospital would acknowledge that a patient's family has a role in ensuring the continuity of information for the medical team. However, if you speak with doctors and nurses privately they will share a different perspective.

A nurse or doctor seeing an ICU patient for the first time who has been in the hospital for weeks has to navigate an archaic system with hundreds of notes, labs, images, and procedures and, if time permits, have a couple of short conversations with the nurse, fellow, or resident on rounds. Their experience with countless patients lets them quickly plug your loved one into a framework, but it's impossible for them to know every juncture in medications, procedures, setbacks and reaction in your individual case.

Even in the best care settings, information continuity is a challenge. The rotation of specialists and care teams means new providers are nearly always ramping on the case, and the poor quality of today's hospital IT systems aren't making the situation any easier.

Speaking Up

Doctors make decisions quickly and with the best information they have. In some settings there are clear experts and hierarchies that develop as a result. Because there is so much rotation of staff, in the moment individuals may not know or be comfortable that they know information that would lead to a different path. Your role in speaking up and asking a question or providing a piece of information can directly change a decision or create a necessary pause to allow broader participation in providing inputs to a decision.

In one situation, a nurse who had not consistently seen my mom stated that she thought she was getting anxious and breathing fast as a result. One of the senior surgeons had reacted to this and pushed for having her take a mandatory klonopin dose both at night and in the day (her dose of klonopin at night had been reduced since the procedure and she did not take it during the day). Without a doubt, prior to the transplant, the actions and decision-making of this surgeon had saved my mom's life. There was no one whose medical opinion we respected and believed in more. Yet it was clear she didn't have the right information available to her in pushing for this course of action. Others on the team did not have the full set of information or were hesitant to challenge such a senior team member.

We said the klonopin clearly made her very sleepy and having it during the day would impact her PT. It was not a brilliant observation, just one that was clear because we had seen her reaction to this medicine closely and several times over the weeks. Based on our relaying these observations, the senior doctor shrugged and said fine. Instead my mom was temporarily given more pain reliever and her episodes of “anxiety” diminished. Her PT continued to progress and in a few days she was ready to move out of the ICU.

The Human Aspect of Care

As you move along in your ICU journey, it’s important to remember that care is driven by and provided to people. Unlike machines, people have good days and bad days. They make mistakes, get along better with some than others, and are not always unified in their opinions. Acknowledging this is important in ensuring your loved one gets the best care with the least emotional trauma for him, you, and those around you.

Handling Conflict

Compared to many stories of trauma in the ICU, ours was dramatic in the dimension of my mom’s condition and care (there are only ~2000 lung transplants a year in the United States), but [fortunately less eventful](#) in terms of massive medical errors or conflict. Nevertheless, less eventful is not the same as drama-free.

Early in my mom’s time in the ICU she had declining oxygen levels. It was likely she was going to eventually need the help of a ventilator to breathe. Yet the manner in which she ended up on life support was abrupt and traumatic for her and her caregivers. Late one evening a staff member decided it was important to put in an arterial line (a relatively minor procedure that does not require consent and allows for constant monitoring of oxygen in the blood and blood pressure). My mom had thin veins and the nurse practitioner struggled to place the line. She was crying out in pain and her oxygen began to drop rapidly as I stood and watched. Instead of backing off and resetting or getting some help from one of the attending physicians, the NP just persisted in a procedure that was not urgent. The reaction of the nurses in my mom’s room and adjacent ICU rooms reinforced they were very uncomfortable with what was happening. Despite my standing

silently outside the immediate room as instructed, I was asked to leave and go to the waiting room. As soon as I exited I sent a short message to my mom's primary doctor at the time. Regardless of if things worked out it was clear (for me) the process had been dramatically mishandled:

Not sure when you will get this; they are attempting to put an arterial line in and her oxygen dropped to the low 50s while they struggled to get it in, I was asked to leave as silently watching was potentially disruptive. Not sure if they got it in or not and if the oxygen went any lower; but it certainly wouldn't seem to be what I'd expect from a line placement.

A few minutes later they urgently asked me to come in to try to calm my mom down as she was panicked and they needed to get her to allow them to put a mask on to increase the flow of her oxygen. She was scared and having difficulty breathing which made it harder to get her to calmly breathe in the higher flow oxygen. By now the ICU physician on call was there and the NP was communicating what had happened with a clear lack of detail. My mom's O2 rose back into the 80s but she was still struggling and had to be intubated. It would be the last time she would be able to speak for two months.

In addition to observing what had happened directly to my mom, I also knew it was extremely rare for the insertion of an arterial line to trigger an intubation. I was angry and scared that my last interaction with my mom could be watching her writhing in pain. At the same time, my mom's O2 levels had been slowly dropping. It was likely in a day or two intubation would have been necessary regardless. So instead of expressing that anger with the intensity I felt, I was more matter of fact. I expressed that I thought it was poorly handled and even though we may have ended up in this state (intubating her), those actions had taken away a chance for the family to talk to my mom and help her understand what was going to happen.

I hoped that she would survive this crash and we were at the beginning - not the end- of her journey at the hospital. I needed this group to help her survive and get on the lung transplant list. My anger was less important.

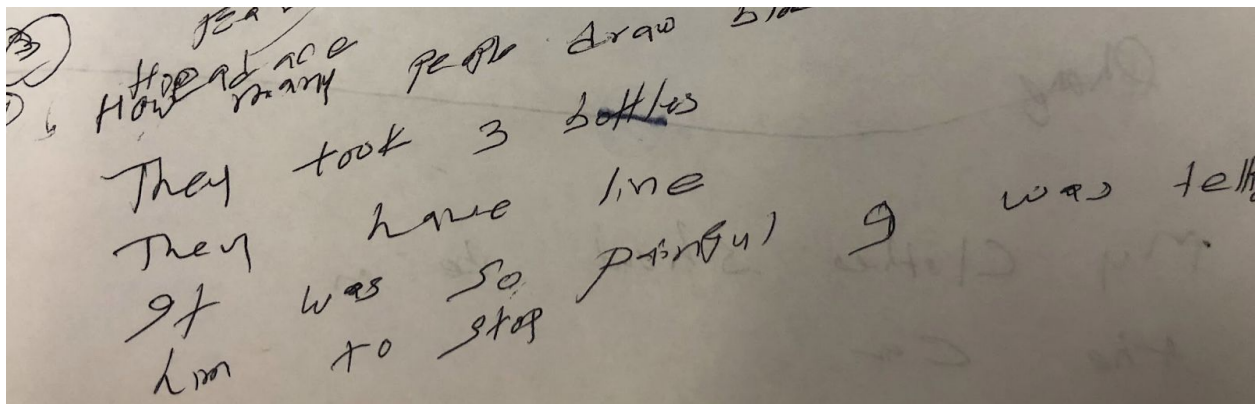
It is impossible for anyone to not be influenced at least subconsciously by their personal feelings. Disagreements with those caring for your loved one can occur, but significant conflict and especially directed anger towards those caring for them can result in worse care -- regardless of who is at fault.

Interpersonal Dynamics Matter

A hospital like any other workplace has organizational politics, and different opinions on who provides the best care. It has people who get along wonderfully and those that don't. You are a part of that dynamic and if you earn trust through your actions, your words and perspectives will gain credibility that can help your loved one and help you through the roller coaster of emotions. We experienced the ups and downs of this journey.

After my mom had been intubated (and later switched to tracheal intubation) she was going through testing so she could get onto the transplant list. She was unable to speak but was conscious and writing. One evening they were unexpectedly trying to change her arterial line and having trouble. She was in extreme pain and asked them to stop (in the future we proactively suggested the smallest needles, preemptively giving her pain meds or mild sedative and had no further problems related to line placements). My uncle, for whom English was a second language, expressed his displeasure and stated my mom wanted them to stop.

The next morning my mom communicated to the rounding doctor on call how unhappy she was with the process. The doctor listened and explained to her that blood draws were sometimes necessary but that at this point she did not even need the arterial line.



Later that afternoon one of the NPs said they needed to talk to me. As we entered the room, 2 nurse practitioners, two nurses, a social worker, charge nurse and doctor on call all squeezed in. I was physically cornered and petrified something had happened that made my mom ineligible for a transplant. As the doctor started speaking she communicated there had been some complaints about our family in the ICU. It took a few moments for me to shift out of my anxiety over her fate on the list. I reflexively apologized for anything we might have done and just kept saying how grateful we were to be at UCSF. As my head cleared I asked what we had done. The doctor on call reminded us that only two people could be in the ICU room and no one could be asleep in it. I immediately agreed, apologized and ensured her it would never happen again.

I asked if that was what led to us being in such a large meeting. After some jumbling on the rules being important, one nurse said we were asking a lot of questions. But then a nurse practitioner said of course questions were ok. Another nurse suggested that maybe, perhaps our being there so much was making my mom anxious - to which my mom vigorously objected.

I asked graciously for specific examples we could learn from and change our actions. As the doctor on call listened, she appeared to become more sympathetic to the lack of clarity amongst the nursing staff about what the problem actually was. She shifted the conversation to reinforcing it would be a long road and it was good to be clear, open and respectful to best get to what we all wanted (she was exceptional in her expertise and bedside manner amongst even a strong cohort of pulmonologists).

The incident from the evening before - which I believed triggered the meeting - never came up. Potentially because a subset of the group did not want those specifics discussed with my mom's primary care team. It's natural that no one wants to have folks constantly watch them doing their job, especially if they make errors due to skill or capacity. Since these deeper drivers will never be voiced aloud, second order concerns are raised. Regardless of the actual drivers, direct conflict is seldom effective in making your case or in helping your loved one receive the best possible care.

The nurses, NPs, doctors etc. work together but do not have a management relationship. Yet if a nurse complains about the family, it's likely the doctor who will lead the interaction with the family. With no other context they would naturally be expected to support the hospital staff -- whether or not the doctor was witness to what had occurred. Even when the care team presents in a unified manner, it's possible individuals have varying and even counter perspectives. It's important not to color the entire care team based on the actions of an individual.

Over the coming weeks we got to know the nurse practitioners, regular doctors and many of the nurses. Trust built based on how we interacted with them. Many weeks later (after the transplant), we had a charge nurse chastise a member of our family for not leaving the ICU when an emergency was occurring in an adjacent room despite the fact the room nurse had said to stay. Because the charge nurse referenced that we had been "spoken to before", we felt it important to immediately send a message clarifying what had happened with the nurse practitioner. The nurse practitioner replied -- before even speaking to us -- that the nurse's actions were not appropriate and that he would address the matter.

The difference in the two incidents were the level of trust that had developed between us and the NP over time. Once you are known (hopefully as calm, informed, well reasoned and respectful), the default dynamics of team and organization apply differently. You're a source of information for others on what is occurring when they are not present. So much of the care process is a game of telephone between shifts and roles that clear, accurate information is valued -- even if it comes from you.

Resolving Trust and Space Away From You

Ultimately, you have to trust the experts to make critical medical decisions for your loved one. If that trust is lacking in your situation, you might be able to find another expert you do trust on the care team or relocate to another hospital, although that could be difficult or impossible in many cases. Most of your questioning is to make sure all the right information was considered, the logic is sound, they are checking with the other experts they need to, etc. Even that, however, can be difficult to do and you will have to trust the care team.

Pre transplant there was a critical juncture where my mom's lungs were failing even with ventilator support and her right ventricle was enlarged. Her lungs were so fibrous it was hard for her ventricle to push the blood through them. At a certain point this could disqualify her from the transplant. To subsidize the function of her lungs they were going to put her on ECMO (ECMO is a device that oxygenates your blood and removes CO2 from it -- replacing/augmenting what your lungs do naturally). It is a significant procedure and not taken on lightly. They told us this would be needed but were adamant my mom could not handle the version of ECMO that was more significant, VA(that also took pressure off the ventricle), so they would do the other version, VV (in this version, the blood is returned to the venous system, so the right ventricle had to do the same amount of work). They explained this might not be enough, but was the best we could hope for. The procedure would be done near the end of the day.

I went home to tell the family, and we knew we were grasping at straws. When I returned a few hours later the pulmonologist said they had decided instead to do VA ECMO. He said the head of the department would discuss it with us and perform the procedure. When the department head arrived it was less of a conversation and more of her bluntly stating that VV might make us feel better for a few days but it would never get to the right outcome. She said that VA was the only real chance for being able to get a transplant but that it shortened her window for getting a lung to 24-36 hours. We signed the consent, the surgery worked and my mom received a lung transplant less than a day later.

Clearly there had been discussion without us there. Colleagues discussing bluntly the best course of action. Perhaps disagreement over the right course of action had even remained. Yet it's clear that our involvement in that would have not been helpful. It would have potentially led to a less direct and more filtered conversation. This was a medical judgement call and we were trusting that judgment. We were trusting the decision making process of a department and its leader that had the best transplant success rate in the country.

As a caregiver, you are an important part of a patient's journey but at some point there has to be separation and trust between you and your care team -- even when you want to be

involved and informed of everything that is happening. In high stakes decisions, that space and faith in your experts does not mean you will get that second chance at life, but it gives you the best chance. Most importantly, regardless of how it makes you feel, it is what is in the best interest of your loved one.

Closing Thoughts

As I relived our course through writing this document it's evident my perception of events and lessons is true...for me. It would have helped me to read such a guide before we began my mom's journey. It's equally clear that much is missing - insurance, the changes of life with survival, death, serious medical errors, and much more.

As a result, for certain people and circumstances the thoughts here could be the wrong path. Your family, your care team, your loved one, and your loved one's condition are all unique, and there are just too many variables for a single best approach. Yet I am certain that some subset of this truth will apply to every journey, and that hospitals generally do not do enough to support you in navigating that journey.

Whether it's because of capacity, real or perceived liability, the difficulty of change, skepticism on its importance, or other factors, the status quo in critical care does not invest in empowering patients or caregivers. I very much hope that changes and this guide is rendered obsolete. Until then, I hope its lessons and others provided through the comments section will help you walk through these difficult times. There is community even through this lonely journey.

Resources

It's not the care team's responsibility to provide you a crash course in medicine for all the details of your loved one's condition. They are responsible for conveying the concepts of the condition, but not conduct medical school classes. If you have a desire to go deeper, it's on you to pursue that knowledge. In doing that there are a few sources that I found most helpful.

- [A list of equipment and devices you might find in an ICU and their purpose](#) (Sunnybrook Health Sciences Centre).
- [Common equipment, devices and procedures in the ICU from a European perspective](#) (NHS Trust)
- [General guidance on navigating the ICU and a caregiver's role](#) (U.S. News & World Report)
- [ICU procedures and handbook from a resident's perspective](#) (University of Illinois, College of Medicine at Chicago).
- [Guidelines for family-centered care in the ICU](#) (Critical Care Medicine Journal)
- [Uptodate.com](#), a subscription-based site targeted to doctors and patients that provides in-depth articles, resources and graphics for point-of-care decisions (uptodate.com).

If you have access, physicians who have relevant expertise can be an extremely helpful resource. We were fortunate to have such a network and spent hours with them learning how things work, what was happening, and what could happen next. At certain stages, this proved invaluable as it gave us more time to process what was happening. They will be able to spend time with you on what might happen with detail most care settings don't allow time for. We did not attempt to use them to create another doctor for our mom, but to help us understanding what decisions were coming, how they might be evaluated, and what was routine vs. exceptional. It made us better and faster at providing consent to various procedures (which for both minor and major procedures cautioned of the risk of death).