

# The ICU Family Advocacy Playbook

*How to Partner with Your Loved One's Medical Team — A Structured Guide for Families*

## Why This Playbook Exists

Having a loved one in the ICU is one of the most disorienting experiences a family can face. The machines beep constantly, teams rotate every 12 hours, and medical jargon flies past at a pace no one prepared you for. But here's what the research consistently shows: **families who actively participate in ICU care improve patient outcomes.** Not by getting in the way — by partnering with the team.

Studies published in *Critical Care Medicine* demonstrate that structured family engagement reduces ICU delirium by up to 30%, shortens hospital stays, and decreases post-ICU PTSD — for both patients and family members. This playbook gives you the tools to be an effective advocate without overstepping clinical boundaries.

**How to Use This Guide:** Read through each section before your next ICU visit. Mark the checklists and templates that apply to your situation. Share this with other family members so everyone is on the same page — literally. The single biggest source of family-team friction is conflicting messages from different relatives.

## The ABCDEF Family Bundle: Your Role at the Bedside


The ABCDEF Bundle is an evidence-based framework used by ICU teams worldwide to improve outcomes. Each letter represents a clinical strategy — and each one has a family participation component that many hospitals underutilize.

Letter	Clinical Strategy	Your Family Role
A	Assess, prevent, and manage pain	Report pain cues: grimacing, restlessness, guarding. You know your loved one's baseline pain behaviors better than any nurse who met them yesterday.
B	Both spontaneous awakening & breathing trials	Be present during wake-up trials when possible. Familiar voices and faces reduce agitation during sedation lightening. Speak calmly; orient them to where they are and why.
C	Choice of analgesia and sedation	Share your loved one's history with medications, allergies, substance use. Include OTC supplements — they matter.

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<b>D</b>	Delirium assessment and management	You are the delirium early-warning system. See the delirium recognition checklist below.
<b>E</b>	Early mobility and exercise	Encourage and assist with physical therapy when the team clears it. Hold their hand during first chair transfers. Motivation from family is irreplaceable.
<b>F</b>	Family engagement and empowerment	That's this entire playbook. You're already doing it.

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 **Clinical Pearl:** The ABCDEF Bundle was developed by the Society of Critical Care Medicine's ICU Liberation initiative. When fully implemented with family participation, it's associated with lower mortality, more ventilator-free days, and less ICU-acquired delirium. Your involvement isn't optional kindness — it's therapeutic.

## How to Request and Prepare for Family Meetings

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Family meetings are structured conversations between the medical team and family about goals of care, treatment plans, and prognosis. They are not casual bedside chats — they are formal, documented discussions. You have the right to request one, and doing so is not confrontational.

### When to Request a Family Meeting

- Within 48–72 hours of ICU admission (if one hasn't been offered)
- When the treatment plan changes significantly
- When you don't understand the prognosis or goals of care
- When family members disagree about decisions
- Before any major procedure or surgery
- When transitioning from curative to comfort-focused care
- When your loved one has been in the ICU for more than 7 days without a clear trajectory

### How to Request One

**Script you can use:** "We'd like to schedule a family meeting with the attending physician. We have some questions about [the treatment plan / goals of care / what to expect next]. Could we set up a time when the attending and primary nurse can sit down with us for 20-30 minutes?"

### Pre-Meeting Preparation Checklist

- Designate one family spokesperson (reduces confusion and conflicting messages)
- Write down your top 3–5 questions in advance (you will forget them under stress)
- Bring a notebook or ask permission to record (many hospitals allow audio recording)
- Know the patient's advance directive status and healthcare proxy designation
- List the patient's values: What would they want? What would they consider unacceptable?
- Identify who needs to be present (either in person or by phone)

□ Ask: "What is the best realistic outcome? What is the worst realistic outcome?"

### **Key Questions to Ask in Every Family Meeting:**

1. "What is the current diagnosis, and has it changed since admission?"
2. "What is the treatment plan for the next 24–48 hours?"
3. "What are we hoping to see that would indicate improvement?"
4. "What would make you concerned that things are getting worse?"
5. "Are there decisions we need to make, and what are the options?"
6. "Who should I call if I have questions between meetings?"

## Daily Rounding Participation Guide


Morning rounds are when the ICU team reviews each patient's overnight course, lab results, imaging, and plan for the day. Increasingly, hospitals invite families to participate — and the evidence supports it. A 2019 study in *JAMA Internal Medicine* found that family presence during rounds improved understanding of the care plan by 40% and reduced anxiety scores significantly.

### How to Join Rounds

1. **Ask the charge nurse** what time rounds typically start (usually 8–10 AM)
2. **Arrive 15 minutes early** and let the bedside nurse know you'd like to participate
3. **Stand near but not in the way** — the team needs access to monitors, the patient, and each other
4. **Listen first, then ask questions** at the end of your loved one's presentation
5. **Take notes** — rounds move fast and use medical terminology

### What You'll Hear During Rounds

Rounds Element	What It Means	Your Opportunity
Overnight events	What happened since the team last rounded	Correct any inaccuracies about behaviors you witnessed
Vital sign trends	Heart rate, blood pressure, oxygen, temperature patterns	Ask what trend they're watching and what it means
Lab results	Blood work, cultures, imaging findings	Ask which results are most important for the plan
Ventilator settings	How much breathing support is being provided	Ask if settings are trending toward less support (good sign)
Medication changes	New drugs, dose adjustments, discontinuations	Report any reactions or changes you've noticed
Plan for the day	Procedures, tests, consultations, therapy goals	Ask how you can help with the plan (mobility, orientation)

 **Pro Tip:** Keep a small "family rounding notebook" at the bedside. Before rounds, jot down overnight observations: "Dad seemed more agitated around 2 AM," "She opened her eyes and tracked my voice at 6

PM," "He pulled at his lines twice overnight." These observations are clinically valuable — nurses chart what they see, but you're there during the hours between nursing assessments.

## Delirium Recognition Checklist for Families

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ICU delirium affects 50–80% of mechanically ventilated patients and up to 30% of non-ventilated ICU patients. It increases mortality, prolongs hospital stays, and causes long-term cognitive impairment. **Family members detect delirium earlier than clinical staff** because you know the patient's baseline personality and behavior.

**⚠ Critical:** Delirium is NOT the same as dementia. Delirium comes on suddenly (hours to days), fluctuates throughout the day, and is often reversible. If you notice these changes, tell the nurse immediately — don't wait for rounds.

### Signs to Watch For

#### 1 Acute change in mental status

- They don't seem like themselves — personality is different
- They're confused about where they are, what year it is, or who you are
- They're saying things that don't make sense or seeing things that aren't there
- The change happened suddenly (not gradually over weeks)

#### 2 Fluctuating consciousness

- They're alert and conversational one hour, then unresponsive the next
- They seem to "come and go" throughout the day
- Sleep-wake cycle is reversed (awake all night, sleeping all day)

#### 3 Inattention


- They can't follow a conversation or track what you're saying
- They're easily distracted by sounds, movement, or nothing visible
- They can't squeeze your hand on command consistently

#### 4 Behavioral changes

- Hyperactive:** Agitation, pulling at lines/tubes, trying to climb out of bed, combativeness
- Hypoactive:** Unusually quiet, withdrawn, flat affect, decreased movement (this type is MORE dangerous)

because it's often missed — "they're just tired")

- **Mixed:** Alternating between agitated and withdrawn periods

 **Clinical Pearl:** Hypoactive delirium (the quiet kind) is missed in up to 70% of cases by clinical staff. Families often describe it as "she's just not there" or "he seems checked out." If your loved one was previously engaged and responsive but now seems withdrawn and flat, that's a red flag — even if they're not agitated.

## What Families Can Do to Prevent and Manage Delirium

- **Reorient frequently:** "Mom, you're in the hospital. It's Tuesday afternoon. You had surgery on your hip. You're getting better."
- **Bring familiar objects:** Photos, a favorite blanket, their own pillow (ask the nurse first)
- **Maintain day/night cycles:** Open curtains during the day, dim lights at night, minimize nighttime disruptions
- **Provide cognitive stimulation:** Read to them, play their favorite music at low volume, discuss familiar topics
- **Encourage mobility:** When cleared by the team, help them sit up, stand, or walk
- **Ensure hearing aids and glasses are in place** — sensory deprivation worsens delirium dramatically
- **Advocate for sleep protection:** Ask the team to cluster nighttime care tasks and minimize unnecessary wake-ups

## Communication Templates for Coordinating Updates

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One of the most exhausting parts of having a loved one in the ICU is fielding calls, texts, and visits from concerned friends and family. This drains emotional energy you need for decision-making and bedside presence. Use these templates to streamline communication.

### Template 1: Designate a Communication Lead

#### **Text/Email to Extended Family:**

"Hi everyone — thank you for your love and support for [Patient Name]. To keep things organized and make sure everyone gets accurate information, [Spokesperson Name] will be sending daily updates. Please direct all questions to [him/her/them]. We're asking that calls and texts go to [Spokesperson] rather than the family members at the bedside, so they can focus on being present. We'll share updates by [time, e.g., 7 PM daily]. Thank you for understanding."

### Template 2: Daily Update Format

#### **Daily Update — [Date]**

**How [Patient Name] is doing today:** [1–2 sentence plain-language summary]

**What happened today:** [Tests, procedures, therapy sessions, any changes]

**What the team is watching:** [The key metric or concern]

**Next steps:** [What's planned for tomorrow]

**How the family is doing:** [Optional — people want to know about you too]

**What would help:** [Meals, pet care, specific errands — be concrete]

### Template 3: Visitor Coordination

**Visiting Guidelines for [Patient Name]:**


- ICU visiting hours: [check with the unit — many are now flexible/open]
- Maximum visitors at bedside: [usually 2 at a time]
- Please check in with [Family Contact] before coming — some days are better than others
- When visiting: speak calmly, avoid discussing the patient's condition in front of them as if they can't hear (they often can), keep visits to 15–20 minutes to avoid overstimulation
- Please don't bring: flowers (infection risk in ICU), food (dietary restrictions may apply), strong perfumes
- What to bring: cards, photos, a short playlist of their favorite music (on a phone with headphones)

## When to Call Patient Advocacy

Every hospital has a Patient Advocacy or Patient Relations department. They exist to mediate between families and clinical teams when communication breaks down. Calling them is not adversarial — it's a resource, like calling IT when your computer won't work.

### Situations That Warrant a Patient Advocacy Call

Situation	What to Say
You've requested a family meeting multiple times and it hasn't happened	"We've asked for a family meeting on [dates] and haven't been able to schedule one. Can you help facilitate this?"
You feel the team isn't addressing your concerns	"We've raised concerns about [specific issue] with the nursing staff and feel they haven't been adequately addressed. We'd like help escalating this."
You're receiving conflicting information from different team members	"We're getting different answers from different doctors about [specific topic]. We need clarity on the plan."
You feel your loved one's pain isn't being adequately managed	"We believe [Patient] is in pain that isn't being controlled. We've communicated this to nursing and would like the pain management team involved."
You feel cultural, religious, or language needs aren't being met	"We need [interpreter services / chaplain / cultural accommodation] and haven't been able to access them."
You want a second opinion and aren't sure how to request one	"We'd like to understand our options for a second opinion on [specific diagnosis/treatment plan]."

 **Pro Tip:** Document everything. Dates, times, who you spoke with, what was said. This isn't about building a legal case — it's about having accurate records when memory is unreliable under stress. A simple note in your phone after each significant conversation is enough.

## Post-ICU Transition Planning: The Critical 72-Hour Window

The transition out of the ICU is one of the highest-risk periods in a hospitalization. Patients move from 1:1 or 1:2 nursing ratios to 1:4 or 1:6. Monitoring decreases dramatically. The team changes completely. And families often feel abandoned after the intensive attention of the ICU.

## The 72-Hour Transition Checklist

### Before Leaving the ICU (Day 0)

- Ask: "What should we watch for that would mean they need to come back to the ICU?"
- Ask: "What medications changed, and what are the side effects we should know about?"
- Get the name and contact information of the floor team (attending, resident, primary nurse)
- Ask about the physical therapy and rehabilitation plan going forward
- Confirm that all ICU-initiated treatments (antibiotics, blood thinners, etc.) are continuing or intentionally stopped
- Ask if the patient needs any follow-up appointments already scheduled before discharge

### First 24 Hours on the Floor (Day 1)

- Introduce yourself to the floor nurse and confirm they received the ICU handoff
- Verify the medication list matches what was given in the ICU (medication reconciliation errors are common)
- Watch for signs of ICU delirium continuing or worsening (it doesn't stop at the ICU door)
- Ensure physical and occupational therapy sees the patient within 24 hours
- Monitor pain — the transition from IV to oral pain medications often undertreats

### Days 2–3 on the Floor

- Ask about the discharge plan: "When are we likely going home? What needs to happen first?"
- Discuss post-discharge needs: home health, rehabilitation facility, follow-up appointments

Request a case manager or social worker meeting to coordinate discharge services

Begin preparing the home environment: medication organizer, mobility aids, follow-up appointment schedule

Ask about Post-Intensive Care Syndrome (PICS) — cognitive, physical, and emotional recovery after ICU

**⚠ Post-Intensive Care Syndrome (PICS):** Up to 50% of ICU survivors experience lasting cognitive impairment, physical weakness, or PTSD symptoms. This also affects family members (PICS-Family). If your loved one — or you — are struggling weeks to months after discharge, this is a recognized medical condition, not "just stress." Ask for a referral to a PICS clinic or neuropsychological evaluation.

## Your Rights as an ICU Family Member

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You may not know these, and hospitals don't always volunteer them:

- **The right to information:** You can request and receive clear explanations of diagnosis, treatment, and prognosis in language you understand
- **The right to participate in care decisions:** If you are the designated healthcare proxy, you have legal authority to participate in medical decisions
- **The right to a second opinion:** You can request consultation from another specialist at any time
- **The right to an interpreter:** Hospitals that receive federal funding must provide language interpretation services
- **The right to access medical records:** You (or the healthcare proxy) can request copies of the medical chart
- **The right to refuse treatment:** On behalf of the patient, the healthcare proxy can decline recommended interventions
- **The right to pastoral/spiritual care:** Hospitals must accommodate religious and spiritual needs
- **The right to complain without retaliation:** Filing a concern with patient advocacy should never affect the quality of your loved one's care

## Self-Care for the ICU Family

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This section is not optional. Burned-out, sleep-deprived family members make worse decisions, communicate less effectively with the medical team, and are more likely to develop PTSD, depression, and complicated grief. Taking care of yourself is taking care of your loved one.

### The ICU Family Self-Care Minimum:

- **Sleep:** Get at least 5-6 hours per night. You cannot advocate effectively on 2 hours of waiting-room sleep.
- **Eat:** One real meal per day minimum. Hospital cafeterias count. Vending machines don't.
- **Leave:** Leave the hospital for at least 2 hours per day. The ICU will call you if something changes.
- **Talk:** Talk to someone outside the situation — friend, counselor, chaplain, support group. Processing out loud is not weakness.
- **Rotate:** If multiple family members are available, create a bedside schedule. 24/7 vigils are unsustainable and unnecessary.

**You're already doing the most important thing:** You're educating yourself, preparing to advocate, and showing up. That matters more than you know. Visit [icu-family-hospital-partnership.wedgekit.com](https://www.wedgekit.com/icu-family-hospital-partnership) for interactive tools, family meeting planning worksheets, and community support resources.

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