You Are Not Alone: Fighting for a Loved One on a Ventilator

Families' FAQ: “Why do I feel like I'm fighting alone?” | Quick tip for families in intensive care

A wife whose husband spent 16 days on a ventilator wrote that she felt very alone and as if she was fighting for him by herself, until she found support and a sense of comfort and safety. Her words echo what ICU families say almost every week. Here is what families in this situation need to know.

Q. Why do so many ICU families feel alone?

Sixteen days on a ventilator is sixteen days of ward rounds you may or may not attend, medical terminology you are hearing for the first time, and wondering whether you're being told the full picture. Families commonly say: *“I feel like I'm not getting the full story.” “I don't know what questions I'm even supposed to ask.” “Every doctor tells me something slightly different.” “I feel like I have to fight to be heard.” “I don't know if what's happening is normal or a red flag.”*

Q. Does that mean the ICU team is doing a bad job?

No. Most ICU doctors and nurses are skilled, dedicated professionals. But ICUs are high-pressure, fast-moving environments, and the system isn't designed to give families the time, the plain-English explanations or the second opinion they desperately need in the moment. **That gap is where families end up feeling they are “fighting alone.”**

Q. What is the single most important thing I can do?

Request access to your loved one's medical records. In Australia, as next of kin or person responsible, you are entitled to them. Records are the most reliable source of truth about what is actually happening, and they shift you from a frightened bystander to an informed advocate: you can re-read, cross-reference and return to the ICU team with specific, informed questions instead of relying on memory of a rushed hallway conversation.

Q. What do medical records actually show?

In black and white: **1.** the actual ventilator settings and how they have changed day to day; **2.** blood gas results and trends (is your loved one really improving, or just described as “stable”?); **3.** sedation levels and weaning attempts; **4.** nursing notes, which often hold detail that never makes it into a two-minute ward round; **5.** test results, imaging and specialist reviews; **6.** the reasoning behind decisions, not just the decisions themselves.

Q. How can a consulting call help?

On a consulting call with Patrik Hutzel or one of our experienced Critical Care Registered Nurses, we go through the records and the clinical picture with you in plain English before you speak with the ICU team. It helps you: **1.** understand what is written in the records and what it means clinically; **2.** identify whether the trajectory is improving, plateauing or concerning; **3.** prepare specific, pointed questions that are hard to brush aside; **4.** know what “normal” looks like at day 5, day 10 or day 16 on a ventilator, so you can tell a normal recovery curve from a stall that needs to be challenged; **5.** advocate with confidence. You don't need someone to take over: you need someone who understands the ICU from the inside and can translate it for you.

Q. What if the ventilator stay doesn't end in ICU?

Sixteen days on a ventilator often ends in extubation and recovery, but for some patients long-term ventilation becomes reality: invasive ventilation via tracheostomy, BiPAP/CPAP, or a tracheostomy that can't yet be weaned. Many families don't realise there is an option beyond an indefinite hospital stay. **Intensive Care at Home** provides 24/7 home nursing by experienced Critical Care Registered Nurses for invasive ventilation, BiPAP/CPAP, tracheostomy care and **palliative care at home** for those who wish to be cared for, and pass away, at home surrounded by family. It is Australia's only third-party accredited specialist home ICU nursing provider (ISO 9001:2015, NDIS registered, 150+ Critical Care Registered Nurses, all states and territories) and can help families in the USA, UK, Canada, India and elsewhere too.

Q. What is the bottom line?

You don't have to fight alone. Get access to the medical records, get an experienced second set of eyes on the clinical picture, ask pointed questions and advocate with confidence. If long-term ventilation becomes part of your story, home, not an indefinite hospital stay, can be a safe, accredited, predictable option.

Need independent expert advocacy? Intensive Care Hotline can help.
Patrik Hutzel brings 25 years of critical care nursing experience. We go through the medical records and clinical picture with you in plain English, before you go back to the ICU team. Book a **free 15-minute diagnostic consultation**.
Call +1 415-915-0090 (USA / Canada) | +61 3 8658 2138 (Australia / New Zealand) | +44 118 324 3018 (UK / Ireland)
Mobile 041 094 2230 (within Australia) or email via **info@intensivecareathome.com**
Book a free 15-minute appointment: http://intensivecarehotline.com/scheduling-appointment/ | **intensivecarehotline.com**

General information for families, not a substitute for advice from your loved one's treating medical team.