

## How to Advocate for a Loved One in the Hospital

1. **Demand effective treatment** for your loved one (inhaled budesonide using a nebulizer) from the hospital and doctors treating your loved one. Get an attorney if needed. (See sample Demand letter written by an attorney below). Assert your rights as a Stakeholder and assert your rights under the Federal [Right to Try](#) (see *NIH's COVID-19 Treatment Guidelines, page 217, regarding ongoing trials*). If they refuse, request an **ethics consultation with the hospital ethics committee** with a complaint of “failure of communication.”
2. **Prepare for Ethics Committee meeting.** Read the articles & studies on the [Validation page](#). Start with the evidence from Oxford showing inhaled Budesonide is 90% effective; the underlying science for the effectiveness is germane to explaining Budesonide’s effectiveness for your loved one’s current condition. If your loved one is on a ventilator, have the study that shows how Budesonide is highly effective at weaning people off the ventilator with ARDS (hint: if on a ventilator, your loved one is mostly coded by insurance with a secondary diagnosis of ARDS). Bring as many studies as necessary to ensure each participant has a copy. If it’s a Zoom meeting, ask for the email to send your studies.
3. **Bring a written Agenda** to the Ethics Committee meeting. Outline the articles you want to discuss and present in the order on your Agenda.
4. **Show up at meeting with a powerful presence.** Have copies of the studies printed out in a nice folder. Bring a lawyer if you have one. Dress professionally. Show them you mean business. Stand your ground; do NOT back down.
5. **Negotiate at Ethics Committee meeting.** Make your demands, show evidence and follow the Agenda. Demand a retest for COVID to determine whether your loved one has an active COVID infection. If objection that the hospital does not retest until after 21 days, ask the hospital whether they follow the same protocol for their employees. Most likely they accept two COVID negative tests and then allow the physicians and nurses to circulate among the hospital’s vulnerable patient population. Ask them how the hospital can reconcile this double standard? (Hint: they can’t.) A negative COVID test can reframe your options (i.e. ability to transfer, in-person visitation, and treatments for the inflammatory condition).
6. **Talk in their language:** Ethics Committees look at “Risks, benefits and reasonable options”. This is the same language as consent language. Remember that the physician cannot exaggerate the risks to circumvent your wishes. To do so in your presence is an automatic Medical Board complaint, Joint Commission/DNV complaint, and Department of Health complaint. Informed and truthful presentation of facts for consent is sacrosanct in medicine.
7. If they still refuse to give treatment, **decide which avenue to go** - fire/switch doctors, transfer your loved one to another facility that will properly treat, or bring your loved one home to continue treatment if not on a ventilator. If the patient is “end of life” per the hospital, and hospice is an option, demand Budesonide as hospice requires comfort measures and Budesonide will assist with inflammation and oxygen exchange for more comfort.

8. **Get out** – If loved one is not on a ventilator, make plans to check them out of the hospital. **Get prepared to treat from home.** Contact a [provider](#) to get prescribed meds & nebulizer sent to home. Ensure someone can help your loved one receive the proper level of care at home.
9. **Communicate with all levels of authority.** *Remember: the more eyes on your problem, the better.* CC all State Representatives, the Health Department, your Attorney General, and Hospital Medical Executive Committee as well as the Board of Trustees/Hospital District members. (Board members are especially important as they have the responsibility under the Accreditation Standards for Joint Commission/DNV for Hospital quality, including the medical staff's quality. Most Board members are public members without medical training. Remind them of their fiduciary duty to the public they serve.)
10. **Keep good records.** When possible, have more than one person listen to hospital communications. That includes every person you communicate with-- from housekeeper, to administrator, to nurse, to physician. Everyone. Keep good records and have a witness.
11. **In the end, you are the best advocate for your loved one.** You got this.