

the hospital. Often the hospital will send a “chaplain” versus a priest for the “Catholic” patient even when the patient/family requests a “priest”. In addition, they may claim “there is no one available at this time.” When all else fails, at the very least, you can call the local Catholic Church.

When you may need an attorney

When family members are concerned that a hospital or health care provider is not providing the level of care they believe their loved one needs, the first impulse may be to enlist the help of an attorney. While it can be helpful to discuss the situation with an experienced lawyer, it is not always advisable to rush into litigation. Once an attorney engages with the hospital, subsequent communications are often transmitted between attorneys, rather than directly between the medical team and the patient’s family or loved one(s).

Many health care issues can be resolved without resorting to hiring an attorney. For example, concerns involving visitation restrictions, including visits from a member of the clergy, are often best handled by a skilled patient advocate or support person who can negotiate with the hospital. However, there are circumstances where an attorney may be needed to ensure the continued provision of life-sustaining care.

Following are situations where an attorney should be consulted immediately:

1. The patient executed an advance health care directive such as a durable power of attorney (POA), living trust, or Physician’s Order for Life-Sustaining Treatment (POLST/MOLST) and the hospital refuses to recognize the named decision-maker or follow the patient’s health care instructions.
2. The medical team states that continuing care and treatment is futile or no longer beneficial.
3. The medical team states that they believe the patient may be brain dead and/or wants to perform brain death exams, including an apnea test.
4. The hospital has scheduled an ethics committee meeting or family meeting to discuss the withdrawal of care.
5. The hospital is threatening to imminently withdraw life-sustaining care such as nutrition and hydration and/or mechanical ventilation.

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EFFECTIVELY NAVIGATING HOSPITALS WHEN ADVOCATING FOR A LOVED ONE



General Principles

This document sets forth general principles and attempts to help people advocate for themselves and their loved ones. Patients and their families are in the best position to determine to what degree this advice pertains to them and can assist them in advocating for their loved ones. What is contained in this document is not legal or medical advice, but simply educational material to help you advocate for yourself or a loved one. With Christ, all things are possible (St. Matthew 19:26).

Giving excellent care to patients in the hospital should be a top priority for every healthcare professional. This is the goal for most professionals in healthcare. Nonetheless, the reality in most hospitals is lack of staff, overworked and often frustrated professionals, and an increasingly complex patient population.

Patients and families may respond, “That’s not my problem. You need to give the best care.” This response is incorrect. It is true that the best care should be given. It is also true that my loved one is the most important person to me. Yet, there is a bigger context. Healthcare professionals who are being overly taxed trying to provide good care to increasing numbers of sick patients is the problem of all of us, and we have no choice but to cooperate in charity given the reality we face, and not the situation we want. This context is important when advocating for loved ones.

1. **Act and speak with kindness.**
2. **Assume the best about people.**
3. **Be self-aware. How are my actions, tone of voice, and words being received by others?**
4. **Be judicious about requests. Repeated demands and impatience take precious time from healthcare professionals and put other patients at risk.**
5. **Find the good wherever you can and identify and compliment it. This is not only an act of charity, but it also wins people over! People well-disposed to you are more responsive.**
6. **Ask someone who has a gift for advocacy (for example, a friend or another family member) for help if conflict and advocacy are too stressful or otherwise emotional.**
7. **Seek the support of loved ones, a chaplain, or one’s own minister/priest.**
8. **Be prepared with clear details and written talking points regarding your need or your loved one’s need.**
9. **Consider keeping a log of conversations and details relevant to your care or the care of the person you are advocating for.**
10. **Consider having a doctor that you trust speak on your behalf.**

The Need for Navigating the Hospital System

There are serious issues that arise in the care of a loved one. These may include:

1. **Not getting needed answers from the medical team (lack of communication).**
2. **Deteriorating/new health concerns that do not seem to be getting addressed.**
3. **Treatments and directions of care being taken without communication with, and even without the consent of, the patient or responsible person(s).**
4. **Seeming neglect or denial of patient care, such as regarding medical futility issues, pressure from providers to remove life support, refusing to provide nutrition and hydration, over sedation, etc.**
5. **The dismissal of family or patient concerns.**

Understanding the “Chain of Command”

The most effective and respectful way to get results in a hospital is to properly navigate the chain of command. Following is a list of persons and their roles according to the order they should be approached with your issues. Generally, one only proceeds to the next level if there are no results at the current level, but sometimes it is necessary to work outside the chain of command if a loved one is in imminent danger or there are just reasons for doing so. This chain of command applies to any important issue.

1. **Staff Nurse.** The patient’s nurse is always the first person with whom to seek resolution for all patient care needs. Be patient. Ask/remind more than once, if necessary. Ask, “How long might it take [to get an answer, etc.].?” Ask, “Is there someone it would be best to speak with about this issue?”
2. **Charge Nurse.** Most units have a nurse who supervises the unit, who may also have a patient assignment. Only move to this level if the Staff Nurse is unable or unwilling to seek resolution. If there is no resolution here, ask, “Would the Nurse Manager or Director be the next person I should speak with?” Your issue might be resolved with that question.
3. **Unit Nurse Manager/Director.** Nursing Managers and Directors are often eager to resolve patient and family issues. If not, or if there is no resolution, ask, “Who would be the next person I should speak with to find resolution to this issue?”
4. **House Manager/Nursing Supervisor.** If the issue is urgent and after hours (when Unit Managers/Directors are not working), ask for the House Manager/Nursing Supervisor to be paged.
5. **Administrator On Call.** If the matter is urgent, after hours, and there is no resolution at the House Supervisor level, request the Administrator On Call be paged.
6. **Patient Advocate.** Every hospital must have a Patient Advocate whose sole duty is to advocate for patients and assist in resolving issues that arise between patients, family, and staff/the medical team. The Patient Advocate often works under the supervision of the Risk Manager, who helps keep the hospital in line with regulations and navigates potential legal issues.

7. **Chief Nursing Officer/Executive.** If there is no resolution at the unit director level, it is time to request a conversation with the CNO/CNE of the hospital. The CNO/CNE oversees all nursing and patient care issues. She/he is a member of the executive team and has regular conversations with the CEO and other executives.
8. **Chief Medical Officer.** The CMO is another option, particularly if one’s issue primarily involves the medical team. Nonetheless, a conversation with the CNE is also still advisable at this level.
9. **Director/Vice President of Mission.** If one is in a Catholic hospital and there has been no resolution at any level thus far, ask the Staff Nurse (or call the switchboard) and request to see the Director of Mission. He or she is part of the executive team and is responsible for assuring that the overall Catholic mission and ethics of the hospital are being followed.
10. **Chief Executive Officer (CEO).** This would be the last resort internally before going outside the facility.
11. **Outside Advocacy.** If none of the above achieves resolution, it may be time to seek outside advocacy help [Healthcare Advocacy & Leadership Organization (HALO), Terri Schiavo Life and Hope Network, Life Legal Foundation, Christ Medicus Foundation, and NCBC Ethics Consults are all resources].
12. **Legal Counsel.** It is advisable to seek an attorney as a last resort for grave matters when a loved one is hospitalized. If all other avenues have achieved no results and the matter is grave, this may be the only option left (see back page, *When you may need an attorney*).
13. **Local Elected Official.** In urgent and grave situations that involve issues of neglect and/or possible regulatory violations and when the chain of command has failed, one’s local state elected official may be helpful.
14. **Federal Representative.** If the patient is on Medicaid, Medicare or TriCare, or if the patient receives VA benefits, a constituent services representative from a Member of Congress or Senator’s office may be able to assist.
15. **JCAHO (Joint Commission for the Accreditation of Healthcare Organizations).** If the patient care issue is a grave matter that seems to involve neglect, malpractice, or a serious hazard to one’s loved one, a complaint can be filed online with the Joint Commission [<https://www.jointcommission.org/>].

Spiritual care denial to a patient or staff suggesting to the patient or family member that none is available due to off shift hours

- ◆ This is a consistent standard which applies to facilities accepting federal funds: “Facilities must ensure patients have adequate and lawful access to chaplains or clergy in conformance with the Religious Freedom Restoration Act and Religious Land Use and Institutionalized Persons Act” (Center for Clinical Standards and Quality/Quality, Safety & Oversight Group Ref: QSO-20- 13,(QSO-20-13-Hospitals-CAHs REVISED (cms.gov)).
- ◆ Suggest the patient/ family member might contact their parish priest to visit their family member while in