

The Deadly Failure of a Hospital to Follow a Patient's Decisions about his Medical Care

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HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 4/1/2011)

EMSA
EMERGENCY MEDICAL SERVICES AUTHORITY
CALIFORNIA

First follow these orders, then contact physician. This is a Physician Order Sheet based on the person's current medical condition and wishes. Any section not completed implies full treatment for that section. A copy of the signed POLST form is legal and valid. POLST complements an Advance Directive and is not intended to replace that document. Everyone shall be treated with dignity and respect.

Patient Last Name: _____ Date Form Prepared: _____
 Patient First Name: _____ Patient Date of Birth: _____
 Patient Middle Name: _____ Medical Record #: (optional) _____

A CARDIOPULMONARY RESUSCITATION (CPR): *If person has no pulse and is not breathing. When NOT in cardiopulmonary arrest, follow orders in Sections B and C.*

Attempt Resuscitation/CPR (Selecting CPR in Section A requires selecting Full Treatment in Section B)
 Do Not Attempt Resuscitation/DNR (Allow Natural Death)

B MEDICAL INTERVENTIONS: *If person has pulse and/or is breathing.*

Comfort Measures Only Relieve pain and suffering through the use of medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. *Transfer to hospital only if comfort needs cannot be met in current location.*

Limited Additional Interventions In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

Full Treatment In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/ cardioversion as indicated. *Transfer to hospital if indicated. Includes intensive care.*

Additional Orders: _____

C ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible and desired.*

No artificial means of nutrition, including feeding tubes.
 Trial period of artificial nutrition, including feeding tubes.
 Long-term artificial nutrition, including feeding tubes.

Additional Orders: _____

D INFORMATION AND SIGNATURES:

Discussed with: _____ available and reviewed →
 Patient (Patient Has Capacity) Legally Recognized Decisionmaker
 Health Care Agent if named in Advance Directive:
 Name: _____
 Phone: _____

Advance Directive dated _____
 Date signed: _____
 Date available: _____
 Physician License Number: _____

Introduction

California law has long recognized a competent adult's right to make decisions about his/her health care. This includes consenting to and refusing medical treatment, including life-sustaining treatment. This advisory describes a hospital and its medical staff which ignored a patient's well-documented end of life treatment wishes and, when he lapsed into unconsciousness, decided to terminate his life-sustaining treatment, resulting in his untimely death.

Although the hospital and medical staff took this grave course after some thoughtful deliberation, no one who was independent from the hospital or the medical staff and who knew the patient participated in the deliberations – no family member, no close personal friend, no one from the nursing facility which he had called home for years, no disability rights advocate or representative from the disability community. Such decisions deserve the careful consideration of people knowledgeable about the individual's wishes and designated as a surrogate decision maker in addition to the facility or the medical staff. If no such individual is available, court oversight must be sought.

Case Study

Mark Turner¹ was slowly dying. He had end stage renal disease and was living in a nursing home, without any contact with his family and with no close personal friends.² He had moved to California years ago from the south, cutting all ties to his family. Eventually, the staff at the nursing home and the health care providers with whom he relied became his only personal relationships.

Mr. Turner's renal functioning was inadequate. He went several times a week from the nursing home to get dialysis at an outpatient dialysis

¹ Pseudonyms have been used for the names of all individuals contained in this report.

² The records show that Mr. Turner was also diagnosed with schizoaffective disorder for which he was medically treated. This condition did not impair his capacity to make medical decisions.

program. But he wasn't ready to give up. He wanted to live. He and his doctors talked about his prognosis and what he wanted to have happen in the event of the inevitable health crisis. He told them he wanted to live.

Mr. Turner gave his physicians clear written instructions that, should he go into cardiac arrest and require life-sustaining treatment, he wanted all possible life saving measures. In the event of a cardiac arrest, he wanted full resuscitation and full treatment of medical interventions, including intubation, advanced airway support, mechanical ventilation, and defibrillation. In the fall of 2010, he memorialized these instructions on a POLST (physician orders for life-sustaining treatment) form. Mr. Turner executed identical POLSTs with the two physicians involved in his care: Dr. Castro³, the physician overseeing his care at the nursing home, and Dr. Roper, his nephrologist.

At the time the POLSTs were completed, Mr. Turner was lucid and capable of making medical decisions. The physician signature on the POLSTs indicates that, at the time executed, the individual has capacity for health care decision making and that the instructions given are consistent with the individual's medical preferences. In later months, Mr. Turner would have periods of confusion because of toxins accumulating in his body between dialysis treatments. But, at the time he gave these instructions, the nursing home records show that Mr. Turner was clear-headed and understood the decisions that he was making. And the physicians' signatures on his POLSTs confirms this.

On February 2nd, Mr. Turner was sent from the outpatient dialysis unit to the hospital yet again, because his blood pressure had dropped to dangerous levels. He was admitted to the local hospital, part of a large system of Catholic hospitals in Northern California. The admitting physician ordered a "full code" should Mr. Turner run into difficulties. For five days, Mr. Turner's mental condition fluctuated. The medical record shows that, at times, he was "alert" and "responding to questions." However, medical staff at the hospital reported later to Disability Rights California that Mr.

³ Pseudonyms have been used for the names of all individuals contained in this report.

Turner was often incoherent and lacked capacity to give or withhold consent.

WITHOLDING & WITHDRAWING LIFE-SUSTAINING TREATMENT

The California Hospital Association (CHA) provides guidelines and a model policy regarding a process for making treatment decisions on behalf of patients who lack capacity and for whom there is no surrogate decision maker. The guidelines state:

If it is determined that the patient has expressed a desire to have life sustaining measures applied under all conditions, an order to withhold or withdraw life sustaining treatment should not be issued unless authorized by a court. (Emphasis added).

The CHA provides a model policy for “unrepresented patients” and cautions that it is applicable in guiding medical treatment decisions where there is no clear knowledge of an unrepresented patient’s specific treatment preferences and when “there is no individual health care directive or instruction in the patient’s medical record....” The policy again reminds facilities about the option to seek judicial remedies, including a court order authorizing withdrawing or withholding treatment.

The hospital treating Mr. Turner adopted the CHA’s unrepresented patient policy with a few minor revisions that are not relevant to Mr. Turner’s situation (mostly involving decisions regarding treatment of minors). Based on this policy, it was inappropriate to refer Mr. Turner’s case to this committee as he had clearly documented his treatment preferences.

Dr. Roper requested that a physician from the Palliative Care team consult on Mr. Turner’s case. This physician noted that Mr. Turner’s “schizoaffective disorder” made it difficult to obtain his goals and treatment decisions. She concluded that, on the day of her consult, he did not have the capacity for medical decision making. She noted that Dr. Roper had informed her that, in private conversations he had with Mr. Turner, Mr. Turner said that he did not want to continue treatment if there was no chance of recovery. She noted, however, that there was no evidence of this decision in his medical record.

Mr. Turner's case was then referred to the Unassigned Patient Committee, a subcommittee of the hospital Ethics Committee. This committee was established to guide medical decisions for patients who lack capacity to make health care decisions, who have not provided instructions about what care they wish to receive, and for whom there is no identified or available surrogate decision maker. Referral of Mr. Turner's case to this committee was inappropriate because he had given clear instructions about what care he wished to receive.⁴ Nonetheless, the Unassigned Patient Committee discussed his case and decided that dialysis was futile and that the risk of further dialysis outweighed the benefit. The committee's unanimous decision was to stop dialysis. Without dialysis, Mr. Turner would die.

The legal representative of an incompetent patient may exercise the right to withhold life-sustaining treatment. *Conservatorship of Drabick*, 200 Cal.App.3d 185 (1988). Such decisions by the patient's legal representative must be guided first by his knowledge of the patient's own desires and feelings. *Barber v. Superior Court*, 147 Cal.App.3d 1006 (1983).

No one sought appointment or was appointed to act as Mr. Turner's legal representative. The decision to terminate dialysis was wholly inconsistent with Mr. Turner's desire and feelings as recorded on the POLST. Mr. Turner's POLSTs directed full resuscitative efforts and full treatment.

Dr. Roper told the Ethics Committee members that Mr. Turner wanted "everything done unless there is no chance of any meaningful recovery." There is no evidence supporting this statement or to show that Mr. Turner expressed anything other than what he had repeatedly said about wanting full treatment. There is no evidence that the committee ask for evidence supporting Dr. Roper's assertion.

On February 7th, the committee voted to disregard the POLSTs executed by Mr. Turner and drafted a new POLST which ordered comfort measures

⁴ A year earlier when hospitalized, Mr. Turner's case was referred to the same committee. Hospital records show that, before the committee could act, Mr. Turner's condition improved and he reiterated his instructions for full treatment.

only in lieu of full medical treatment and ordered “Do Not Resuscitate” in the event of the inevitable cardiac arrest. Notes in the record indicate that the hospital discussed petitioning the court to appoint a conservator but did not proceed with that plan. A referral was made to the local hospice program who advised that, “[Mr. Turner] needs to be conserved” in order to be accepted into the program.⁵ The hospital explored transferring Mr. Turner back to his nursing home for hospice care but the nursing home refused to accept him without proper consent.

⁵ Hospice requires a patient’s informed consent (or that of the patient’s legal representative) before being accepted into their program.

POLST

A Physician Orders for Life-Sustaining Treatment (POLST) are physician's orders for what an individual has expressed he/she wishes regarding life-sustaining medical treatment and end-of-life care. In particular, it specifies the individual's desire to have or refuse cardiopulmonary resuscitation (CPR) and the degree of life sustaining medical intervention and nutritional support desired. A POLST accompanies the individual to whatever setting s/he is receiving care, including in his/her own home, in a nursing facility or long term care facility, or in the hospital. Health care providers are required to treat an individual in accordance with the POLST.

The POLST is completed after an individual's physician has explained to the individual the range of medical interventions and procedures detailed on the form. At the time the POLST is completed, the individual must have legal capacity, meaning the present cognitive ability to understand the treatment options and to make an informed choice about what care s/he wishes to receive. The POLST must be signed by the individual (or his/her legal healthcare decision maker) and a physician, certifying that the decisions noted on the form are consistent with the individual's medical condition and preferences.

POLSTs are documented on a statewide, standard form, printed on bright pink paper so that it is easily found amongst the individual's records or belongings. The form becomes a set of medical orders that moves with the individual where s/he goes and must be honored across all settings, including paramedics responding to an individual's home, in a nursing home, in a long-term care facility, and in a hospital.

At any time, the individual with capacity may request alternative treatment to that which is documented on the POLST. Similarly, the individual may revoke a previously executed POLST at any time and in any manner that communicates his/her intent to revoke. A physician may modify an existing POLST or issue a new POLST based on the individual's health and goals for care but only after consulting with the individual or the individual's legally recognized health care decision maker. California law governing POLSTs is found at Section 4780 et. seq of the Probate Code.

So, when the hospital was unable to find a legal representative to sign a new POLST and unwilling to proceed with a court process to have one appointed, a physician at the hospital signed the POLST as Mr. Turner's representative. This POLST was expressly contrary to every election Mr. Turner had previously expressed. It ordered no resuscitation (i.e. DNR) allowing "natural death, comfort measures only, and no nutritional support.

Mr. Turner died several days later, alone.

Advocates in the community filed a complaint with the Department of Public Health, Licensing and Certification Division (Department) alleging that the hospital neglected to provide medical interventions consistent with Mr. Turner's POLST and that he was denied the right to make medical decisions. Although the Department substantiated the complaint, they found that the facility, "did not violate any State and/or Federal laws or regulations." Ultimately, the Department took no action against the hospital. Surveyor notes indicate that she reviewed regulations pertaining to patients' rights⁶ but, ultimately, the hospital's conduct did not violate these regulatory provisions.

The hospital and medical staff claim that they were doing what Mr. Turner wanted based on representations by Dr. Roper. However, they acknowledged that there was no evidence supporting Dr. Roper's claim, no notations in Mr. Turner's medical records, and no witnesses who overheard the statement that Mr. Turner wanted anything other than all medical interventions necessary to live.

Findings

1. The decision of the medical staff directly caused Mr. Turner's premature death.

Although Mr. Turner's medical condition was inevitably terminal, the decision to terminate dialysis hastened his death. The directives in the hospital executed POLST ensured that, when Mr. Turner's cardiopulmonary system collapsed, he would not be resuscitated and would die. The combination of terminating dialysis and not performing CPR

⁶ Cal. Code of Reg., Title 22, § 70707.

dramatically hastened his death. These decisions by the medical staff were precisely contrary to Mr. Turner's clearly documented directives and directly caused Mr. Turner's death.

2. There is no evidence that Mr. Turner wished to forego life sustaining treatment or that he revoked or revised his decisions regarding end-of-life care, as documented on his POLST.

Mr. Turner was clearly aware of the chronic nature of his condition. In the year preceding his death, he was hospitalized several times and received dialysis several times a week. Mr. Turner was knowledgeable about how to memorialize his treatment decisions and his end-of-life wishes. He had executed two POLSTs in the months preceding his death which specified his consistent desire for complete medical care and life-sustaining treatment.

California law gives every legally competent adult the right to refuse medical care, including life-sustaining treatment. Physicians are required to inform a patient about the risks of refusing medical care. *Truman v. Thomas*, 27 Cal.3d 285 (1980). It is advisable and standard medical practice to document a patient's refusal in the medical record. The California Hospital Association (CHA) further recommends that a patient's refusal of medical care also be documented on an incident report or notification form and include a description of the nature of the patient's refusal, the fact that the physician discussed with the patient information about the consequences of refusing the medical treatment, and the fact that the patient still decided to refuse.

There is no evidence that Dr. Roper provided Mr. Turner with the necessary information to give an informed refusal, as required. Furthermore, there is no evidence that Mr. Turner expressed his desire to terminate dialysis if "it was futile," as subsequently claimed by Dr. Roper. At best, it is remarkably poor medical practice for a physician to not document Mr. Turner's informed refusal, a monumental change in Mr. Turner's decisions about his end of life care. At worst, it is an unreliable statement that was wholly inconsistent with Mr. Turner's actual desires – an unsupported exercise of medical decision-making by a physician.

Although a competent individual may revise or revoke a previously executed POLST at any time and in any manner, including orally, such

decisions should be clearly documented. The medical staff at the hospital claimed that it is too burdensome for physicians to assist a patient in executing a revised POLST. However, given the importance of such documentation and the simple check-box format of the standard POLST form, this claim seems overstated. Nonetheless, some notation is minimally necessary to evidence the patient's decisions. There is no evidence that Mr. Turner revised or revoked his POLST.

3. The medical staff had no authority to discontinue Mr. Turner's dialysis.

The decision to discontinue Mr. Turner's dialysis was terminal. Without dialysis, Mr. Turner died within a matter of days. The hospital and medical staff had a duty to carry out Mr. Turner's expressed wishes and lacked the authority to contradict them. No such decision should have been made without seeking court review or court appointment of a legal representative to act on Mr. Turner's behalf.

The facility's referral of Mr. Turner's case to the hospital's Unrepresented Patient Committee was inappropriate. According to the facility's policy, endorsed by the CHA, this committee's review of cases is limited to situations in which the patient has not provided his/her treatment preferences. Mr. Turner had clearly expressed his treatment decisions. Therefore, review by this committee was improper.

The committee relied entirely upon the statements of Dr. Roper. There is no evidence that they attempted to reach out to others who might be familiar with Mr. Turner's wishes, including staff and his primary physician at the nursing home where he had resided for years.

4. Medical staff lacked the authority to execute a new POLST on Mr. Turner's behalf.

A POLST is physician's orders implementing a patient's instructions regarding end of life care. The POLST form requires signature by the patient or his/her legally recognized decision maker. The physician's signature on the POLST acknowledges that the orders are consistent with the patient's preferences.

The final POLST in Mr. Turner's case was signed by a physician specialized in treating hospital patients (i.e. hospitalist). This physician had

no legal authority to execute a POLST on behalf of Mr. Turner, regardless of decisions by the Unrepresented Patient and Ethics committees to terminate Mr. Turner's treatment and trigger his death.

5. The Department of Public Health failed to find that the hospital violated any law or regulation despite their determination that the facility violated Mr. Turner's right to make medical and end of life care decisions.

The Department of Public Health (Department) conducted an investigation into a complaint, filed by a patient advocate that the hospital neglected to provide medical interventions consistent with Mr. Turner's POLST and violated his right to make medical decisions, thereby denying his right and expressed desire to live. The Department "substantiated" the complaint, but, remarkable, found that the hospital had not violated any State or Federal law or regulation. Surveyor notes indicate review of state regulations pertaining to hospital patients' rights, including the right to give informed consent. There is no indication that the surveyor reviewed State law that clearly grants every competent adult the right to make health care decisions, including affirmative end-of-life decisions. This is most concerning in a case where this patients' rights violation was the direct cause of the patient's death.

Recommendations

1. Medical staff should document a patient's refusal of medical care and any changes an individual makes to an election in his/her POLST.

The decision to withhold life-sustaining medical care is weighty. California law, while acknowledging a patient's right to make such decisions, requires the physician to fully inform the patient (or his/her legal representative) about the risks and consequences. To ensure a patient has been provided with necessary medical information and has, in fact, refused medical care, such decisions must be documented. Disability Rights California recommends that physicians document both the information they provided to patients about the consequences of foregoing treatment and a patient's informed refusal in a patient's medical record and on an incident report or notification form, as advised by the California Hospital Association.

Similarly, medical staff should document an individual's revisions to or revocation of a previously executed POLST. Disability Rights California recommends that physicians urge patients to memorialize any subsequent revisions on a POLST form. Given the importance of such documentation and the simple check-box format of the standard POLST form, this format is the simplest means by which to clearly document the patient's revised end-of-life treatment decisions.

2. A health care facility should seek court approval or appointment of a legal representative before foregoing life-sustaining treatment of a patient who lacks capacity when there are questions regarding his/her end of life decisions and no designated representative.

Disability Rights California recommends that hospitals seek authorization from a court before withholding or withdrawing life sustaining treatment when a patient lacks capacity, does not have a legal representative and there are questions regarding his/her end of life decisions, most specifically regarding life-sustaining treatment. This may involve petitioning the court to appoint a conservator or designee to make health care decisions on behalf of the individual.⁷ Such decisions by the patient's legal representative must be guided first by his knowledge of the patient's own desires and feelings. Similarly, health care facilities may petition a court for an order authorizing (or withholding) health care for a patient who lacks capacity, taking into account the patient's best interest and personal values.⁸ Seeking court involvement ensures objectivity in the decision making and independence from the health care providers involved who may have interests or motives in conflict with the unrepresented individual.

3. Hospital ethics committees should have at least one member for the disability community who is independent of the hospital and/or medical staff.

For decades, people with disabilities have been excluded from society and their input and ideas marginalized. The medical model of health care treatment and our paternalistic society has created a closed system in

⁷ Probate Code §3201(b).

⁸ Probate Code §3208

which the voice of people with disabilities regarding their care and treatment is heard in whispers, if at all. Passage of the Americans with Disabilities Act marked the beginning of moving away from the medical model that reviews individuals with disabilities as needing to have their impairments “fixed” to the social model of disability that views disability as a natural and normal part of the human experience. With recent advances in assistive and medical technology, people with even the most significant disabilities live longer and have productive, quality lives of their choosing.

Disability Rights California recommends that all hospital ethics and unrepresented patient committees include at least one member with a disability from the local community (independent from the hospital and medical staff) who can provide input into committee discussions from the civil rights perspective regarding the experience of people with disabilities. What the health care providers may deem to be in the best interest of the individual with a disability may conflict with the expressed interest of that individual. Including a person with a disability on hospital and medical staff committees that review controversial treatment decisions not only brings the perspective of the disability community to these discussions but immeasurably enhances the committees’ awareness and recognition of the social experience of people with disabilities.

4. The Department of Public Health must enforce a patient’s right medical and end-of-life decisions.

California law clearly grants every competent adult the right to make health care decisions, including the right of every patient to make medical and end-of-life decisions. State regulations grant patients the right to “participate actively in decisions regarding medical care...”⁹ Remarkable, the Department did not find that this regulation extended to the right that a patient’s medical decisions are honored by the hospital or medical staff providing care and treatment.

The Department must ensure that a competent patient’s informed decisions regarding his/her health care are respected and carried out as directed by the patient. Disability Rights California recommends that the Department

⁹ Cal. Code of Regs., tit. 22, § 70707(b)(5).

review regulations pertaining to a patient's right to make health care decisions to ensure that they are consistent with State law. If current regulations do not ensure this right, the Department must adopt regulations that expressly address this most basic patient right.