MAKING DECISIONS FOR INCAPACITATED PATIENTS:

The Role of the Court, Hospitals, Guardians & Conservators

Ventura County Bar Association
Estate Planning & Probate Section

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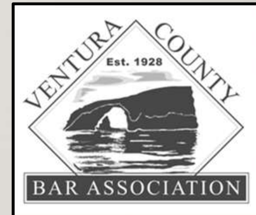

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"EVERY HUMAN BEING OF ADULT YEARS AND OF SOUND MIND HAS A RIGHT TO DETERMINE WHAT SHALL BE DONE WITH HIS BODY."

JUSTICE BENJAMIN CARDOZA
SCHLOENDORFF V. SOCIETY OF NY HOSPITAL (1914)

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"ANGLO-AMERICAN LAW STARTS WITH THE PREMISE OF THOROUGHGOING SELF-DETERMINATION. IT FOLLOWS THAT EACH MAN IS CONSIDERED TO BE MASTER OF HIS OWN BODY, AND MAY, IF HE IS OF SOUND MIND, PROHIBIT THE PERFORMANCE OF LIFE-SAVING SURGERY OR OTHER MEDICAL TREATMENTS."

KANSAS SUPREME COURT
NATANSON V. KLINE (1968)

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"PATIENTS WITHOUT DECISION-MAKING CAPACITY HAVE THE SAME RIGHTS CONCERNING LIFE-SUSTAINING TREATMENT DECISIONS AS MENTALLY COMPETENT PATIENTS."

AMERICAN COLLEGE OF PHYSICIANS ETHICS MANUAL, 7TH EDITION, 2019

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CASE 1 (2023)

JADA TRAUMA 1
UNIDENTIFIED FEMALE (AGE EST.40) INVOLVED IN A PEDESTRIAN V. AUTO ACCIDENT (APPROX.45 MPH).

ER PRESENTATION: CARDIAC ARREST, COMA MULTIPLE BLOOD CLOTS IN BRAIN, UNSTABLE C1 NECK FRACTURE, RIB FRACTURES, BLADDER AND DIAPHRAGM RUPTURE, INJURY TO NECK ARTERIES AND HEMORRHAGIC SHOCK.

HOSPITAL COURSE:
DAY 1: TAKEN TO OR, ABD. LEFT OPEN.
DAY 2: BACK TO OR WITH NECROTIC COLON AND OVARIES.
DAY 3: UNSTABLE IN ICU ON 2 PRESSORS. UNABLE TO IDENTIFY PATIENT (FACIAL RECOGNITION AND FINGERPRINTING BY SHERIFF, AGGRESSIVE SOCIAL WORKERS EFFORTS.) MULTI-ORGAN FAILURES.
DAY4: ICU ATTENDING DECIDED NOT TO ESCALATE CARE AND TO 'AND' (DNR) IF ARRESTS.
DAY 5: ETHICS CONSULT REQUESTED TO ASSIST WITH EOL DECISION-MAKING.

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CASE 2 (2023)

TERM NEWBORN MALE HAS UNEVENTFUL BIRTH BUT SOON DEVELOPS HEMOLYTIC DISEASE OF THE NEWBORN (RH INCOMPATIBILITY BETWEEN THE MOTHER AND THE NEWBORN.)

NEONATOLOGIST WISHES TO TREAT WITH EXCHANGE TRANSFUSION BUT PARENTS REFUSE BECAUSE THEY ARE JEHOVAH'S WITNESSES. VENTURA COUNTY SUPERIOR COURT IS ASKED FOR A COURT ORDER TO ALLOW TRANSFUSION OVER THE PARENTS RELIGIOUS OBJECTIONS. THE PARENTS APPEAR RELIEVED.

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CASE 3

RB 27YO F CONSERVED BY A PUBLIC GUARDIAN (FROM 2013-2019) ADMITTED FOR ASPIRATION PNEUMONIA, RESPIRATORY FAILURE, ESOPHAGEAL ATRESIA/STENOSIS, FRAILTY & DEBILITY.

PAST HISTORY
DANDY-WALKER SYNDROME
VATER SYNDROME
SEVERE INTELLECTUAL AND DEVELOPMENTAL DELAYS
AUTISM
REQUIRED PEG TUBE FOR NUTRITION (WHICH PT. FREQUENTLY PULLED OUT W/ CURRENT INFECTION
REMOVED FROM HOME DUE TO MATERNAL ABUSE (PER APS).

HOSPITAL COURSE
PT. DID NOT WANT ANOTHER FEEDING TUBE REINSERTED.
PT. DID NOT WANT TO BE INTUBATED AND/OR TRACHED
FAMILY AGREED PT. WOULD NOT WANT AGGRESSIVE TREATMENTS.
ATTENDING PHYSICIAN AND PALLIATIVE CARE DOCTOR ADVISES TRANSITIONING TO COMFORT CARE/HOSPICE.
PUBLIC GUARDIAN CALLED TO CONSENT TO TRANSITION TO COMFORT CARE RECOMMENDATIONS.

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PRINCIPLES OF MEDICAL ETHICS

- Respect for Patient Autonomy
- Beneficence
- Non-Maleficence
- Respect for Justice

Principles of Biomedical Ethics
Tom Beauchamp & James Childress
Oxford University Press, 1979

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#1 Respect for Patient Autonomy

Patients have the right to make their own health care decisions.
(Self-determination; liberty)

Practically speaking:

- Informed consent
- Confidentiality
- Keeping promises
- Avoiding deception and non-disclosure

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#2 Beneficence

Doctors should actively promote the best interests of their patients.
(Fiduciary; Paternalism)

Practically speaking:

- Actively promote the welfare of others (parentalism)
- Patient's needs come first
- Avoid conflicts of interest
- "Duty to do good for patients"

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#3 Non-Maleficence

Doctors have a duty to avoid preventable harms.
("Primum non nocere": Above all, do no harm. Hippocrates)

Practically speaking:

- A physician should not by carelessness, malice, haste or avoidable ignorance cause injury to a patient.
- A physician should practice at least at the "Standard of Care".
- A breach of the duty of non-maleficence may lead to a legal tort (malpractice).

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#4 Respect for Justice

Doctors should be fair and treat equals equally
(Non-discrimination; fairness)

Practically speaking:

- "Physicians have a responsibility to the community to promote access to care and address disparities in health outcomes across populations of patients." AMA Code of Ethics 2017
- As part of their professional obligations, physicians should involve themselves in eliminating sexual discrimination & harassment.
- Eliminate racial discrimination & bias; address social determinants of care.

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Facts About Informed Consent

- "The patient's consent allows the physician to provide care."
  AMA Ethics Manual 2017
- "The unauthorized touching of a person is battery even in the medical setting."
  ACP Ethics Manual 2020
- There are five core elements of informed consent.
  Resolving Ethical Dilemmas 2018

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5 ELEMENTS OF INFORMED CONSENT

1) An explanation of the patient's illness and prognosis.
2) The nature of the proposed test or treatment.
3) The benefits, risks and consequences of the intervention.
4) The alternatives and their benefits, risks and consequences.
5) Answer questions, clarify concerns, promote shared decision-making and allow the patient to express their decision.

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PRACTICAL FACTS ABOUT INFORMED CONSENT

- The best decision-maker for the patient is the patient.
- All patients are presumed to have decision-making capacity.
- Informed consent may be either implied or expressed.
  Resolving Ethical Dilemmas 2018

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EXEMPTIONS TO INFORMED CONSENT

1) Emergency care
2) Routine care
3) "Therapeutic privilege"
4) Patient waiver of consent
5) Lack of decision-making capacity

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EXEMPTIONS TO INFORMED CONSENT

"Implied Consent"

1) Emergency care.

Both ethically and legally, the courts have recognized the doctrine of "implied consent" (CA Probate Code 3210).
Because a reasonable person would consent to treatment in an emergency situation, physicians may presume that an incapacitated patient in a true emergency would consent.

2) The "2-Doctor Rule". The "2-Doctor Rule is an urban myth. It is unnecessary in a true emergency and is not valid at any other time.

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EXEMPTIONS TO INFORMED CONSENT

"Implied Consent"

2) Routine care.

(i.e. vital signs, blood draws, standard physical exams, simple x-rays, IV's)

3) "Therapeutic privilege"

Under extremely rare circumstances, a physician may withhold information when disclosure would seriously harm the patient.

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EXEMPTIONS TO INFORMED CONSENT

"Expressed Consent"

1) Aside from emergency and routine care, informed consent must be "expressed" (either verbally and/or in writing) by the patient, their surrogate or by an advance directive prior to treatments or procedures being done.
2) The best decision maker for the patient is the patient.
3) Clinicians should not turn to surrogates or alternatives unless necessary.
4) Patient Waiver of Consent. In general, patients have the right to waive their right to informed consent.

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EXEMPTIONS TO INFORMED CONSENT

"Expressed Consent"

5) Lack of decision-making capacity

- All patients are presumed to have decision-making capacity.
- As long as the patient can understand significant benefits, risks and alternatives and can make and communicate a reasoned decision, the patient has DMC.
- The presence of mental illness, cognitive impairment, dementia or other comorbidities does not (in-and-of itself) mean the patient lacks DMC.

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EXEMPTIONS TO INFORMED CONSENT

"Expressed Consent"

5) Lack of decision-making capacity (cont'd).

- Capacity is a decision specific determination. A patient may lack DMC for a complex decision (i.e. surgery) but may have DMC for a simple decision (i.e. naming a surrogate).
- If a patient lacks DMC and has no AD or POLST forms or a surrogate decision-maker, they are, by definition, 'unrepresented'.

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INFORMED CONSENT FOR UNREPRESENTED PATIENTS

- Regarding emergency care, consent is implied and it is permissible to treat.
- Regarding routine care, consent is implied and it is permissible to treat.
- For all other decisions, actual informed consent is impossible to obtain.
- What to do?

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INFORMED CONSENT FOR UNREPRESENTED PATIENTS

- No national standards exist.
- Various states have different approaches:
  - Alabama: Attending physician and Ethics Chair make unanimous decision.
  - Colorado and Montana: Ethics Committee makes EOL decisions.
  - Texas: Rotating members of the clergy make decisions.
  - California: A doctor or healthcare institution files a petition in probate court. A judge can authorize treatment or appoint a guardian to make decisions.

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INFORMED CONSENT FOR UNREPRESENTED PATIENTS

- Why that's good: Neutrality, impartiality and public accountability.
- Why that's bad: Process is slow, expensive, guardians' knowledge of medicine often limited.
- Why that's confusing: Each of the 58 counties in California interpret their roles in patient decision-making differently.
- In Ventura County, the role of the court has recently changed. As of 2021, the court requests that decisions be handled in the hospital setting without court intervention or file for conservatorship.

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VCMC (and CMHS) policies on Decision-making for Unrepresented and Incapacitated Patients

Goal: Create a process which clinicians can use to justify providing care to an unrepresented patient without going to court.

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VCMC (and CMHS) policies on Decision-making for Unrepresented and Incapacitated Patients

Policy and Procedure:

#1 Attending physician determines and documents the patient:

- Lacks DMC
- No family, no friends, no surrogates
- No advance directives, no POLST, no PCP, no previous hospital records of preferences

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VCMC (and CMHS) policies on Decision-making for Unrepresented and Incapacitated Patients

Policy and Procedure:

#2 Process:

- Ethics sub-committee (Bioethics Independent Review; BIR)
- 3 members, multidisciplinary, no direct involvement with the patients care
- Diversity of gender, race, ethnicity, religion (if possible)
- Can meet within 24 hours

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VCMC (and CMHS) policies on Decision-making for Unrepresented and Incapacitated Patients

#2 Process:

- Attending physician presents informed consent to BIR (diagnosis, prognosis, recommended treatment, risks, benefits, alternatives, conflicts of interest, other healthcare workers views.
- BIR evaluates the treatment request based upon the patients' best interest standard.
- If BIR determines the physicians' recommendations are within the "medically and ethically acceptable range of options" then the physician may implement the treatment decision.

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THE CASE OF JADA TRAUMA 1

5 Dilemmas of Informed Consent

1) Who consented for the emergency treatments? Why? Justification?
2) Who consented for the ongoing treatments and tests in the ICU? Why?
3) Who consented for withholding CPR on day 3? Why?
4) Who consented for withdrawing life-support on day 4? Why?
5) Who consented for organ-harvesting prior to withdrawal of life-support? Why?

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Q1: Who consented for the emergency treatments? Why?

A1: Attending ED and trauma physicians. Why? Emergency exemption; "implied consent"(CA Probate Code 784.291).

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Q2: Who consented for the ongoing treatments and tests in the ICU? Why?

A2: Attending physicians.
Why? Routine and emergency exemptions; "implied consent" (CA Probate code 784.291, sec.853).

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Q3: Who consented for withholding CPR on day 3? Why?

A3: Attending physician.
Why? Non-maleficence and Beneficence;
(non-beneficial care can harm patients while offering no benefits).

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Q4: Who consented for withdrawing life-support on day 4? Why?

A4: Attending physician and the Bioethics Independent Review subcommittee.
Why? Respect for patient autonomy; non-maleficence and beneficence.

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Q5: Who consented for organ-harvesting prior to withdrawal of life-support? Why?

A5: VCMC Administration.
Why? Non-maleficence and Respect for Justice.

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CASE 2:

REQUEST FOR COURT ORDER TO TRANSFUSE AGAINST PARENTS RELIGIOUS BELIEFS.

ETHICAL CONFLICT: AUTONOMY V. BENEFICENCE
ETHICAL DISCUSSION: NOT IN BABY'S HEALTH INTEREST TO REFUSE TRANSFUSION (LOW RISK INTERVENTION NEEDED TO SAVE LIFE)
VENTURA COUNTY SUPERIOR COURT: WILL APPOINT A GUARDIAN BUT NO COURT ORDER WILL BE GIVEN.

HEC CONSULT:
ETHICALLY JUSTIFIED TO TREAT TO SAVE THE BABY'S LIFE
LEGALLY JUSTIFIED TO TREAT BECAUSE PARENTS CANNOT MAKE MARTYRS OF THEIR CHILDREN

RESOLUTION: TRANSFUSION IS IN THE 'ETHICALLY ACCEPTABLE RANGE OF OPTIONS' FOR THIS CHILD.
BUT, PROBATE SEC. 3200 RAISES THE QUESTION OF THE APPROPRIATE ROLE OF THE COURT WHEN THE LAW SUPPORTS TREATMENT OVER THE PARENTS RELIGIOUS BELIEFS.

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CASE 3:

REQUEST FOR PUBLIC GUARDIAN TO CONSENT FOR PALLIATIVE/COMFORT CARE.

HOSPITAL COURSE:
PUBLIC GUARDIAN DID NOT BELIEVE THEY HAD THE RIGHT TO CONSENT TO LIMITING TREATMENTS OR REMOVING EXISTING LIFE SUPPORT. ASKED THAT THE CASE BE RETURNED TO THE COURTS.

HEC: ETHICAL CONFLICT: AUTONOMY V. JUSTICE (EQUALS BEING TREATED EQUALLY).
ALL OF THE DOCTORS, NURSES, PALLIATIVE CARE SERVICE, PATIENTS FAMILY AND THE ETHICS COMMITTEE FELT THAT R.B. HAD THE RIGHT TO REFUSE TREATMENTS AND BE TRANSITIONED TO COMFORT CARE.
THE PUBLIC GUARDIAN WAS NOT ACTING IN THE PATIENT'S BEST INTERESTS OR HER SUBSTITUTED JUDGEMENT.

HEC: TRANSITIONING TO COMFORT CARE IS 'WITHIN THE ETHICALLY ACCEPTABLE RANGE OF OPTIONS,' AND THE DOCTORS TRANSITIONED THE PATIENT.
THE PUBLIC GUARDIANS NEVER RESPONDED.

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Thank you!

Questions?
Comments.

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