Health Care Decisions for Unrepresented Nursing Home Residents after *CANHR v. Smith*

Making health care decisions for unrepresented nursing home residents (those who lack the mental capacity to make decisions and also lack a surrogate to make decisions on their behalf) has always been tricky. The California legislature attempted to address the uncertainty by adopting Health and Safety Code Section 1418.8, also known as the "Epple Act," in the 1990's. Section 1418.8 uses an inter-disciplinary team ("IDT") approach, led by the resident's physician, for reviewing options and deciding treatment for unrepresented residents.

Nursing homes have failed to properly use Section 1418.8 since its inception and the Department of Public Health ("DPH") has never made any effort to enforce or otherwise review compliance with the statute. More troubling, the statute has significant constitutional deficiencies which render the IDT decision making process likely to produce bad decisions that are neither consistent with the resident's wishes, if they could be determined, or the resident's best interests.

Due to the significant problems with Section 1418.8, CANHR, along with nursing home resident Gloria A., sued DPH in 2013 to have the statute declared unconstitutional. The case is called CANHR v. Smith. On July 22, 2019, the California Court of Appeal rendered its decision, finding the statute had two critical constitutional deficiencies but was not "unconstitutional." The court's 71-page opinion clarifies how decisions need to be made for unrepresented nursing home residents but also raises some important questions that will have to be answered by others - likely the state legislature.

The following steps highlight our best understanding of how to make health care decisions for unrepresented nursing home residents, based on the statute, the court opinion, and common sense.

Before You Begin - Ensuring the IDT is the Last Resort.

No one should come into a nursing home as an unrepresented resident. Nursing homes provide significant medical care and hold the residents financially liable. Such a relationship can only be formed through contractual consent which must be memorialized upon admission. If the resident cannot consent, a surrogate’s consent is needed. Nursing homes that care for and charge residents without proper consent risk significant civil and criminal consequences.

Section 1418.8 becomes operative after a resident is properly admitted and either 1) loses decisionmaking capacity and has no surrogate or 2) never had capacity, their surrogate becomes unavailable, and no new surrogate is available. For these residents, nursing homes are encouraged to seek a public guardian appointment as conservator for the resident. If the public guardian cannot be appointed, the facility can rely on Section 1418.8 for health care decisionmaking.
Some readers may wonder why a facility would seek a public guardian appointment for unrepresented residents when it can use Section 1418.8. Public guardians are known for turning nursing home resident cases down because the resident’s needs for food, clothing, shelter, and health are being met. However, the involvement of a public guardian surrogate could be more efficient for unrepresented nursing home residents than relying on Section 1418.8. Going through multiple steps and using the time of multiple participants during the IDT process for every health decision will be very resource intensive. Having a conservator to serve as a surrogate means health decisions could be handled much quicker and simpler.

Having a conservator surrogate rather than relying on IDT decisions provides two other key advantages to nursing homes and unrepresented residents. First, a conservator can seek authority to manage a resident's income and finances to pay for the resident's care and other bills - something an IDT simply cannot do. (Remember, nursing homes are prohibited from acting as representative payees for residents - 22 Cal. Code Regs. Sec. 72529(c)) Second, a conservator can make decisions outside of the nursing home setting, where Section 1418.8 does not apply. This improves overall health care decisionmaking and continuity for the individual resident's care.

When public guardian's offices are reluctant to seek conservatorship for unrepresented residents, nursing homes should consider filing a court petition pursuant to Probate Code Section 2920(b). A successful petition will compel the public guardian to take the case.

**First Step: Determining Capacity, Searching for Surrogates.**

The Section 1418.8 process begins with the resident’s physician finding the resident lacks decisionmaking capacity and lacks a surrogate. These findings are necessary when “any medical intervention” is proposed by the physician. (Decision, p. 70): The physician’s determinations, and the “basis for those determinations,” as to both matters have to be documented in the resident’s medical record. (1418.8(l)) The physician must interview the resident and conduct an investigation pursuant to subsections 1418.8(b) and (c). Though not required by the CANHR court, the physician should notify the resident that their capacity is being assessed and a search for surrogates is being made. (“giving notice . . .would maximize protection of the patient's constitutional rights” (p. 33)

A resident **lacks decisionmaking capacity** if they are “unable to understand the nature and consequences of the proposed medical intervention, including its risks and benefits, or is unable to express a preference regarding the intervention.” (1418.8(b) and (c) and Probate Code 4609)

A resident **lacks a surrogate** when there is no “person designated under a valid Durable Power of Attorney for Health Care, a guardian, a conservator,” or a family member or friend available and willing to “take full responsibility” for health care decisions. (1418.8(c) and (f))

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1 All subsequent citations to page numbers refer to the Court of Appeal decision.
Second Step: Notice.

Once the resident’s physician has documented that the IDT decisionmaking process is warranted, written and oral notice to the resident is required, in a language the resident will understand. (pp. 27-28) The notice must tell the resident the following:

1. The resident has been found to lack decisionmaking capacity.
2. No surrogate decisionmaker is available.
3. A description of the proposed treatment being contemplated.
4. The treatment decision will be made by the IDT.
5. The resident has the right to have a patient representative participate in the IDT decisionmaking. The notice should include the name and contact information, if available, of the patient representative who will participate in the IDT. (p. 32)
6. The resident has the right to judicial review to contest the physician’s findings, the use of the IDT, or the decisions of the IDT. (pp. 70-71)

The notice must be given immediately after the physician’s determinations of incapacity and lack of surrogate and before the recommended medical intervention. (p. 12) The notice should therefore be given before the IDT meeting in Step 3 and invite the resident to participate in that meeting. A copy of the written notice must go to "at least one competent person" willing and able to discuss the notice with the resident. (p. 28) The court described this second recipient of notice as a "supportive person" (p. 59) and it seems most practical for that person to be the patient representative. It may be a good idea to send the notice to the local long term care Ombudsman as well. If the resident disagrees with any aspect of the decisions made or the use of the IDT decisionmaking process, judicial intervention must be sought. (p. 41)

Bottom Line Regarding Notice

<table>
<thead>
<tr>
<th>What Is In the Notice?</th>
<th>The physician’s determinations of incapacity and lack of surrogate. A description of the proposed treatment, and the right to judicial review if there is any disagreement.</th>
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<tbody>
<tr>
<td>Who Does Notice Go to?</td>
<td>The resident, the patient representative, and (recommended but not required) the local long term care Ombudsman program.</td>
</tr>
<tr>
<td>How is Notice Given?</td>
<td>Orally to the resident in a language the resident understands. In writing to the resident (in a language the resident understands), the patient representative, and the local long term care Ombudsman program.</td>
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<tr>
<td>When is Notice Given?</td>
<td>Immediately after the physician’s determinations, and before the IDT review and the proposed intervention is initiated. In emergencies, the notice can be given after the intervention. (informed consent is presumed in emergencies - Section 1418.8(h), pp. 35-36)</td>
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Third Step: Deliberating the Options.

Once proper notice has been given, the nursing home can convene the IDT. The IDT must consist of the resident’s attending physician, a registered nurse, other “appropriate” staff in disciplines as determined by the resident’s needs, and a patient representative independent of the nursing home. Ideally, the resident is also part of the IDT. Since the inception of 1418.8, the participation of a physician and patient representative has been, at best, intermittent. The CANHR opinion makes clear that if the resident’s physician and an independent patient representative are not part of the meeting, the IDT is not complete, the physician loses immunity from liability, and health care decisions may not be made. If an IDT lacks the required participants, nursing homes should start over and secure their attendance.

The IDT’s first task is to review the physician’s determination about capacity. The team should scrutinize the evidence the physician relied upon to make their capacity decision. Was any mental status testing performed? Was the resident assessed at various times to ensure a more comprehensive assessment? The physician should be made to elucidate and justify their conclusions. As the court stated: “determination of incapacity is far from an exact science . . . mistakes are made.” (p. 39)

The second task of the IDT is to review the physician’s determination about surrogates. This requires scrutiny of the effort to identify and locate a surrogate and ensure the effort was diligent and exhaustive. The IDT should be almost certain that no surrogate exists, or if one exists, they couldn't be persuaded to serve.

Once the IDT has reviewed the physician’s determinations (capacity, surrogate), it must next consider the physician’s recommendations. Section 1418.8(e) sets forth the items that must be reviewed in assessing the “prescribed” (indicating a physician’s order is needed) medical intervention before the intervention may be undertaken. The IDT must consider each of the following:

1. The physician’s assessment of the resident’s condition;
2. The reason for the proposed use of the medical intervention;
3. The desires of the resident, based on a patient interview, medical records review, and consultation with any identified family or friends;
4. The type of medical intervention to be used in the resident’s care;
5. The probable impact on the resident’s condition, with and without the use of the medical intervention; and
6. Reasonable alternative medical interventions considered or utilized and reasons for their discontinuance or inappropriateness. (1418.8(e)(1)-(6))

The court set at least one boundary on scope of medical interventions that may be considered under Section 1418.8: IDTs may not approve decisions that will "directly and inexorably" lead to the death of a resident. (p. 66) This would include disconnecting a ventilator assisting a resident to breathe or a feeding tube providing nutrition and hydration to a resident. However, decisions made "in the anticipation of end-of-life," such
as hospice elections, advance directives/physician orders regarding resuscitation, and comfort care, may be made by an IDT. (pp. 68, 71)

A note regarding the patient representative. The court's decision leaves a lot of uncertainty about who will serve as the patient representative. The court stated the patient representative must be unaffiliated with the nursing home, independent, and is the IDT member "most likely to dissent." The court did not indicate what should happen if the resident prefers a different patient representative or does not want the assistance of a patient representative, but those cases would likely be best pursued in judicial review. (See Step 6)

The patient representative is the most important IDT member. Among other roles, the patient representative must ensure the IDT meaningfully reviews the physician determinations regarding capacity and the alleged lack of a surrogate. The patient representative must meet with the resident, discuss the IDT process and the decisions being considered, review medical records, and articulate the resident's views or, if those views are not easily discernible, the "best approximation possible of the patient's perspective." (pp. 30-31) Most importantly, the patient representative is supposed to advocate for the resident ("give nursing home residents something as close as possible to a voice" (p. 32)) and initiate judicial intervention when needed.

Fourth Step: “Making” the Decision.

Decisions by IDTs must achieve consistency with the resident's wishes or, if the resident’s wishes are unclear, consistency with the best interest of the resident.

Consensus. If every member of the IDT agrees the resident lacks capacity, lacks a surrogate, and the proposed medical intervention is consistent with the resident’s wishes or best interests, the medical intervention may be initiated, provided the resident is notified and reminded of the right to judicial review.

No consensus. If there is any disagreement among members of the IDT, either the proposed treatment is rejected (because no substitute consent was obtained) or judicial review is required by filing a petition for substituted judgment under Probate Code Section 3201. (pp. 30, 35) For end-of-life decisions, mere "reservations" should trigger judicial review. (p. 67)

Fifth Step: Judicial Review.

Judicial review is required in the following cases:

- The resident disagrees with any part of the IDT process, the physician’s determinations, or the IDT's decisions.
- The patient representative disagrees with any part of the IDT process, the physician’s determinations, or the IDT’s decisions.
• Consensus is not achieved but someone nonetheless wants to provide the proposed intervention. In this case, judicial review would be sought by the person desiring to make the proposed medical intervention.
• End-of-life decisions that will “directly and inexorably” lead to the death of a resident. (p. 66)

Judicial review is initiated by filing a petition for substituted judgment under Probate Code Section 3201. A 3201 petition seeks a court’s authorization to provide, withdraw, or withhold medical treatment and may be filed by a health care provider or patient representative. Probate Code Section 3204 details what must be stated in the petition.

Another judicial review option is to seek a conservator as previously discussed in “Before You Begin - Ensuring the IDT is the Last Resort.” If the IDT anticipates the resident will need several health care decisions made in the future or will object to future health care decisions, having a legally appointed surrogate may be much more efficient than having frequent IDT meetings.

Section 1418.8 and the court’s decision leave many questions with regard to judicial review unanswered. For example, who pays the filing fees? Who hires and pays for the lawyer expected to prepare the required petitions? In addition, it is unclear who has to initiate judicial review. On one hand, if the resident or the patient representative are dissenting, they should be the ones who initiate review. On the other hand, a resident’s objections or a patient representative’s disagreement should automatically stop the 1418.8 process and it is up to the health care providers to seek authority to continue. Under that rationale, the onus for intervention should fall to the party that seeks to change the status quo.

Sixth Step: Implementing the Intervention.

The intervention may be implemented once the IDT has reached consensus, but only after the resident has received notice of the IDT’s decision and had an opportunity to seek judicial review. (p. 71) In cases where the resident objects to the IDT’s determinations or refuses the proposed treatment judicial review is required before the intervention may be initiated. An IDT may never authorize non-emergency treatment on an unwilling resident as such an infringement of rights requires a court order. (p. 55)

Seventh Step: Reevaluation.

Section 1418.8(g) requires the IDT to meet “at least quarterly or upon a significant change in the resident’s medical condition” to reevaluate the treatment decisions made. During these reevaluations, the IDT should also review the prior determinations regarding the resident’s alleged incapacity and lack of surrogate to ensure nothing has changed. (p. 46) The IDT reevaluations are required in addition to other IDT reviews needed for any new health decisions requiring informed consent, including changes or adjustments to prior treatment decisions, e.g. increasing the dosage or frequency of a resident’s medications.