

TALES FROM THE TRENCHES:  
WHAT HAPPENS (IN THE REALWORLD)  
WITH END OF LIFE DECISIONS  
AND ADVANCE HEALTHCARE DIRECTIVES?

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## BASIC COMPONENTS OF ADVANCE HEALTHCARE DIRECTIVES

Probate Code sections 4600 *et seq.* (Effective July 1, 2000). The legislative findings contained in Probate Code section 4650 set forth the laws of public policy which recognize a patient's right to control decisions relating to his or her own health care. A patient's right of individual autonomy, privacy and dignity, includes the right to exercise control over health care decisions when modern medical technology has made possible the prolongation of life beyond natural limits.

An individual has the right to appoint an agent to make medical and other important and related decisions (e. g. housing). The intent is that the designated agent will be aware of and carry out the patient's wishes. The agent is appointed within the Advance Healthcare Directive. This document is intended to give the agent and treating providers guidance on the patient's wishes for his or her care.

People assume they will always be able to make their own healthcare decisions. Often, this is true until the very end, yet other times, sadly, it is not true at all. In the first case, consider that you are dying of cancer. You have time to make and communicate your decisions to your health care team and to your family. On the other hand, take the example of someone who suffers a traumatic brain injury as the result of a car accident, a drug overdose, or another accident. This person often can't contribute anything at all to medical decision making. It is interesting to note that most of the legal cases surrounding Advance Healthcare Directives involve such, often younger, individuals.

## DESIGNATED AGENTS: ERRONEOUS ASSUMPTIONS

Selection and appointment of an agent or agents who make health care decisions is a threshold consideration. In the event of one's incapacity, an Advance Healthcare Directive authorizes that agent or agents to follow the directed detailed instructions, including end-of-life decisions, relief from pain, organ donations, and designation of a primary care physician. The statutory form may be modified or supplemented as an individual may desire to include personal preferences and values, treatment desires and directives, and requested consultations.

It is a common misconception that spouses automatically assume agency authority when their spouse has become unable to make medical decisions. there is no automatic right or entitlement of a spouse to make such decisions. Probate Code section 4717 places a spouse in the generic category of family member, with no expressly provided priority. Case law provides that marital status alone does not provide an agency relationship between spouses

Similarly, most parents don't think about the fact that once their son or daughter is 18, they have no decision-making authority for their child's health care in the absence of an advance directive.

Another erroneous assumption is that the Advance Directive is like a cookbook that can be followed literally. However, often, the decision to be made is not black or white or there is disagreement among physicians or family members.

*EXAMPLE – Mrs. C, a lady in her 80s, has two adult daughters. The sisters have a long history of animosity and this has continued during their mother’s last years of life. One sister allegedly exerted undue influence on her mother, prevented her sister and family from having contact with her mother, and committed financial elder abuse. Eventually, a neutral conservator of the person and estate had to be appointed to handle Mrs. C’s affairs because her daughters couldn’t agree on anything. All existing appointing documents were suspended and decision making was in the hands of the professional fiduciary who was appointed as the conservator. Even this didn’t stop the bickering. The conservator did his best to manage the situation and negotiate pretty much everything between the sisters. This worked reasonably well for six months or so until Mrs. C became quite ill and was hospitalized. She took a sudden turn for the worse and decisions had to be made regarding her care. Despite the fact that the conservator had authority to make medical decisions on behalf of Mrs. C, the “bad” daughter presented her suspended “proof” that she was to make her mother’s healthcare decisions to the hospital administrators. They were unaware that the documents had been suspended, and allowed the “bad” daughter to make the decision to admit Mrs. C to the ICU where she was being kept alive by machines and medications. The “good” sister was horrified because she knew that her mother did not want heroic measures and she demanded that the hospital accept the conservator’s decision and not her sister’s. The relationship between the conservator and the “bad” sister was so damaged that his attorney advised him to resign from his position. Meanwhile, Mrs. C was still in the ICU. A successor conservator was appointed at an ex parte hearing with authority for end-of-life decisions. We’ll return to Mrs. C later when we discuss how the conservator made these important decisions.*

## AUTHORITY OF DESIGNATED AGENTS

The decisions to be made by a designated agent may include:

- A. Which decisions can my health care agent make? At what point can they start making these decisions for me?
- B. What guidelines will I establish for the selection or dismissal of health care providers and the consent or refusal of particular medications, tests and treatments?
- C. What should happen to my body and organs after I die?
- D. What legal action(s) may be needed to carry out my wishes?
- E. What end-of-life care decisions do I wish to direct to my physician and designated agent(s)?

Even if a health care agent is properly designated, the agent's authority is often less than certain. For example, it is unclear whether an agent can consent to the off-label administration of a drug or to the principal's enrollment in a clinical trial. Another example: case law is less than consistent on whether a designated agent has the authority to enter into an arbitration agreement (for example, at a health care facility or retirement home) on behalf of his or her principal.

Determination of capacity becomes an important consideration in the use of Advance Healthcare Directives. It is typical for these documents to require written declarations from one, and sometimes two, physicians before the agent can take over. It makes sense *why* we do this – no one wants to fear that their agent will “pull the plug” prematurely and we must protect our older and vulnerable adults from undue influence and other forms of elder abuse. How is capacity determined? This often depends upon whether the client/patient is in an acute care setting or is living in the community. In the acute care setting, it is usually not difficult to obtain the required capacity declarations (although we will have an example of an exception) but when a client/patient is in the community with, for example, signs of dementia, it can be a bit tricky to obtain the necessary declaration(s). Often, the longtime family physician is uncomfortable being the “bad guy” and breaching her relationship as a trusted advocate for her patient. In some cases, the client will be referred for neuropsychological testing to determine capacity but client's will sometimes refuse to attend and/or cooperate. This “grey area” period of time can be dangerous for the client and frustrating for the family who want to be sure he is safe and properly cared for. As a trusted advisor, you can help to explain the importance of allowing the capacity determination to be made in a timely fashion.

*EXAMPLE – Ms. R was 63 when she was diagnosed with stage 4 cancer. Having never married nor had children, Ms. R had the foresight to engage a professional fiduciary immediately and to update her estate planning documents to reflect this person as her legally authorized decision maker. A year or so after her diagnosis, Ms. R became acutely ill and was transported to the hospital. After several weeks in the hospital, Ms. R decided that she wanted her fiduciary to take over her financial and healthcare decision making. She recognized that she was no longer capable of doing so on her own. Ms. R's documents stated that they would not go into effect until she was declared incapacitated in writing by one of her treating physicians. As a result, the fiduciary requested a consult with the geriatric psychiatrist at the hospital. The psychiatrist interviewed Ms. R and concluded that she did not lack capacity because, “she was able to clearly tell me why she needs help.” He refused to write a capacity declaration indicating that Ms. R could no longer make her own decisions. The fiduciary and Ms. R decided to have Ms. R's attorney prepare documents that would allow the fiduciary to take over immediately without the physician's declaration. Once the documents were prepared, the attorney came to the bedside with his traveling notary. The fiduciary took over decision making. While the outcome was good the terms of Ms. R's original documents created an unexpected roadblock that led to a delay of a couple of weeks in implementing Ms. R's desire to have her agent take over. Needless to say, this was some very stressful two weeks for all concerned.*

## THE NEED FOR COUNSELING REGARDING IMPORTANT DECISIONS

Too often, when estate planning documents are sent to the client with a cover letter of explanation, inclusion of an Advance Healthcare Directive is often an afterthought, i.e., check off the boxes in the enclosed Healthcare Directive form and return it. A client deserves counseling and discussion as to the importance and alternatives in making significant health care and end-of-life decisions to properly fill out an Advance Healthcare Directive. This is an often-over-looked task. We hope one of the take-aways from this presentation is that estate planning lawyers will give higher sensitivity and priority to explaining and exploring the sensitive decisions to be made in filling out these personal health care directives.

It is beneficial for all clients to complete a Life Transition Plan. This is essentially an owner's manual for someone's life. While it covers practical matters like financial information, it also prompts clients to consider and articulate their views regarding important decisions that their agent might have to make on their behalf. End-of-life decision making and final wishes is a critical element of the Life Transition Plan. If these thoughts are properly documented the agent will know exactly how the client felt about these issues and how they would handle them if they could do so for themselves. In this way, the agent can employ substituted judgment rather than being limited to determining what is in the client's best interest. A benefit of this process is that it will often lead to less disagreement among family members and less stress for all concerned.

*EXAMPLE – I was referred to a lovely couple, Mr. and Mrs. H, by their estate planning attorney. Mr. H was 88 and Mrs. H was 91. This couple married late in life and neither had any children or living relatives. Their estate planning attorney suggested that they appoint a professional fiduciary. I sat with them over several sessions to develop their Life Transition Plans. When it was Ms. H's turn, he said, "I will know when I've had enough". When I pushed him to explain to me what the specific signs were that would allow him to "know", he struggled. He told me, "I'll know when I know." When I pointed out that he might not have the capacity to understand the signs at the time and that I was the one who "needed to know" so I could uphold his wishes, he became more willing to engage in a meaningful discussion. I documented what he told me and then prepared a draft for his review. Upon reflection, Mr. H made several modifications. This was not a check-off-the-box exercise, but rather, a series of thoughtful, guided conversations.*

## CALIFORNIA'S END-OF-LIFE OPTION ACT

California's End-of-Life Option Act became effective in June 2016, as Health and Safety Code sections 443 *et seq.* The Act provides a mechanism for a physician to prescribe a lethal dose of a drug for a qualified individual. A physician may not assist the administration of the lethal dose of the drug; the drug must be self-administered by the qualified individual. To qualify to receive the prescription, the individual must be mentally competent, have the capacity to make medical decisions. California requires that the individual seeking to qualify for an end-of-life prescription must follow a

procedure of formal request. The attending physician must determine whether the individual has legal capacity to make medical decisions. A second physician - the consulting physician - independent from the attending physician, must confirm the diagnosis, prognosis, mental capacity of the individual, and all requirements of the Act.

The Act specifically precludes making a decision under the End-of-Life Option Act by means of a Power of Attorney, Healthcare Directive, or similar document.

*EXAMPLE: While I have not yet had the opportunity to work with a client who is ready to implement the End-of-Life Option Act, I do receive a lot of questions and comments about this. It is not unusual for clients to tell me to “take me out back and shoot me if I can no longer \_\_\_\_\_” or “just send me to Oregon.” Now that the Act provides a real option in California, I expect that more and more clients will inquire.*

#### ALLIED INSTRUCTIONS: POLST/DNR

A POLST is a Physician’s Order for Life-Sustaining Treatment. A POLST is intended to complement an Advance Healthcare Directive; it is not intended to replace that document. A POLST is a directive with respect to cardio-pulmonary resuscitation (CPR), medical interventions, and artificially administered nutrition. California law requires that a POLST form be followed by healthcare providers, and provides immunity to those who comply in good faith. In the hospital setting, a patient will be assessed by a physician who will issue appropriate orders. A POLST is a part of the patient’s medical record. It must be signed by the physician, nurse practitioner or physician assistant who is caring for the patient as well as the patient or, if the patient lacks capacity, by his or her legally acting decision maker. A POLST is more specific than the typical Advance Healthcare Directive in that it addresses very specific interventions. The physician completing the form makes reference to the Advance Directive if one is available and this is documented directly on the POLST.

*EXAMPLE – Back to Mrs. C whom we left in the ICU... how did the conservator make the decision about whether to remove Mrs. C from live support? It turns out that Mrs. C had a properly executed POLST on file in her medical record. This POLST had been completed many months prior by Mrs. C’s personal physician, Mrs. C and her conservator. The document made Mrs. C’s wishes very clear. She did NOT want treatment with the goal of prolonging life by all medically effective means. She wanted comfort-focused treatment only. The conservator convened a meeting of the attending physician, the hospital’s social worker, a representative from a hospice provider and Mrs. C’s two daughters. The conservator reviewed Mrs. C’s condition and prognosis and discussed the meaning of her election on the POLST. The conservator allowed the daughters to ask their questions, but ultimately the conservator made the decision to remove the treatments that were not in compliance with the POLST and move Mrs. C to hospice care. Mrs. C passed away a few days later.*

*EXAMPLE: A conservator has a client who is a long-term resident of a nursing care facility. This patient does have a POLST. The facility is insisting on the insertion of a feeding tube because their physician and director of nursing feel that the patient would have additional life expectancy but for the fact that she refuses to take food by mouth. Her POLST only allows for a “trial period” of artificial nutrition. The conservator has to decide whether to allow this trial or not. If she does allow it, she will have to go to court for an order to allow her to remove the feeding tube later. In this case, the conservator declined to have the feeding tube placed based on the advice of two clinicians unrelated to the nursing facility.*

### IMPLEMENTATION IN TIMES OF STRESS

Upon the signing of an Advance Directive, adults should make sure to give a copy to their primary care physician, their designated agent, and should keep a duplicate original copy readily accessible. Copies can also be delivered to and scanned into the electronic medical records at their local hospital or health care facility for easy access in the event of emergency.

### RISKS IN ABSENCE OF A SIGNED ADVANCE HEALTHCARE DIRECTIVE

Very often, a patient is admitted to the hospital and there is no Advance Healthcare Directive on file and no family member or friend produces one. In this case, some hospitals will simply take the expedient way out of the situation and accept instructions from whomever has presented him or herself as the “next of kin”. While we know this is not legally proper, the hospital just wants someone to make a decision or sign a paper. So if someone presents as the spouse of the patient, the hospital will frequently turn to that person even though that person is not the authorized legal representative. This also occurs when the adult child who lives near mom or dad shows up and starts making decisions when their out of town sibling is in fact the named decision maker. This is why it is so important to not only have a valid document but to put it in on file with each of your physicians and at the hospital you typically would be admitted to. Clients should also be advised to keep a copy in the glove compartment of their cars.

*EXAMPLE: Mr. D is a 91 year old retired engineer who never married and who lived alone. He fell in his apartment and a neighbor found him and called 911. He was transported to the hospital where he was stabilized. The hospital wanted to discharge Mr. D to a rehab facility, but Mr. D was unable to consent to the discharge and transfer and there was no known family or Advance Healthcare Directive. The hospital petitioned the court for a temporary (emergency) conservator to be appointed so that Mr. D could be discharged to rehab and so that plans could be made for his further care. The conservatorship process can be time consuming, is expensive, and puts personal health information in the public domain.*

## CONCLUSION

When clients, patients, or attorneys need inspiration beyond medical technology and legal technicalities, they can look to the wise words from the Book of Ecclesiastes, which serve as a reminder that dying has been part of life since time immemorial.

Remember then thy Creator in the days of thy youth,  
Before the evil days come,  
And the years draw nigh, when thou shalt say:  
“I have no pleasure in them”,...  
Before the silver cord is snapped asunder,  
And the golden bowl is shattered,  
And the pitcher is broken at the fountain,  
And the wheel falleth shattered, into the pit;  
And the dust returneth to the earth as it was...  
*Ecclesiastes 12:1-7.*

And in the end, from the same source, there are further words of comfort:  
“[T]o everything there is a season, a time to be born and a time to die...” *Id.* At 3:1-2.



## INCLUDED RESOURCE MATERIAL

Marshall S. Zolla, *Incorporating Personal Values into Advance Healthcare Directives*, Los Angeles Lawyer Magazine, October 2015 [Attached]  
Marshall S. Zolla, *Lasting Wishes*, Los Angeles Lawyer, December 2000 [Attached]  
“25 Tough Questions You Must Answer to Face Your Finish” – excerpt from the workbook accompanying Facing the Finish: A Road Map for Aging Parents and Adult Children by Sheri L. Samotin (used with permission)  
Blank POLST form  
UCLA Health materials (provided with permission):

- California End of Life Option Act: Information for Our UCLA Patients
- Aid-In-Dying Options: Finding One’s Way to Clarity
- California End of Life Option Act: Information, Suggestions and Options for Patients
- Preparing for Your Own Death: Instructions and Essential Information
- Preparing for Your Own Death: Personal Checklist
- Preparing for Death: Guidelines for Your Family, Loved Ones or Caregivers

## ADDITIONAL RESOURCES

### Websites:

Aging Life Care Association – professional care managers - [www.aginglifecare.org](http://www.aginglifecare.org)  
Compassion & Choices – [www.compassionandchoices.org](http://www.compassionandchoices.org) and [www.truthintreatment.org](http://www.truthintreatment.org)  
Five Wishes – [www.agingwithdignity.org](http://www.agingwithdignity.org)  
National Hospice and Palliative Care Organization – [www.nhpco.org](http://www.nhpco.org)  
The Conversation Project – [www.theconversationproject.org](http://www.theconversationproject.org)

### Books:

Being Mortal: Medicine and What Matters in the End by Atul Gawande  
Knocking on Heaven’s Door: The Path to a Better Way of Death by Katy Butler  
Facing the Finish: A Road Map for Aging Parents and Adult Children by Sheri Samotin

## Incorporating Personal Values into Advance Healthcare Directives

**THE PATIENT PROTECTION AND AFFORDABLE CARE ACT**,<sup>1</sup> health insurance, Medicare, deductibles, prescription medication, copays, portability, stop-loss caps—the components of healthcare in California are a mélange dizzying enough to confuse most people. Nevertheless, the California Health Care Decisions Law<sup>2</sup> grants individuals the power to make their own decisions about their healthcare plans, including decisions regarding future incapacity. Attorneys advising clients with respect to the designation of a healthcare agent or agents, end-of-life decisions, alleviation of pain directions, and other aspects of medical care, should encourage discussion of these issues with family members and ensure that their decisions are recorded with specific and appropriate documentation.

The U.S. healthcare system is costly. America's total healthcare bill for 2014 was \$3 trillion.<sup>3</sup> The complicated insurance maze also adds to the stress that a spouse or family member faces when making healthcare decisions for another person. Given this daunting landscape, an advance personal healthcare directive can help prevent uncertainty, family tensions, and decisions that may run contrary to the patient's wishes. A completed advance healthcare directive should be given to and discussed with one's designated agent(s), primary care physician, and personal attorney. Many hospitals will scan an advance directive into one's personal medical record for ready reference and safekeeping.

As the legislative findings set forth in Probate Code Section 4650(a) acknowledge, "an adult has the fundamental right to control the decisions relating to his or her own health care, including the decision to have life-sustaining treatment withheld or withdrawn." In furtherance of this policy, Probate Code sections 4670 et seq. provide the statutory guidance for advance healthcare directives. The key term "healthcare decisions" is defined in specific statutory provisions.<sup>4</sup>

Selection and appointment of an agent or agents<sup>5</sup> to make healthcare decisions is a threshold consideration. In the event of one's incapacity, an advance healthcare directive authorizes that agent or agents to follow the directive's detailed instructions, including end-of-life-decisions, relief from pain, organ donation, and the designation of a primary care physician.<sup>6</sup> The statutory form may be modified or supplemented as an individual may desire<sup>7</sup> to include personal preferences and values, treatment desires and directives, and requested consultations. Preprinted forms are available from the California Medical Association (CMA),<sup>8</sup> the California Hospital Association (CHA),<sup>9</sup> and local hospitals such as Cedars-Sinai Medical Center.<sup>10</sup>

It can be instructive (and personally beneficial) for attorneys, before counseling clients, to complete our own advance healthcare directives.<sup>11</sup> The decisions to be made include:

- Whom should I choose to be my healthcare agent(s)?
- Which decisions can my healthcare agent make?
- What guidelines will I set for the selection or dismissal of healthcare

providers and the consent or refusal of particular medications, tests, and treatments?

- What should happen to my body and organs after I die?
- What legal action(s) may be needed to carry out my wishes?
- What end-of-life care steps do I wish to direct to my physician and designated agent(s) to take?

This last question involves many choices. An advance healthcare directive addresses whether a person elects to prolong his or her life artificially under certain circumstances such as: 1) the person is close to death, which mechanical life support would only delay, 2) the

**Even if a healthcare agent is properly designated, the reach of the agent's authority is often less than certain.**

person is unconscious or in a persistent vegetative state, and the treating doctors do not expect the person to recover, 3) the person has a terminal illness, and there is little or no likelihood of improvement, 4) the person's quality of life would not be acceptable to the person under standards described in the directive. Alternatively, the advance healthcare directive may specify that the person has chosen to prolong his or her life as long as possible within the limits of generally accepted healthcare standards. Whatever one's choices are about artificially prolonging life, additional decisions may be made about its end. Hospice and palliative care preferences may be specified in an advance healthcare directive.

### Recent Cases

To validly execute an advance healthcare directive, however, a person must have legal capacity.<sup>12</sup> The mental capacity of a client is measured by the standards set forth in the Due Process in Competence Determination Act,<sup>13</sup> and the attorney's role in assessing a client's capacity to sign an advance directive is not without ethical considerations.<sup>14</sup> In addition, the scope of a designated healthcare agent's authority has been the subject of recent California appellate court decisions, particularly regarding the scope of an agent's authority to consent to arbitration of healthcare disputes. These cases offer guidance for the drafting of advance directives and counseling of clients about how to set forth their healthcare goals.

In *Garrison v. Superior Court*,<sup>15</sup> the court held that a daughter who had a durable power of attorney to make healthcare decisions for her mother could bind her mother to an arbitration agreement

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in the admission documents of a residential care facility. In so holding, the court reasoned that the decision whether to agree to an arbitration provision in an admissions document was “part of the health care decision making process.” The *Garrison* court concluded that under the terms of the durable power of attorney and the applicable provisions of the Health Care Decisions Law,<sup>16</sup> the daughter had the authority to enter into the arbitration agreement on behalf of her mother. The opinion referenced three provisions in the Probate Code. First, Probate Code Section 4683(a) provides that, subject to any limitations in the power of attorney for healthcare, “An agent designated in the Power of Attorney may make health care decisions for the principal to the same extent the principal could make health care decisions if the principal had the capacity to do so.” Second, Probate Code Section 4684 provides that “[a]n agent shall make a health care decision in accordance with the individual’s health care instructions, if any, and other wishes to the extent known to the agent. Otherwise, the agent shall make the decision in accordance with the agent’s determination of the principal’s best interests.” Third, Probate Code Section 4688 provides: “Where this division does not provide a rule governing agents under powers of attorney, the law of agency applies.”

In *Hogan v. Country Villa Health Services*,<sup>17</sup> following *Garrison*, the court held that a mother’s designation of her daughter in a durable power of attorney for healthcare authorized the daughter to enter into a binding arbitration agreement. The *Hogan* court explained that “an agent under a health care power of attorney...is empowered to execute arbitration agreements as part of a long-term health care facility’s admissions package, without violating the principal’s constitutional right to a jury trial.”<sup>18</sup> In this case, the mother signed a healthcare power of attorney designating her daughter as her agent, but chose not to limit the authority of her agent to select or discharge healthcare providers or institutions. The court considered whether that grant of authority included the right of the daughter to sign an admission agreement that contained an arbitration provision. Applying the general law of agency and Probate Code Section 4617 (which addresses the selection and discharge of healthcare providers and institutions as a healthcare decision), the *Hogan* court answered in the affirmative. The daughter had the authority to sign an admissions agreement containing an arbitration provision. In following the analysis in *Garrison*, the *Hogan* court determined that in the suit for elder abuse filed by children of the decedent against the nursing home, the arbitration clause in the admissions contract should have been enforced.

*Flores v. Evergreen at San Diego LLC*<sup>19</sup> reached a different result on different facts. The court of appeal affirmed the trial court’s denial of the nursing home’s motion to compel arbitration, finding that there was no evidence that a wife, suffering from dementia and other ailments, had authorized her husband to act as her agent to bind her to a nursing home arbitration agreement. In this case, there was no advance healthcare directive, and husband did not have power of attorney, and he had not been declared her conservator or guardian. The *Flores* court rejected the nursing home’s contention that the husband’s act of signing the arbitration agreement created agency status, explaining that the conduct of the principal was necessary to show agency. The *Flores* opinion further explained that although the nursing home presented evidence that the husband had acted as if he were his wife’s agent, establishment of agency required conduct on the part of the wife conferring that status. A person cannot become the agent of another merely by representing himself or herself as such. To be an agent, a person must actually be so empowered by the principal.<sup>20</sup>

A different result was seen in an unpublished case.<sup>21</sup> *Waterman v. Evergreen at Petaluma LLC*<sup>22</sup> was a civil action for personal injuries and elder abuse brought by Waterman as successor-in-interest to her deceased father and for wrongful death brought in her individual capacity. She had signed two arbitration agreements at the time she admitted her father into Evergreen Skilled Nursing Facility. Her father had signed an advance healthcare directive containing a power of attorney for healthcare. Waterman was his designated agent for healthcare decisions and his attorney-in-fact. In this case, the wording of the arbitration agreement signature lines was ambiguous, leaving it unclear whether Waterman signed the agreement as her father’s agent or merely as the responsible party. She also signed the resident agreement with the nursing home as her father’s responsible party, not as his agent or attorney-in-fact. In addition, neither the advance healthcare directive nor the financial power of attorney had been triggered so as to empower Waterman to waive her father’s jury trial rights by binding him to arbitration. The advance healthcare directive provided that her authority as her father’s agent became effective only when his primary physician determined that he was unable to make his own healthcare decisions. The financial power of attorney provided that it would take effect only if Waterman’s father became incapacitated or unable to manage his own financial affairs, and that his incapacity was required to be determined by written declaration of two licensed physicians. None of the trigger events occurred.

The court of appeal affirmed the trial court’s conclusion that there was no statutory or contractual basis for concluding that Waterman was authorized to waive her father’s right to pursue legal action rather than arbitration. Consequently, no valid arbitration contract existed, and the Evergreen Nursing Home’s petition to compel arbitration was properly denied.

Another unpublished but instructive case found no agency authority and no right to bind the patient to arbitration. In *Hatley v. Superior Court*,<sup>23</sup> the Hanford Nursing and Rehabilitation Hospital sought arbitration of two civil actions for negligence and elder abuse. The trial court ordered arbitration of the entire case, but the court of appeal granted a writ and held that the petition to compel arbitration should not have been granted. (The Supreme Court had granted a hearing, then ordered the case transferred back to the appellate court with directions.) As in the *Waterman* case, there was no advance healthcare directive signed by the patient. The evidence made it not difficult to conclude that the decedent’s nephew did not have authority to bind the decedent to an arbitration contract. Another question was whether the decedent’s spouse validly executed the arbitration agreement on the decedent’s behalf. The answer was no; the evidence established no such authority. The court, following *Flores*, held that no statutory basis existed for a person, including a spouse, to agree to arbitration based solely on a familial relationship with the patient absent express authority to do so.<sup>24</sup>

The *Flores* and *Hatley* opinions further illustrate that a detailed and comprehensive statutory scheme exists in the Health and Safety Code<sup>25</sup> regarding the signature of a patient’s agent, responsible party, or legal representative on an admission contract to a nursing home and the authority for medical decisions if a patient lacks capacity. However, the statute does not define the precise scope of that authority, and case law holds that it does not include the right to consent and bind the patient to an arbitration provision.<sup>26</sup>

## Spousal Authority

As the cases above indicate, it is often family members who become agents for patients who lack capacity. It is a common misperception, however, that spouses assume agency when their spouses become unable to make medical decisions. In reality, there is no automatic right or entitlement of a spouse to make such decisions. Probate Code section 4717 places a spouse in the generic category of family member with no expressly provided priority. In addition, case law provides that marital status alone does not create an agency relationship between spouses.<sup>27</sup> Without

direct agency authority (i.e., express appointment of a spouse as designated agent), federal and state law create obstacles for healthcare decisions by limiting access to a patient's medical information and records.<sup>28</sup> The chief goal of these laws is to guarantee protection of an individual patient's health information while balancing the need to provide quality healthcare. Good practice dictates that when drafting advance healthcare directives, express HIPAA<sup>29</sup> and California's PAMRA<sup>30</sup> authorization is to be included.<sup>31</sup>

## Gray Areas

Even if a healthcare agent is properly designated, the reach of the agent's authority is often less than certain. For example, it is unclear whether an agent can consent to the off-label administration of a drug or to the principal's enrollment in a clinical trial. Another issue is if the patient's wishes for treatment for an unanticipated condition are unknown, may the agent apply his or her own values to make a decision, or can the agent base a decision on the substituted judgment standard of Probate Code sections 2580-86? These decisions often have no clear guidelines, which is why hospitals and medical centers have ethics committees to guide healthcare providers, assess risk management, and advise healthcare agents and families who struggle in the emotionally difficult gray area in which many critical decisions affecting loved ones are made. Another potential source of guidance for agents and family members is a hospital's chaplaincy service, which offers consultation with clergy of diverse faiths in times of stress and ultimate decision making.<sup>32</sup>

The UCLA Medical Center and Cedars-Sinai Medical Center, for example, have chaplaincy programs with clergy from a diversity of faiths. It has been wisely observed that "[c]onversations around the hospital bed cut through the intellectual subtleties of theology into hard core of being."<sup>33</sup> Probate Code section 4700 allows an individual to set forth provisions and values regarding personal healthcare preferences other than those set forth in the statutory form. Well-informed counsel often suggest to clients that they add their own personal healthcare wishes and values, including consultation with clergy if they so desire, to assist their designated agents in making future healthcare decisions in unanticipated medical situations.

Personal healthcare planning in anticipation of future incapacity should be made in good health. Designation of a healthcare agent or agents, end-of-life decisions, alleviation-of-pain directions, and other aspects of medical care should be the subject of sober reflection, discussion with family, and specific and appropriate documentation. The Book of Ecclesiastes provides appropriate guidance in this regard:

"So appreciate your vigor in the days of your youth, before those days of sorrow come and those years arrive of which you will say: 'I have no pleasure in them.'"<sup>34</sup> ■

<sup>1</sup> Patient Protection and Affordable Care Act, 124 Stat. 119; 42 U.S.C. §§18001 *et seq.*; see also National Federation of Independent Business v. Sebelius, 132 S. Ct. 2566 (2012); King v. Burwell, 135 S. Ct. 2480 (2015).

<sup>2</sup> PROB. CODE §§4600 *et seq.*

<sup>3</sup> STEVEN BRILL, AMERICA'S BITTER PILL, 473 (2013).

<sup>4</sup> PROB. CODE §§4615, 4617.

<sup>5</sup> PROB. CODE §4607.

<sup>6</sup> PROB. CODE §4701.

<sup>7</sup> PROB. CODE §4700.

<sup>8</sup> See California Medical Association (CMA), at <http://www.cmanet.org>.

<sup>9</sup> See California Hospital Association (CHA), at [http://www.calhospital.org/sites/main/files/file-attachments/forms\\_3.pdf](http://www.calhospital.org/sites/main/files/file-attachments/forms_3.pdf).

<sup>10</sup> See <http://cedars-sinai.edu/AdvanceHealthcareDirective>.

<sup>11</sup> See Cedars-Sinai Medical Center Advance Healthcare Directive booklet, available at <http://cedars-sinai.edu/AdvanceHealthcareDirective>.

<sup>12</sup> PROB. CODE §4609 (capacity); see also PROB. CODE §§4120, 4657; CIV. CODE §2296; In re Marriage of Greenway, 217 Cal. App. 4th 628 (2013).

<sup>13</sup> PROB. CODE §§810-813; PROB. CODE §§1801, 1881, 3201, 3204.

<sup>14</sup> Marshall S. Zolla, *The California Lawyer's Grey Fog of Uncertainty: Assessing a Client's Diminished Mental Capacity*, CAL. FAM. L. MONTHLY (Nov. 2014).

<sup>15</sup> Garrison v. Superior Court, 132 Cal. App. 4th 253 (2005).

<sup>16</sup> See PROB. CODE §§4600-4643.

<sup>17</sup> Hogan v. Country Villa Health Servs., 148 Cal. App. 4th 259 (2007).

<sup>18</sup> *Id.* at 269.

<sup>19</sup> Flores v. Evergreen at San Diego LLC, 148 Cal. App. 4th 581 (2007).

<sup>20</sup> Pagarigan v. Libby Care Center, 99 Cal. App. 4th 298 (2002); Van't Rood v. County of Santa Clara, 113 Cal. App. 4th 549 (2003).

<sup>21</sup> Cal. R. of Ct. 8.1105, 8.1110, 8.1115.

<sup>22</sup> Waterman v. Evergreen at Petaluma LLC, 2008 WL 4359556 (2008).

<sup>23</sup> Hatley v. Superior Court, 2008 WL 240841 (unpublished).

<sup>24</sup> *Cf.* Flores v. Evergreen at San Diego LLC, 148 Cal. App. 4th 581, 589 (2007).

<sup>25</sup> HEALTH & SAFETY CODE §§1250(c), 1326, 1418(a) (1), 1430(b), 1599, 1599.60(b).

<sup>26</sup> *Cf.* Flores, 148 Cal. App. 4th at 549.

<sup>27</sup> *Id.* at 589.

<sup>28</sup> The Federal Health Insurance Portability and Accountability Act of 1996 (HIPAA), Pub. L. No 104-191, 45 C.F.R. ¶160, 164 (Aug. 21, 1996, amended 2002); Patient Access to Medical Records Act (PAMRA), codified at HEALTH & SAFETY CODE §§123110-123149.5.

<sup>29</sup> HIPAA, Pub. L. No 104-191, 45 C.F.R. ¶160, 164.

<sup>30</sup> HEALTH & SAFETY CODE §§123110-123149.5.

<sup>31</sup> See Cozette Vergari, *Providing Spouses with the Power to Make Healthcare Decisions*, LOS ANGELES LAWYER 18 (Nov. 2007); Marshall S. Zolla & Deborah E. Zolla, *Lasting Wishes*, LOS ANGELES LAWYER 42 (Dec. 2000).

<sup>32</sup> See, e.g., JEFF LEVIN & MICHELE F. PRINCE, JUDAISM AND HEALTH (2013); WILLIAM CUTTER & MICHELE F. PRINCE, MIDRASH AND MEDICINE (2012).

<sup>33</sup> Rabbi Harold M. Schulweis, *Conversation with the Angel of Death* (1991), available at <http://www.jewishjournal.com> (quoted with permission).

<sup>34</sup> Ecclesiastes 12.1-12.2.

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## Lasting Wishes

California's new Health Care Decisions Law smooths the procedural path for those who wish to control their medical treatment in their last days

**E**nd-of-life issues and concerns are as ancient as biblical sources and commentaries<sup>1</sup> and as modern as the new California Health Care Decisions Law, effective July 1, 2000.<sup>2</sup> These dramatic issues have affected the American consciousness since 1976, when *In re Quinlan*,<sup>3</sup> a well-publicized and watershed case, brought the age-old and critical issue of decision making at the end of life into contemporary society. In *Quinlan*, Karen Ann Quinlan's father sought a court order to have his daughter, who had long been in a persistent vegetative state, removed from a respirator. The New Jersey Supreme Court held that Karen had a right of privacy that encompassed the right to decline medical treatment under both the U.S. and New Jersey Constitutions and that could be asserted on her behalf by her guardian.<sup>4</sup>

When Karen Quinlan became comatose in 1975, no state recognized a patient's right to set limits on life-prolonging medical efforts. Since then, all 50 states have enacted legislation governing the requirements for some type of advanced healthcare directive.<sup>5</sup>

The California Health Care Decisions Law is codified in Sections 4600 through 4805 of the Probate Code.<sup>6</sup> The Legislative Findings contained in Probate Code Section 4650 set forth the new law's public pol-

icy,<sup>7</sup> which recognizes a patient's right to control decisions relating to his or her own healthcare. A patient's right of individual autonomy, privacy, and dignity includes the right to exercise control over healthcare decisions when modern medical technology has made possible the prolongation of life beyond natural limits.<sup>8</sup>

Before the passage of the Health Care Decisions Law, there were five statutorily recognized ways in California in which a patient could make his or her treatment preferences known in case of subsequent incompetency: 1) advanced directives pursuant to the Natural Death Act,<sup>9</sup> 2) durable powers of attorney for healthcare,<sup>10</sup> 3) statutory surrogacy,<sup>11</sup> 4) a court-appointed conservator,<sup>12</sup> and 5) other judicial intervention.<sup>13</sup> The first two have been superseded by the new law.<sup>14</sup>

Similarly, before this year, there were three primary kinds of documents that addressed the healthcare of incompetent patients: 1) advance directives pursuant to the Natural Death Act, which allowed a patient in good health to authorize his or her doctor to forego life-sustaining treatment in the event of terminal illness; 2) durable powers of attorney for healthcare, which appointed an agent to make appropriate decisions for an incompetent patient; and 3) statutory surrogacy provisions. Conflicts existed among the different forms. Realizing that

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California law did not adequately address numerous important issues concerning healthcare decisions for adults who lack capacity, the California Legislature decided to provide procedures and standards in this area and adopt consistent rules governing healthcare decision making by surrogates.

The Health Care Decisions Law<sup>15</sup> makes numerous revisions to prior law in order to promote the use and recognition of advance directives and improves the effectiveness of directives in the realization of patients' wishes once they become incapable of making decisions for themselves. The Health Care Decisions Law applies to all powers of attorney for healthcare no matter when they were executed.<sup>16</sup> A durable power of attorney for healthcare that was valid under prior law remains valid under the new law.<sup>17</sup> The new law allows patients to execute a directive about the use of life-sustaining treatment and to appoint a third party to carry out their wishes. Appointed individuals are given the authority to act in the principal's best interests when the healthcare wishes of the principal are unknown or unclear in his or her directive.<sup>18</sup>

Included in the new law is a statutory form Advance Health Care Directive<sup>19</sup> that improves on earlier forms by using simpler, more modern terminology that will make the directive easier to use and understand. The new form will help people focus on the decisions that ultimately involve soul-searching questions, such as whether or not to prolong life, whether or not to withhold or withdraw artificial nutrition and hydration, instructions concerning cardiopulmonary resuscitation, relief from pain, and donation of organs at death. The use of the statutory form is not mandatory for an enforceable advance healthcare directive in California,<sup>20</sup> and an individual who chooses to use the form may complete or modify all or any part of it.<sup>21</sup> The form can be found in Probate Code Section 4701.

A patient can still make his or her treatment preferences known by statutory surrogacy.<sup>22</sup> This approach is used when the patient, despite having executed an advance directive, may be faced with unforeseen changes, such as new medical treatments and procedures, that would substantially alter the person's choice of treatment.<sup>23</sup> This approach is commonly used when the patient does not execute a living will and does not appoint a surrogate decision maker pursuant to the durable power of attorney for healthcare law. Surrogate decision makers are also effective when something unexpected happens, such as the expiration of an executed durable power of attorney.<sup>24</sup> Judging from statistics that indicate that only approximately 10 to 20 percent of adults have advance directives, surrogate decision makers are frequently used.<sup>25</sup>

How does a surrogate decision maker elect a choice when none has been made? Who are the individuals or family members charged with the responsibility to make such decisions? There exists a significant gap in the new Health Care Decisions Law because the proposed statutory provision listing possible adult surrogates with a relationship to the patient to be selected by the primary physician was deleted from the proposed legislation and was not enacted as part of the new law.<sup>26</sup> Courts have responded by looking for what the patient would have chosen.<sup>27</sup> A judgment based on a search of the patient's competent life for his or her preferences, values, and commitments is appropriate—not because it

is required by the patient's right of autonomy but because it is in the patient's best interests to achieve a treatment plan that the patient would have wanted if the patient had been able to so designate.<sup>28</sup>

The doctrine of "substituted judgment" focuses on the patient's treatment preferences to the extent they are discoverable. This decision-making standard considers factors such as statements made by the patient while competent regarding medical decisions and the religious, moral, and philosophical convictions of the patient. When the patient's wishes are unexpressed or unclear, it becomes harder to justify third-party treatment decisions because there is too little information to ensure that the decision reflects the patient's own preferences. In such a case, the surrogate decision maker's own standards and philosophy exert a substantial influence on the treatment decision. In effect, the surrogate decision maker makes the treatment decision rather than giving voice to the patient's decision. This situation is one in which the surrogate decision maker evaluates the patient's then-existing status and makes a treatment decision based on what he or she concludes is in the patient's best interests.<sup>29</sup>

There is no simple solution to the complex problem of determining future medical decisions. It requires balancing the interests of many different parties and concerns. Patients and their families have an interest in being treated with respect and dignity. The state has an interest in protecting its citizens from premature death. The medical profession has an interest in protecting its integrity and ensuring that scarce medical resources are put to the best uses. Finally, the judicial system, in the absence of direct legislative guidance, has an interest in ensuring that existing legal standards are not violated in the pursuit of these conflicting interests.<sup>30</sup>

Attorneys drafting advance healthcare directives should be aware of potential ethical pitfalls. The client is the person for whom the document is being drafted, not the spouse, adult child, or friend who may have first contacted the attorney.<sup>31</sup> One of the main decisions for the principal is naming his or her agent. The issue of capacity raises another ethical dilemma. The Due Process Incompetents Determin-

## In Honor and Memory

Theodore Zolla, father and grandfather of the authors, completed and signed a durable power of attorney for healthcare on June 1, 1992. The directive was signed as part of his estate plan after careful financial planning and discussions with his family. He was 87 years old.

In May 2000, at age 95 and still active playing bridge, golf, and traveling, he fell ill. After being admitted to the hospital, the family was asked to obtain his advance healthcare directive so that his medical wishes could be known and carried out. In reviewing his directive, in the midst of his deteriorating health condition, the authors noticed that the seven-year time limitation in the directive had expired. That sparked an inquiry into the California statutes governing advance healthcare directives, in which the authors discovered that the seven-year limitation of former Civil Code Section 2436.5 was continued in 1994 in Probate Code Section 4654 and then repealed in 1999. In addition, state, federal, and case law had changed to cope with evolving medical technology. In particular, California had enacted its new Health Care Decisions Law, which became effective on July 1, 2000.

As he slipped into unconsciousness, end-of-life decisions had to be faced, discussed, and resolved with family, attending physicians, and rabbis. The authors decided to research and write this article in honor and memory of their father and grandfather.

Theodore Zolla died on July 5, 2000, at the age of 95.—M.S.Z. & D.E.Z.



ations Act<sup>32</sup> sets forth standards for determining if a person has the capacity to perform particular acts, including the capacity to give medical consent.<sup>33</sup>

For 15 years following *Quinlan*, various state courts struggled with the right-to-die issue and arrived at conflicting decisions. More than 100 cases covering some aspect of right-to-die issues and dilemmas were litigated throughout the country, with withdrawals of medical care permitted in some instances and denied in others. Each case contributed its own special nuance to the ongoing debate.

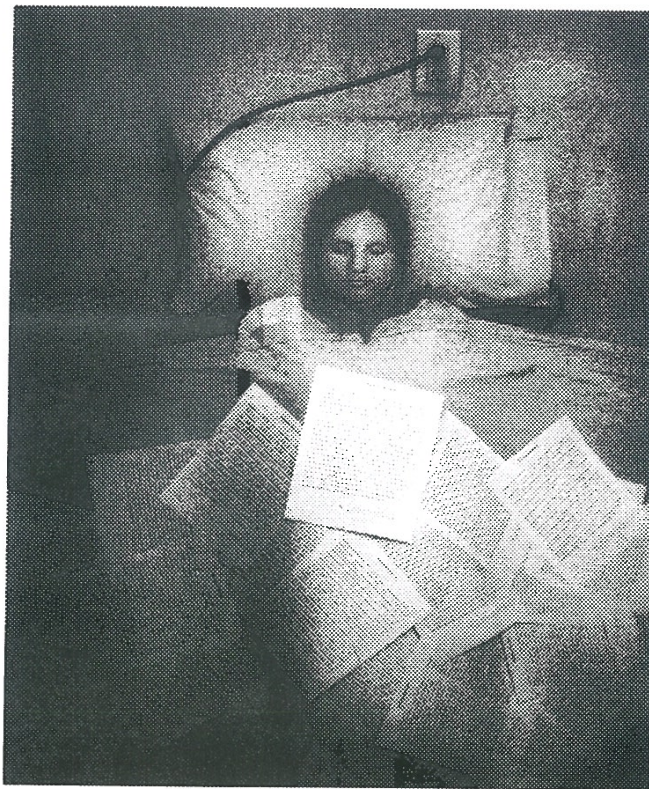
### Evolution of California Statutory and Case Law

With the enactment of the 1976 Natural Death Act, California became a pioneer in the area of healthcare decision making for adults without decision-making capacity.<sup>34</sup> Durable power of attorney statutes had been in effect since 1979,<sup>35</sup> and durable power of attorney for healthcare statutes were enacted in 1983.<sup>36</sup> In 1990, the federal Patient Self-Determination Act was codified.<sup>37</sup> However, not until 1994 were a diverse number of statutes consolidated and expanded into the California Power of Attorney Law.<sup>38</sup> As indicated in the 1994 recommendation report from the California Law Revision Commission,<sup>39</sup> placement of the Power of Attorney Law in the Probate Code reinforced its nature as an estate planning device.

The years between the the enactment of the durable power of attorney statutes in 1979 and the Power of Attorney Law in 1994 saw a number of groundbreaking and widely cited judicial decisions dealing with these practical and increasingly difficult medical, ethical, and legal issues. In 1983, in *Barber v. Superior Court*,<sup>40</sup> two physicians were charged with murder and conspiracy to commit murder after life support measures were terminated for a deeply comatose patient in accordance with the wishes of the patient's immediate family.<sup>41</sup> The doctors petitioned the court of appeal for a writ of prohibition to dismiss the charges. The court of appeal granted the writ, holding that cessation of heroic life support measures was not an affirmative act but rather a withdrawal or omission of further treatment.

The *Barber* court emphasized that the physicians' omission to continue life support procedures, although intentional and with the knowledge that the patient would die, was not an unlawful act. The doctors had no legal duty to continue medical treatment when the patient had virtually no chance of recovering and when the family consented to the termination. Further, the court underscored that the failure to institute formal guardianship proceedings did not render the physicians' conduct unlawful. There was no such statutory requirement for guardianship and, under the circumstances, the wife was the proper person to act as surrogate decision maker for the patient.

The court also held that there was no legal requirement for prior judicial approval of a decision to withdraw treatment.<sup>42</sup> Moreover, the opinion stated, "Although there may be a duty to provide life-sustaining machinery in the aftermath of a cardio-respiratory arrest, there is no duty to continue its use once it has become futile in the opinion of qualified medical personnel." Despite the breadth of its language, however, *Barber* did not dispose of the issue of who can consent to treatment because the issue arose as part of a defense to a charge of murder—specifically, whether the doctors could rely on requests from the family of the patient. Indeed, the court was aware of the difficulty of



determining who should be included in the patient's "family" for the purpose of decision making by surrogate.<sup>43</sup>

The *Bartling v. Superior Court* decision<sup>44</sup> came one year after *Barber*. William Bartling had executed a living will and a durable power of attorney for healthcare evidencing his wish to discontinue ventilator life support. The Glendale Adventist Medical Center refused to withdraw the ventilator. The trial court denied Bartling's request for an injunction against further treatment; the court of appeal reversed, holding that his expressed wishes in his advance directive should have been honored. The appellate court held that the right of a competent adult patient to refuse medical treatment is a constitutionally guaranteed right that must not be abridged<sup>45</sup> and "if the right of the patient to self-determination as to his own medical treatment is to have any meaning at all, it must be paramount to the interests of the patient's hospital and doctors."<sup>46</sup>

In 1986, the *Bouvia v. Superior Court* case, which involved a patient's desire to refuse nutrition and hydration, generated a great deal of controversy.<sup>47</sup> In *Bouvia*, the trial court denied the patient's request to have her feeding tube removed. The court of appeal issued a writ of mandate reversing the trial court order and holding that a competent patient had the right to remove a feeding tube even though she might be kept alive for 15 or 20 years if it were left in place. The language of the court majority is as direct as its ruling: "[The] [p]etitioner sought to enforce only a right which was exclusively hers and over which neither the medical profession nor the judiciary have any veto power."<sup>48</sup>

The divided opinion in the *Bouvia* case was not without dissension and controversy. The majority concluded that the patient's decision to allow nature to take its course was not equivalent to an election to commit suicide.<sup>49</sup> A concurring opinion struggled with the suicide issue and poignantly observed, "Whatever choice Elizabeth Bouvia may ultimately make, I can only hope that her courage, persistence and example will cause our society to deal realistically with the plight of those unfortunate individuals to whom death beckons as a welcome respite from suffering."<sup>50</sup> The Health Care Decisions Law is a signifi-



icant step in that direction.

*Conservatorship of Drabick*<sup>51</sup> is another influential case. In *Drabick*, the conservator sought court approval to remove the nasogastric feeding tube of the conservatee, who was in a persistent vegetative state. No one opposed the action; the conservator simply wanted a court order to protect the healthcare providers.<sup>52</sup> A county public defender appointed to represent the conservatee-patient agreed with the proposed termination of treatment. Nevertheless, the probate court denied the conservator's petition on the ground that continued feeding was in the patient's best interests. The conservator appealed. The court of appeal reversed the probate court and allowed removal of the feeding tube. The court held that, in California, each adult has a right to determine the scope of his or her own medical treatment, which includes the legal right to refuse medical treatment such as artificial nutrition and hydration. Further, incompetent patients retain the right to have appropriate medical decisions made on their behalf. An "appropriate medical decision" was defined as one that is made in the patient's best interests, as distinct from one made in the interests of the hospital, the physicians, the legal system, or anyone else.<sup>53</sup>

The *Drabick* court observed that under Probate Code Section 2355, which provides that the conservator need not obtain judicial approval of its decision absent disagreement among interested parties, the probate court will review a conservator's proposed decision only if there is a dispute among interested parties or if the conservator seeks confirmation of a proposed action.<sup>54</sup> Thus, as a practical matter, the court will become involved only if, for example, there is a family dispute, a doctor demands judicial confirmation, or a conservator seeks judicial confirmation as a precaution.

In 1990, the U.S. Supreme Court decided its first right-to-die case, *Cruzan v. Director, Missouri Department of Health*.<sup>55</sup> In *Cruzan*, the existence of a constitutionally protected right to refuse treatment was affirmed on a national level. The *Cruzan* opinion upheld a constitutional right to die and recognized a constitutionally protected liberty interest to refuse treatment—but the Court left to the individual states the task of establishing their own guidelines on life or death treatment decisions for incapacitated persons. The Supreme Court's opinion opened the door to enactment of advance directive statutes like those enacted in California by holding that an appointed surrogate decision maker would have the right to refuse treatment on behalf of an incapacitated individual. But the *Cruzan* Court also made it clear that a patient's rights are jeopardized if he or she fails to leave explicit advance instructions.

### Conflicts between Healthcare Providers and Patients

In our society, sensitive services such as termination of life support create potential conflicts between healthcare providers and patients. Tension arises when healthcare providers insist on providing care in accordance with their own beliefs and refuse to grant patients access to medical care that the providers find objectionable.<sup>56</sup>

The constitutional complication inherent in this provider-patient conflict emerges in an analysis of the interaction between the free exercise and establishment clauses of the First Amendment and patients' right to privacy.<sup>57</sup> If religious healthcare providers, institutions, and health plans are allowed to refuse to provide services on religious or moral grounds, patient access to healthcare may be significantly curtailed.<sup>58</sup> Although the right to refuse life-sustaining medical treatment is constitutionally protected, patients may experience difficulty in getting religious providers to implement their advance directives.<sup>59</sup> No federal or state law has established a fundamental right to healthcare. Thus, in conflicts between religious beliefs and healthcare choices, it is not surprising that religious beliefs have received more statutory and legal protection. However, consistent with the constitutional protections that prevent both the imposition of religious

beliefs as well as limitations on individuals to refuse life-sustaining treatment, patient rights to services must not be compromised. Policymakers should devise alternative means to ensure that patients can go to providers willing to honor their treatment requests.<sup>60</sup>

The fact that a patient has the right to refuse continued medical treatment, however, does not give rise to a concomitant physician duty to discontinue care upon request. This principle is illustrated by *Conservatorship of Morrison v. Abramovitch*.<sup>61</sup> In that case, the conservator-daughter of a 90-year-old woman in a persistent vegetative state sought removal of a nasogastric feeding tube from her mother. The hospital physicians refused the daughter's request due to "personal moral objections."<sup>62</sup> At issue was whether a conservator can require a physician to comply with a treatment request against the physician's personal moral objections. The court answered this question by basing its holding on the prevailing view among medical ethicists that a physician has the right to refuse to follow a conservator's direction to withhold life-sustaining treatment on personal moral grounds, but must be willing to transfer the patient to another physician who will follow the conservator's direction.<sup>63</sup>

Physicians not only have the right to refuse to follow a patient's direction to withhold life-sustaining treatment but customarily are not punished for ignoring a patient's preferences about life-sustaining care. Accumulated evidence indicates that physicians and healthcare providers often ignore patient preferences about life-sustaining care.<sup>64</sup> But the likelihood of wrongfully treated patients recovering compensatory damages has been placed in doubt. Courts and commentators alike have suggested that actions for life support not consented to by the patient are analogous to actions for wrongful life and should, for that reason, be rejected.<sup>65</sup>

End-of-life issues continue to be presented to the judicial system for resolution, as evidenced by the recent grant of review by the California Supreme Court in *In re Conservatorship of Wendland*.<sup>66</sup> The *Wendland* case involves a struggle between the wife, mother, and sister of a 42-year-old man who was brain damaged and cognitively impaired in a motor vehicle accident but is conscious and sometimes able to respond to simple commands. The patient's wife sought permission to remove the feeding tube and to allow her husband to die; the mother and sister objected. The trial court refused permission to remove the feeding tube. The court of appeal reversed with directions in a lengthy and detailed opinion that has now been superseded by the supreme court's grant of review.

The debate over adequate and affordable healthcare and ethical decision making at the end of life has permeated political, medical, legal, religious, and bioethics discourse during most of the past decade<sup>67</sup> and continues to command widespread national and international attention.<sup>68</sup> Technological advances in the medical field persist in outpacing the ability of society to accommodate them.<sup>69</sup> Because no one knows when tragedy or illness may strike, adults of all ages would best be served by considering, completing, and signing an advance directive under the new Health Care Decisions Law. Upon signing an advance directive, adults should give a copy to their doctor and their family and should keep a duplicate original or copy in a safety deposit box.

The values the patient and physician bring to the bedside are not similarly constituted. A patient's values and considerations may comprise religious, sociological, economic, and psychological influences.<sup>70</sup> A physician's values may be similarly derived but may be tempered by experiences and training in the medical field.<sup>71</sup> The legal counselor can help by providing focus and well-reasoned advice. Mere technical expertise is not enough; concern for the overall well-being of the client requires consideration of the client's financial, moral, religious, family, and personal set of values.

If clients, patients, or attorneys need inspiration beyond medical



technology and legal technicalities, perhaps they can look to the wise words from the book of Ecclesiastes, which serve as a reminder that dying has been part of life since time immemorial:

Remember then thy Creator in the days of thy youth,  
Before the evil days come,  
And the years draw nigh, when thou shalt say:  
"I have no pleasure in them";...  
Before the silver cord is snapped asunder,  
And the golden bowl is shattered,  
And the pitcher is broken at the fountain,  
And the wheel falleth shattered, into the pit;  
And the dust returneth to the earth as it was....<sup>72</sup>

And in the end, from the same source, there are further words of comfort: "[T]o everything there is a season, a time to be born and a time to die...."<sup>73</sup> ■

<sup>1</sup> 2 Kings 4:8-37; Psalms 23, 41:4; Isaiah 38:1-8; Jeremiah 17:14; TALMUD (*Shabbat* 151b); JOSEPH CARO, SHULCAN ARUCH, YOREH DE'AH 339.

<sup>2</sup> PROB. CODE §§4600 *et seq.* (effective July 1, 2000).

<sup>3</sup> In re Quinlan, 355 A. 2d 647 (N.J. 1976), *cert. denied*, 429 U.S. 922 (1976). Chief Justice Rehnquist described Quinlan as a "seminal decision" on the issue of the right to refuse treatment.

<sup>4</sup> *Id.*

<sup>5</sup> Bretton J. Hottor, *A Survey of Living Will and Advanced Healthcare Directives*, 74 N.D. L. REV. 233 (1998). This article surveys selective state statutes concerning end-of-life treatment decisions, living wills, healthcare agent designation laws, and surrogate decision-maker laws. See also Rachel Pergament & Brian Raphael, *Gerontology and the Law: A Selected Annotated Bibliography: 1995-1998 Update*, 72 S. CAL. L. REV. 1461, 1502-03 (1999); Ernie W. D. Young, *Ethical Issues at the End of Life*, 9 STAN. L. & POL'Y REV. 267 (1998). Young's article discusses ethical issues related to end-of-life decisions and the challenge facing "courts, legislatures, healthcare professionals and bioethicists to discern humane and morally acceptable ways of assisting patients and their families as death approaches."

<sup>6</sup> The provisions of the Power of Attorney Law governing powers of attorney for healthcare and the Natural Death Act were repealed, and the Power of Attorney Law no longer applies to powers of attorney for healthcare. PROB. CODE §§4010-4310, 4600-4805; HEALTH & SAFETY CODE §§7185-7194.5; PROB. CODE §4050(a).

<sup>7</sup> PROB. CODE §4650.

The Legislature finds the following: (a) In recognition of the dignity and privacy a person has a right to expect, the law recognizes that an adult has the fundamental right to control the decisions relating to his or her own health care, including the decision to have life-sustaining treatment withheld or withdrawn. (b) Modern medical technology has made possible the artificial prolongation of human life beyond natural limits. In the interest of protecting individual autonomy, this prolongation of the process of dying for a person for whom continued health care does not improve the prognosis for recovery may violate patient dignity

and cause unnecessary pain and suffering, while providing nothing medically necessary or beneficial to the person. (c) In the absence of controversy, a court is normally not the proper forum in which to make health care decisions, including decisions regarding life-sustaining treatment.

<sup>8</sup> *Id.*

<sup>9</sup> 1976 Cal. Stat. ch. 1439.

<sup>10</sup> 1983 Cal. Stat. ch. 1204; former PROB. CODE §§4600 *et seq.*

<sup>11</sup> 2000 Health Care Decisions Law and Revised Power of Attorney Law, 30 Cal. L. Rev. Comm'n Rep. 1, at 26-30 (2000).

<sup>12</sup> PROB. CODE §§1400 *et seq.*

<sup>13</sup> PROB. CODE §§3200 *et seq.*

<sup>14</sup> See 2000 Health Care Decisions Law and Revised Power of Attorney Law, 30 Cal. L. Rev. Comm'n Rep. 1, at 7-12 (2000).

<sup>15</sup> PROB. CODE §§4600 *et seq.*

<sup>16</sup> PROB. CODE §4665(a).

<sup>17</sup> PROB. CODE §4665(e); see 2000 Health Care Decisions Law and Revised Power of Attorney Law, 30 Cal. L. Rev. Comm'n Rep. 1, at 43 (2000).

<sup>18</sup> *Id.*

<sup>19</sup> 2000 Health Care Decisions Law and Revised Power of Attorney Law, 30 Cal. L. Rev. Comm'n Rep. 1, at 12-32 (2000).

<sup>20</sup> PROB. CODE §4700.

<sup>21</sup> *Id.* For an example of a medical directive based upon religious precepts, see Elliot N. Dorff, *A Time to Be Born and a Time to Die, A Jewish Medical Directive for Health Care*, reprinted in RON WOLFSON, *A TIME TO MOURN, A TIME TO COMFORT* 285 (1993).

<sup>22</sup> 2000 Health Care Decisions Law and Revised Power of Attorney Law, 30 Cal. L. Rev. Comm'n Rep. 1, at 10 (2000).

<sup>23</sup> Sanford H. Kadish, *Letting Patients Die: Legal and Moral Reflections*, 80 CAL. L. REV. 857 (July 1992).

<sup>24</sup> Former Civ. CODE §2436.5, continued in 1994 in PROB. CODE §2436.5, repealed by 1999 Cal. Stats. ch. 658 (A.B. 891), 2000 Health Care Decisions Law and Revised Power of Attorney, PROB. CODE §§4600 *et seq.*

<sup>25</sup> 2000 Health Care Decisions Law and Revised Power of Attorney Law, 30 Cal. L. Rev. Comm'n Rep. 1, at 10 n.10 (2000).

<sup>26</sup> Proposed PROB. CODE §4712 and the Law Revision Commission's surrogate committee provisions were removed from A.B. 891 and not enacted into the new Health Care Decisions Law; see 30 Cal. L. Rev. Comm'n Rep. 1, at 10-11, 26-30 (2000).

<sup>27</sup> Kadish, *supra* note 23, at 878 n.91.

<sup>28</sup> *Id.* at 888.

<sup>29</sup> Michele Yuen, *Letting Daddy Die: Adopting New Standards for Surrogate Decision Making*, 39 UCLA L. REV. 581 (Feb. 1992).

<sup>30</sup> *Id.* at 617.

<sup>31</sup> CALIFORNIA DURABLE POWERS OF ATTORNEY §5.3 (CEB, Mar. 2000 update).

<sup>32</sup> Due Process Incompetents Determinations Act, PROB. CODE §§810-813, 1801, 1881, 3201, 3204.

<sup>33</sup> See note 31, *supra*.

<sup>34</sup> 1976 Cal. Stat. ch. 1439. The California Natural Death Act was first enacted in 1976, then repealed in 1991. A new Natural Death Act was enacted and codified at HEALTH & SAFETY CODE §§7185-7195.

<sup>35</sup> Former Civ. CODE §2307.1; 1979 Stats. ch. 234.

<sup>36</sup> 1983 Cal. Stat. 1204, former PROB. CODE §§4600 *et seq.*, enacted on recommendation of the Cal. L. Rev. Comm'n; see 2000 Health Care Decision and Revised Power of Attorney Law, 30 Cal. L. Rev. Comm'n Rep. 1, at 9 n.8 (2000).

<sup>37</sup> Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, §§4206, 4751, 104 Stat. 1388, 1388-115 to 1388-117, 1388-204 to 1388-206. See particularly 42

U.S.C.A. §§1395cc(a), 1396a(w)(1) (1998).

<sup>38</sup> Former PROB. CODE §§4000-4947 (repealed effective July 1, 2000).

<sup>39</sup> 24 Cal. L. Rev. Comm'n Rep. 323, 333 (1994).

<sup>40</sup> Barber v. Superior Court, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484, 491 (1983).

<sup>41</sup> *Id.* at 1010.

<sup>42</sup> *Id.* at 1021.

<sup>43</sup> *Id.*; 2000 Health Care Decisions Law and Revised Power of Attorney Law, 30 Cal. L. Rev. Comm'n Rep. 1, at 20-21 (2000).

<sup>44</sup> Bartling v. Superior Court, 163 Cal. App. 3d 186, 209 Cal. Rptr. 220 (1984).

<sup>45</sup> *Id.* at 195.

<sup>46</sup> *Id.*

<sup>47</sup> Bouvia v. Superior Court, 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (1986), *rev. denied* (June 5, 1986).

<sup>48</sup> *Id.* at 1135.

<sup>49</sup> *Id.* at 1144.

<sup>50</sup> *Id.* at 1147.

<sup>51</sup> Conservatorship of Drabick, 200 Cal. App. 3d 185, 198, 245 Cal. Rptr. 840 (1998).

<sup>52</sup> *Id.* at 202.

<sup>53</sup> *Id.* at 205.

<sup>54</sup> *Id.* at 204.

<sup>55</sup> Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 100 S. Ct. 2841, 111 L. Ed. 224 (1990).

<sup>56</sup> Katherine A. White, *Crisis of Conscience: Reconciling Religious Healthcare Providers' Beliefs and Patients' Rights*, 51 STAN. L. REV. 1703 (July 1999).

<sup>57</sup> *Id.* at 1703.

<sup>58</sup> *Id.* at 1748.

<sup>59</sup> *Id.*

<sup>60</sup> *Id.* at 1749.

<sup>61</sup> Conservatorship of Morrison v. Abramovics, 206 Cal. App. 3d 304, 253 Cal. Rptr. 530 (1988).

<sup>62</sup> *Id.* at 306-07.

<sup>63</sup> *Id.* at 310. See COMMITTEE ON BIO-MEDICAL ETHICS OF THE LOS ANGELES COUNTY MEDICAL ASSOCIATION & LOS ANGELES COUNTY BAR ASSOCIATION, GUIDELINES FOR FOREGOING LIFE-SUSTAINING TREATMENT FOR ADULT PATIENTS 4-5 (1990). The joint committee, in its revised 1990 guidelines, removed some of the burden of transferring a patient from the attending physician. Instead of requiring the declining physician to transfer the patient to another qualified physician, the committee urged the withdrawing physician to simply "cooperate" in the transfer to a new physician.

<sup>64</sup> Phillip G. Peters Jr., *The Illusion of Autonomy at the End of Life: Unconsented Life Support and the Wrongful Life Analogy*, 45 UCLA L. REV. 673 (Feb. 1998).

<sup>65</sup> *Id.* at 674.

<sup>66</sup> In re Conservatorship of Wendland, 78 Cal. App. 4th 517, 93 Cal. Rptr. 2d 550 (2000), *review granted* (June 21, 2000).

<sup>67</sup> ALAN MEISEL, THE RIGHT TO DIE (2d ed. 1995).

<sup>68</sup> *When Living Is a Fate Worse than Death*, NEWSWEEK, Aug. 28, 2000, at 12; *Dying on Our Own Terms*, TIME, Sept. 18, 2000; *New Guidelines Issued by British Government to Deal with Controversial "Do Not Resuscitate" Instructions in National Health Service Hospitals*, LONDON DAILY TELEGRAPH, Sept. 5, 2000.

<sup>69</sup> *Mapping of the Human Genome*, LOS ANGELES TIMES, June 26, 2000; TIME, July 3, 2000, at 19.

<sup>70</sup> See, e.g., ELLIOT N. DORFF, MATTERS OF LIFE AND DEATH, A JEWISH APPROACH TO MODERN MEDICAL ETHICS (1998).

<sup>71</sup> See Judith F. Darr, *A Clash at the Bedside: Patient Autonomy v. a Physician's Professional Conscience*, 44 HASTINGS L. J. 1241 n.97 (1993); for a discussion of the role personal values play in a physician's decision making, see SAMUEL GOROVITZ, DOCTOR'S DILEMMAS: MORAL CONFLICT AND MEDICAL CARE 98-111 (1982).

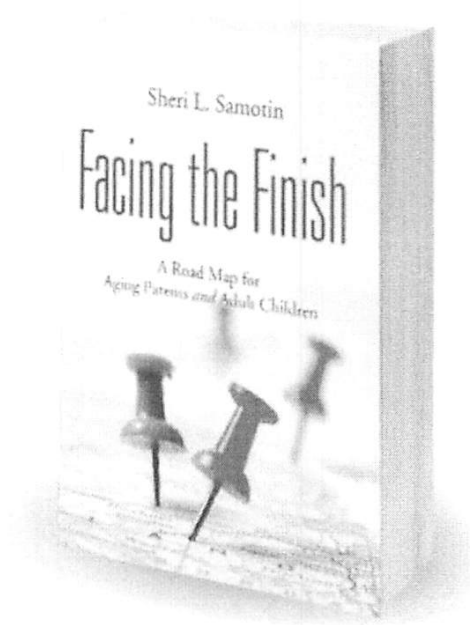
<sup>72</sup> Ecclesiastes 12:1-7.

<sup>73</sup> *Id.* at 3:1-2.

Workbook to accompany . . .

# Facing the Finish

A Road Map for Aging Parents *and* Adult Children



Sheri L. Samotin

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[www.FacingTheFinish.com](http://www.FacingTheFinish.com)

## 25 Tough Questions You Must Answer to Face Your Finish

Take some time to consider the important and tough questions below. Use the space provided to make notes. You may find that it is helpful to come back to these questions after you have worked through the remainder of this workbook.

|   |   |
|---|---|
| 1 | Where would I prefer to live as I age? In my current home or elsewhere?                             |
| 2 | Where do I want to die?   |
| 3 | If I need memory care am I willing to be placed in a memory care specialty unit?                    |
| 4 | If I need help with activities of daily living am I willing to move to an assisted living facility? |

|   |  |
|---|--|
| 5 | If I need custodial care am I willing to move to a nursing home?   |
| 6 | Under what circumstances, if any, would I agree to move in with one of my adult children?  |
| 7 | Who should I choose to make decisions for me if/when I can't make them for myself? Who should act as a backup for my first choice? |
| 8 | What will happen to my "stuff"?  |
| 9 | What needs to be discussed and decided about money?  |

|    |   |
|----|---|
| 10 | Do I want to leave an inheritance for my family or my favorite cause, or do I want to spend my money while I'm still here to enjoy it or for my care?       |
| 11 | How do I feel about surrendering some of my independence? Am I willing to accept certain changes, like giving up driving myself or setting my own schedule? |
| 12 | Am I comfortable with my spouse providing hands on care including bathing and toileting for me?   |
| 13 | Am I comfortable with my adult child providing hands on care including bathing and toileting for me?  |
| 14 | Am I prepared to provide hands-on care including bathing and toileting for my spouse?   |

|    |  |
|----|--|
| 15 | Who will care for me if I can't care for myself and my spouse or children can't either (or I don't have a spouse or children)? |
| 16 | Will I know when I can no longer make my own decisions without help? Is there someone besides me watching out for this?        |
| 17 | Do I want to be resuscitated?  |
| 18 | Do I want a feeding tube or other "heroic" measures?   |
| 19 | How do I feel about hospice care?  |

|    |   |
|----|---|
| 20 | What are my "final wishes"? What kind of funeral do I want?                 |
| 21 | Shall I donate my organs or my entire body to science?                      |
| 22 | Do I want to be buried or cremated? What do I want to become of my remains? |
| 23 | How do I define a meaningful life?  |
| 24 | What do I see as my purpose?  |
| 25 | What is the legacy I hope to leave?   |



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



EMSA #111 B  
(Effective 1/1/2016)\*

## Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact

**Physician/NP/PA.** A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. POLST complements an Advance Directive and is not intended to replace that document.

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

**A**

Check One

**CARDIOPULMONARY RESUSCITATION (CPR):** *If patient has no pulse and is not breathing. If patient is 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**

Check One

**MEDICAL INTERVENTIONS:** *If patient is found with a pulse and/or is breathing.*

- ☐ **Full Treatment** – primary goal of prolonging life by all medically effective means.  
In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
- ☐ **Trial Period of Full Treatment.**
- ☐ **Selective Treatment** – goal of treating medical conditions while avoiding burdensome measures.  
In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
- ☐ **Request transfer to hospital only if comfort needs cannot be met in current location.**
- ☐ **Comfort-Focused Treatment** – primary goal of maximizing comfort.  
Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. **Request transfer to hospital only if comfort needs cannot be met in current location.**

Additional Orders: \_\_\_\_\_

**C**

Check One

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

- ☐ Long-term artificial nutrition, including feeding tubes. Additional Orders: \_\_\_\_\_
- ☐ Trial period of artificial nutrition, including feeding tubes. \_\_\_\_\_
- ☐ No artificial means of nutrition, including feeding tubes. \_\_\_\_\_

**D**
**INFORMATION AND SIGNATURES:**

|  |   |   |
|--|---|---|
| Discussed with:  | <input type="checkbox"/> Patient (Patient Has Capacity) | <input type="checkbox"/> Legally Recognized Decisionmaker |
| <input type="checkbox"/> Advance Directive dated _____, available and reviewed → | Health Care Agent if named in Advance Directive:        |   |
| <input type="checkbox"/> Advance Directive not available                         | Name: _____   |   |
| <input type="checkbox"/> No Advance Directive                                    | Phone: _____  |   |

**Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)**

My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name: \_\_\_\_\_ Physician/NP/PA Phone #: \_\_\_\_\_ Physician/PA License #, NP Cert. #: \_\_\_\_\_

Physician/NP/PA Signature: (required) \_\_\_\_\_ Date: \_\_\_\_\_

**Signature of Patient or Legally Recognized Decisionmaker**

I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name: \_\_\_\_\_ Relationship: (write self if patient) \_\_\_\_\_

Signature: (required) \_\_\_\_\_ Date: \_\_\_\_\_

Mailing Address (street/city/state/zip): \_\_\_\_\_ Phone Number: \_\_\_\_\_

**FOR REGISTRY  
USE ONLY**

**SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED**

\*Form versions with effective dates of 1/1/2009, 4/1/2011 or 10/1/2014 are also valid



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

Name (last, first, middle):

Date of Birth:

Gender:

**M F****NP/PA's Supervising Physician**

Name:

**Preparer Name (if other than signing Physician/NP/PA)**

Name/Title:

Phone #:

**Additional Contact**☐ None

Name:

Relationship to Patient:

Phone #:

**Directions for Health Care Provider****Completing POLST**

- **Completing a POLST form is voluntary.** California law requires that a POLST form be followed by healthcare providers, and provides immunity to those who comply in good faith. In the hospital setting, a patient will be assessed by a physician, or a nurse practitioner (NP) or a physician assistant (PA) acting under the supervision of the physician, who will issue appropriate orders that are consistent with the patient's preferences.
- **POLST does not replace the Advance Directive.** When available, review the Advance Directive and POLST form to ensure consistency, and update forms appropriately to resolve any conflicts.
- POLST must be completed by a health care provider based on patient preferences and medical indications.
- A legally recognized decisionmaker may include a court-appointed conservator or guardian, agent designated in an Advance Directive, orally designated surrogate, spouse, registered domestic partner, parent of a minor, closest available relative, or person whom the patient's physician/NP/PA believes best knows what is in the patient's best interest and will make decisions in accordance with the patient's expressed wishes and values to the extent known.
- A legally recognized decisionmaker may execute the POLST form only if the patient lacks capacity or has designated that the decisionmaker's authority is effective immediately.
- To be valid a POLST form must be signed by (1) a physician, or by a nurse practitioner or a physician assistant acting under the supervision of a physician and within the scope of practice authorized by law and (2) the patient or decisionmaker. Verbal orders are acceptable with follow-up signature by physician/NP/PA in accordance with facility/community policy.
- If a translated form is used with patient or decisionmaker, attach it to the signed English POLST form.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid. A copy should be retained in patient's medical record, on Ultra Pink paper when possible.

**Using POLST**

- Any incomplete section of POLST implies full treatment for that section.

**Section A:**

- If found pulseless and not breathing, no defibrillator (including automated external defibrillators) or chest compressions should be used on a patient who has chosen "Do Not Attempt Resuscitation."

**Section B:**

- When comfort cannot be achieved in the current setting, the patient, including someone with "Comfort-Focused Treatment," should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).
- Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), bi-level positive airway pressure (BiPAP), and bag valve mask (BVM) assisted respirations.
- IV antibiotics and hydration generally are not "Comfort-Focused Treatment."
- Treatment of dehydration prolongs life. If a patient desires IV fluids, indicate "Selective Treatment" or "Full Treatment."
- Depending on local EMS protocol, "Additional Orders" written in Section B may not be implemented by EMS personnel.

**Reviewing POLST**

It is recommended that POLST be reviewed periodically. Review is recommended when:

- The patient is transferred from one care setting or care level to another, or
- There is a substantial change in the patient's health status, or
- The patient's treatment preferences change.

**Modifying and Voiding POLST**

- A patient with capacity can, at any time, request alternative treatment or revoke a POLST by any means that indicates intent to revoke. It is recommended that revocation be documented by drawing a line through Sections A through D, writing "VOID" in large letters, and signing and dating this line.
- A legally recognized decisionmaker may request to modify the orders, in collaboration with the physician/NP/PA, based on the known desires of the patient or, if unknown, the patient's best interests.

This form is approved by the California Emergency Medical Services Authority in cooperation with the statewide POLST Task Force.  
For more information or a copy of the form, visit [www.caPOLST.org](http://www.caPOLST.org).

**SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED**

## **California End of Life Option Act**

### **Information for Our UCLA Patients**

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You have been referred to a patient advocate because you have requested an aid-in-dying drug from your physician or you discussed this issue with another health team member. If you are an adult with a terminal illness, it is your right to make this request, and we at UCLA want to provide the best support and care throughout your illness, whether you receive and use this drug or not.

The California End of Life Option Act, which took effect on June 9, 2016, includes several safeguards and criteria designed to ensure that the law is appropriately used for eligible individuals who request an aid-in-dying drug. At UCLA, we have developed a process that we hope will be helpful to you and your family, as we recognize the significance of these decisions for everyone involved. We have designated a group of specially-trained patient advocates who serve to further educate you and your family about the specifics of the process. Patient advocates also provide physicians with guidance on regulatory compliance, should you choose to proceed with an aid-in-dying drug.

### **What makes you eligible to receive an aid-in-dying drug in California?**

You are:

- An adult, 18 years of age or older
- Terminally ill with six months or less to live, as verified by two physicians
- Mentally capable of making your own healthcare decisions
- Able to prove that you are a resident of California
- Acting voluntarily
- Making an informed decision that includes having information about other end-of-life options that may be helpful to you
- Being informed that you may choose to obtain the aid-in-dying drug but not take it
- Capable of administering and ingesting the aid-in-dying drug all by yourself

In order for you to receive the aid-in-dying drug, your attending physician and a consulting physician must examine you and determine that you are an eligible recipient under the California End of Life Option Act. If there are any concerns about your mental capacity, or indications of a mental disorder, you may be referred to a mental health specialist for an evaluation.

## **Who Will Help You With the California End of Life Option Act?**

Once you have made a request for the aid-in-dying drug, your physician or other healthcare provider will refer you to a patient advocate — a specially-trained psychologist or social worker — for a collaborative consultation. This meeting is intended to educate, inform and assist you with your goals of care. The patient advocate will help you understand what you need to do to obtain the aid-in-dying drug. The patient advocate will also ensure that all the appropriate requests, notes and paperwork are signed and filed in your chart prior to drug prescription. Patient advocates want to make this process as easy as possible for you. If you choose to include your family, the patient advocate will also assist them. You are invited to bring one or more of your family members, a person you identify as your caregiver, or a close friend to the meeting.

## **What Can You Expect During This Consultation?**

The patient advocate will:

- Familiarize you with the law and what is required of you and your physicians.
- Discuss your understanding of your current medical condition, review past psychological and social history, and discuss what an aid-in-dying drug means to you.
- Provide you with appropriate referrals to additional resources that might be helpful to you.
- Facilitate a referral to an independent consulting physician, as required by the law.
- Answer your questions or help you to think through your — and your potential loved ones' — thoughts, concerns and feelings as you go through this process.
- Advocate for you when appropriate and develop a plan to ensure that your needs have been met, and that you have made this decision on your own and have not been pressured by others.

This may be your first referral to a clinical social worker/psychologist or you may have had a clinical social worker/psychologist as a routine part of your care throughout your disease process. In either case, this individual, serving as a patient advocate, will be someone who believes that patients can make decisions for themselves and serve as active participants in their medical care. In addition, the social workers/psychologists on our patient advocate team are all committed to the principles behind the California End of Life Option Act as their participation is voluntary.



## What Topics Might Be Discussed During the Consultation?

Ideas you could consider discussing or getting help with from your advocate include:

- What brought you to this decision?
- What is meaningful to you in your life right now?
- Under what circumstances would you imagine using this drug?
- Are you lacking resources with regard to assistance at home, management of pain or other symptoms, or psychological support?
- What issues are you currently most troubled by?
- What worries, concerns or fears are you currently facing?
- How will this decision impact those who love/care for you?
- What losses have you been facing as a result of your illness and what kind of help have you received?
- Are there specific tasks and goals that you hope to achieve before your life ends?
- Have you prepared any legacies for those you love? (e.g., letters, videos, notes)
- Are there any communications that you hope to have with friends/family/loved ones? If so, do you need help with these?
- Have you made a financial will or an estate plan? Have you made an ethical will?
- Have you completed a current advance healthcare directive?
- Do you or your family have any concerns of faith, conscience or spirituality that would affect your decision?
- Have you and your physician discussed your goals and values of care?
- What questions do you have or information do you need about this process?

## How Is the Consultation Appointment Arranged?

Your physician should request an appointment with a patient advocate. If your physician has not made such a request you may call to schedule such an appointment.

- **For patients with cancer:** Call the Simms/Mann - UCLA Center for Integrative Oncology Center at (310) 794-6644. Ask to schedule an appointment with a patient advocate related to the California End of Life Option Act.
- **For patients with other illnesses:** Call UCLA Care Coordination at (310) 267-9702 and ask to schedule an appointment with a patient advocate related to the California End of Life Option Act.

### **What or Whom Should I Bring to the Consultation?**

- One or more of your family members, a person you identify as your caregiver, or a close friend, if you choose
- Proof of residency in the form of one of the following if you have it: A driver's license or other identification issued by the state of California; registration to vote in California; evidence that you own or lease property in California; filing of a California tax return for the most recent tax year

### **Is This Consultation Required?**

The consultation with the patient advocate is not required by law. At UCLA, it is part of our policy to assign a patient advocate for each patient who makes a request for an aid-in-dying drug and whose physician believes may be an eligible candidate. In order to ensure that you and your physician have the support that you need to move through the process of assessing eligibility and compliance with the law, the appointment with an advocate is required at UCLA.

## **Aid-In-Dying Options: Finding One's Way to Clarity**

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The decision to consider an aid-in-dying drug is only one of the many considerations that need to be taken into account when facing the challenges of an irreversible, life-threatening illness. We believe that having such an illness creates an opportunity for discussion around end-of-life issues and possibly gives you time to make preparations. It may give your family much needed time as well.

We recognize that initiating this process with your physician and with the patient advocate does not necessarily mean that you will use the aid-in-dying drug. In states with a similar law, approximately one-third of the patients who received a prescription for an aid-in-dying drug opted not to take the drug. They may have chosen not to use the drug for a variety of reasons, including never reaching clarity about what to do, changing their minds, deciding to allow the disease process to take its course, adequate symptom control, dying from the disease or other reasons.

Considering the use of an aid-in-dying medication is a major decision that includes a multi-layered and complex process — one that likely affects far more than one person. Perhaps more than any other major life decision, this one is also infused with matters of moral, ethical and spiritual values — values that one may not even share with those nearest and dearest to them.

Sometimes, we may move toward those big life decisions with distinct clarity and certainty, but at the last minute, we might discover: “Oh, I really can’t marry you,” or “I really don’t want to take over the family business.” Discovering our heart’s true intentions can be an ever-evolving journey. Just when we think we are certain, another layer gets pulled back and reveals a deeper truth. Trying to sort out and decide if this is the best option for you and your loved ones will involve a similar exploration.

It is not unusual to hear some patients, feeling so ravaged by treatments, express deep frustration and weariness: “OK! That’s it! I’m done. No more!” Their physician might then say, “But there’s this drug trial coming up.” And the patient’s response might then be, “OK, I’m in!” We don’t always know our own truth until our circumstances demand that we reevaluate.

This may apply to your loved ones and family members as well. It is quite possible that they may have their own hesitations or conflicts in participating in this option. Or, they may honor your choice and want to support you, but they still have their own reservations or struggles.

This is a time for deep reflection and even deeper communication for all those concerned — sorting out possibly competing values in order to arrive at the best choice for you. Please take that time and venture into those conversations with yourself and loved ones. That heartfelt truth-telling may offer its own guidance and clarity to each of you. It is our hope that by talking through this process — potentially many times and at different points in your treatment and illness — and thinking about all of the options available, you will discover your best path.

**Questions to consider for reflection:**

- What circumstances brought me to considering this option?
- What fears might I be bringing to this decision-making process?
- What expectations might I be bringing to this decision-making process?
- Which values would be primary to me in considering this option and making this decision?
- Which of my values might be in conflict with this decision?
- Whose values in addition to my own do I need to consider?
- If I exercise this option, what might I gain and what opportunities might I lose (e.g., for healing, personal growth, relationship to others)?
- If I exercise this option, what might my family gain and/or lose (e.g., time with you, opportunity to provide you with care, healing, conversations, personal growth, relationships)?
- Can I offer loving allowance to myself and those around me to have conflicting feelings and values?

These will likely be ongoing conversations with yourself and loved ones, until a decision feels right. Take advantage of professional support and guidance to facilitate this process. Your patient advocate can be an essential guide in the process. Other resources to consider include an interfaith chaplain, your spiritual community, your loved ones, support groups, your physicians who know you, or a therapist. It may also be a more private discussion with yourself and those most close to you.

Always keep in mind that moving through the process of qualifying yourself to receive the aid-in-dying drug never obligates you to take it. The End of Life Option Act is here to provide one more option for you at end of life.

## **California End of Life Option Act**

Information, Suggestions and Options for Patients

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### **What is the California End of Life Option Act?**

The California End of Life Option Act allows physicians to prescribe an aid-in-dying drug for individuals who qualify under the Act. One goal of this act is to allow specific types of terminally ill patients, those with six months or less to live, to bring about the end to their lives in a peaceful way at a time of their choosing.

### **What makes you eligible for the medical aid-in-dying drug in California?**

The California End of Life Option Act has specific criteria that define which patients can access the aid-in-dying medication. You can qualify if you are:

- An adult (18 years of age or older)
- Terminally ill with a prognosis of six months or less to live, as determined by two physicians (your attending physician and a consulting physician)
- Mentally capable of making your own healthcare decisions without a psychiatric impairment that might interfere with this capacity
- Able to prove that you are a California resident
- Acting voluntarily
- Making an informed decision that includes having information about other end-of-life options that may be helpful to you
- Aware that you may choose to obtain the aid-in-dying drug but not take it
- Capable of self-administering and ingesting the aid-in-dying drug, without assistance from another person
- Willing and able to comply with all procedures, as required by the law

### **How do you obtain the aid-in-dying drug at UCLA?**

- The process begins when you express a request for the aid-in-dying drug to your physician. There is no commitment that you use the drug by making the request. Your request starts a process in which you can obtain more information and your eligibility is determined. You decide if you want to take the next steps.



- If you think you might want an aid-in-dying drug and/or would like more information, you should tell your physician.
- If your physician is a participating physician (meaning he or she chooses to participate in the provision of aid-in-dying drugs as permitted by the Act), he or she will refer you to a patient advocate who will help you and your physician comply with the law. Your advocate will also provide you with the opportunity to explore your thoughts and needs.
- If your physician is not a participating physician, he or she is not obligated by the law to act upon your request. You may choose to go to a different physician who is voluntarily willing to prescribe an aid-in-dying drug.
- If your physician does not prescribe the aid-in-dying drug, you can ask members of your medical team to connect you with a patient advocate who will provide you with more information. No member of the UCLA medical team is obligated by law to participate, and thus, only medical professionals and staff who are voluntarily participating will assist you.

## **What are the responsibilities of the patient under the law to obtain the aid-in-dying drug?**

### **Requests**

- A total of three requests must be made.
  - Make two oral requests, 15 days apart, directly to your doctor. Neither of these requests can come from anyone else; they must be initiated by you and made voluntarily.
  - These requests can only be made to your doctor, and cannot be relayed to your doctor by a resident, fellow, nurse, nurse practitioner or any other medical employee.
  - Make a third written request, which can be done on the same day as the second oral request or at a later time. The written request must be made on the Request for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form. This form is available on the Medical Board of California website: [mbc.ca.gov/Forms/Licensees/aid-in-dying\\_request.pdf](http://mbc.ca.gov/Forms/Licensees/aid-in-dying_request.pdf).

You can also ask your UCLA patient advocate for a copy of the form.

### **Witnesses**

- Your written request form must be signed by you and two adult witnesses.
- The two witnesses attest that to the best of their knowledge and belief, you are:
  - The person requesting the drug
  - Known to them or have provided proof of identity
  - Voluntarily signing the request in their presence
  - Appearing to be of sound mind and not under duress, fraud or undue influence

- There are also specific rules about who can be a witness, including the following:
  - Only one of the two witnesses to the written request may be related to you by blood, marriage, registered domestic partnership, adoption or be entitled to a portion of your estate upon your death.
  - Only one of the two witnesses may own, operate or be employed at a healthcare facility where you are receiving medical treatment, including a health facility where you reside.
  - A witness may NOT be your attending physician, a consulting physician, a mental health specialist or your patient advocate.

#### **Proof of Residency**

- You must provide proof of residency in the state of California. Residency may be proved with one of the following:
  - A driver's license or other identification issued by the state of California
  - Registration to vote in California
  - Evidence that you own or lease property in California
  - Filing of a California tax return for the most recent tax year

#### **Informed Decision**

- You must make an informed decision that is based on an understanding and acknowledgment of relevant facts.
- These relevant facts must come from your physician and include:
  - Your medical diagnosis and prognosis
  - Potential risks associated with taking the aid-in dying drug
  - Taking the prescribed drug will likely aid your dying
  - The possibility that you may choose not to obtain the drug
  - The possibility that you may change your mind and decide not to take it
  - The availability of other feasible alternatives or additional treatment opportunities including, but not limited to, comfort care, hospice care, palliative care (symptom management) and pain control
- You may withdraw the request for an aid-in-dying drug at any time.
- You can decide that you do not want to ingest the drug at any time.

#### **Required Form to Complete Before Using the Drug**

- California state law requires that you complete a Final Attestation for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form 48 hours prior to ingesting the aid-in-dying-drug.

- This form restates your intent to take the drug and your awareness of the consequences. Even if you complete this form, you are not obligated to take the drug and can choose not to take the drug.
- You also need to identify someone who can deliver the final attestation form to your attending physician after your death. The form may be delivered by a family member, your healthcare provider (e.g., hospice) or another representative that you designate.

### **How does your family/caregiver fit into this process?**

- You will be counseled by your physician and the patient advocate about notifying a family member, if you have one, regarding your request for an aid-in-dying drug.
- You will not be denied access to the drug if you do not notify your next of kin or family member, although we at UCLA strongly encourage patients to discuss this important action with family members and/or those you identify as closest to you.
- Your physician and patient advocate will also provide counseling on the importance of having another person present when you take the drug, although this does not have to be a family member. One important reason for this is that the drug must be ingested in a short period of time (two minutes) so that you do not fall asleep before taking the full dose.
- Your patient advocate may be helpful in identifying how and what to tell your family members and if you deem it appropriate for them to participate in counseling sessions that would allow you and your family to talk about this action together.
- We recommend that you think about the impact that this action may have on your family members. End of life can be a particularly meaningful time for you and those who love and care about you. Shortening this phase could leave out the possibility for specific meaningful events and healing. There could be positive effects of shortening this phase and some unintended ones too. If you make the choice to proceed with the aid-in-dying drug, you might want to prepare those closest to you for your impending death. We encourage this for all of our patients as they face serious illness, but as the disease progresses, these communications are even more important.
- The people that love and care for you will miss you and grieve your absence in their lives. This is true whether you die from your illness or from ingesting an aid-in-dying drug. Sometimes, loved ones need time to talk about the loss and think about what it will mean to live without you. Families that approach end of life with open lines of communication are often more prepared and the survivors typically manage the grief process better than families that do not discuss the impending loss.

- End of life also provides an opportunity to express one's wishes and feelings such as sadness and grief. We encourage patients and families to take some time to think about the ways they may want to express themselves to each other. It can be a time to heal relationships, express and feel love, recount accomplishments, and share life histories. We encourage individuals to take this time to be thoughtful about their current situation and to make self-directed choices.
- Your patient advocate will talk to you about whether there are any letters, videos or notes that you may wish to leave to specific people as legacies. Legacies can be last gifts of your words and feelings expressed to your loved ones. These can help facilitate healing through the grief process. (See article on legacies and ethical wills for more information.)

## **What are the responsibilities of the physician under the End of Life Option Act?**

### **Attending Physician**

- Your attending physician is one of your doctors who has primary responsibility for your healthcare. This will most likely be the physician who is caring for your disease (e.g., your oncologist, neurologist, cardiologist), but it could also be your primary-care physician or a palliative-care physician.
- Your attending physician, if he/she is participating in this act, is the one that will be responsible for writing the prescription for the aid-in-dying drug. Some patients may need to be referred to an additional attending physician that will participate and write the prescription. It is common for patients with complex medical conditions to have multiple attending physicians who care for them.

### **Examination**

- The physician must examine you and determine if he/she believes that you have a terminal diagnosis with six or less months to live; he/she must document these findings in your chart.
- The physician must document both of your required oral requests for an aid-in-dying drug in your medical chart, and he/she must make sure that the requests are at least 15 days apart.
- The physician must put the completed Request for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form into your medical record. This form should be your third request (this is your only required written request).

### **Referral to a Patient Advocate**

- UCLA Policy requires that your physician also refer you to a patient advocate.
- The advocate will:
  - Familiarize you with the law and what is required of you and your physicians
  - Discuss your understanding of your current medical condition and the meaning that having an aid-in-dying drug has for you
  - Provide you with appropriate referrals to additional resources that might be helpful to you
  - Facilitate a referral to an independent consulting physician, which is required by the law
  - Answer questions and help you, and potentially your loved ones, think through your thoughts, concerns and feelings as you go through this process
  - Advocate for you when appropriate and develop a plan to ensure that your needs have been met, and that you have made this decision on your own and have not been pressured by others.
  - The patient advocate's goal is to ensure that a uniform practice is used here at UCLA, taking into consideration the needs of each individual patient

### **Counseling by Your Physician**

- Your physician is obligated to discuss the following with you prior to writing a prescription for an aid-in-dying drug:
  - Explain and make sure you understand your medical diagnosis and prognosis and clarify any misunderstandings
  - Tell you about the potential risks associated with taking the aid-in dying drug
  - Inform you of the likely result of taking the prescribed aid-in-dying drug: the hastening of the dying process
  - Inform you that you may choose not to obtain the drug
  - Inform you that you may change your mind and decide not to take it at any time
  - Offer you other feasible alternatives or additional treatment opportunities, including, but not limited to, comfort care, hospice care, palliative care (symptom management) and pain control
  - Suggest to you the importance of telling your family and/or next of kin
  - Inform you that by law, you must take the aid-in-dying drug in a private place, and that it may never be consumed in a public place (beach, park, etc.)
  - Inform you to store the drug in a safe location where other people, such as children or vulnerable individuals, cannot access it
  - Inform you and your loved ones where to return this drug if there is any remaining or if you choose not to use it
- Your physician will request that you have someone involved with your care (a family member or friend) return your Final Attestation for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form to the prescribing physician.

## **Other Obligations on the Part of Your Physician**

- Determine that you have mental capacity to make healthcare decisions
- Refer you to a mental health specialist (psychologist or psychiatrist) if he/she is uncertain of your capacity to make healthcare decisions or if there are indications that you have a mental disorder
- Make certain that you have seen a consulting physician to confirm that you have a diagnosis with an expectation of six months or less to live
- Ask you if you have changed your mind prior to writing the prescription
- Mail or hand deliver the prescription to the designated pharmacy (the physician cannot give you the prescription)
- Make sure that you are a California resident, as defined above
- Complete a checklist to make certain that all steps are followed
- At UCLA, your physician must complete a Physician Orders for Life-Sustaining Treatment (POLST) with you; this form reviews important issues such as Do Not Attempt Resuscitation (DNAR) requests. The POLST is described in more detail below.
- If at any point you are determined ineligible for this act, your physician who accepted the request and referred you to the patient advocate must inform you of disqualifying reasons
- Your physician cannot prescribe this drug solely based on age or a disability
- Within 30 calendar days of writing a prescription for an aid-in-dying drug, the attending physician must submit a copy of your written request (the Request for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form) to the California Department of Public Health (CDPH) through the Office of Regulatory Affairs at UCLA
- Your physician will also be required to submit additional mandatory forms to the CDPH, as required by the End of Life Option Act

## **What are the responsibilities of the consulting physician under the End of Life Option Act?**

- The consulting physician must examine you and determine if you have a terminal diagnosis with six or less months to live; he or she must document these findings in your medical chart
- Determine that you have mental capacity to make healthcare decisions
- Refer you to a mental health specialist (psychologist or psychiatrist) if there are indications that you have a mental disorder

### **What are the responsibilities of the mental health specialist (if you are referred to one) under the End of Life Option Act?**

- The mental health specialist can be a psychologist or psychiatrist.
- The mental health specialist, through one or more appointments with you, will determine in his/her best professional judgment whether you have capacity — as defined by the Act — to make this decision and that you are not suffering from impaired judgment due to a mental disorder.

### **What can you expect from the pharmacist at UCLA under the End of Life Option Act?**

- The pharmacist will fill the prescription and provide it to you or to an individual you have designated to pick up the drug.
- The pharmacist will educate you and provide information about the best way to ingest this drug.
- The pharmacist will educate you about an antiemetic (anti-nausea) medication and how to take it.
- The pharmacist will educate you about a timeline of eating, drinking and how to achieve the desired outcome of the drug while reducing the chance of other effects.

### **What other resources are available to me?**

#### **Psychological Support**

- Having a serious illness is upsetting and it can cause feelings of sadness, depression, anxiety, loss, and fear. These feelings are normal under the circumstances. Many patients who experience these feelings benefit from someone that they can talk to about their worries and concerns.
- One role of the patient advocate is to help address these issues and provide you with recommendations that may be helpful.
- Many times, patients benefit from both psychological counseling — especially by individuals who understand your disease — and appropriate anti-anxiety and anti-depressant medications; together, these interventions can help improve the quality of your life even though the disease may still be progressing.
- We want you to live as well as you can despite the limitations of the disease and even if you decide that using an aid-in-dying drug is the best option for you near the end of your life.
- Receiving psychological support, and/or taking anti-anxiety or anti-depressant medications, can be part of your end-of-life care, regardless of whether or not you choose to have an aid-in-dying drug available to you.

### **Palliative Care**

- Palliative care focuses on symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping, anxiety and depression. It also helps you gain the strength to carry on with daily life.
- Palliative care can and should occur throughout the entire continuum of care for cancer and other serious illness. It is more often associated with more advanced stages of the disease and is an important component of quality end-of-life care.
- Anyone receiving an aid-in-dying drug should be receiving palliative care for symptoms throughout their care.
- For patients who are considering an aid-in-dying drug, it is important that you have been given the opportunity to make certain that your symptoms have been well managed.
- You can arrange an appointment with a palliative-care physician to make certain that your symptoms have been addressed to the best capabilities of modern day medicine.
- In some clinics, there is a palliative-care nurse practitioner that can assist with these same types of symptoms.

### **Hospice Care**

- Cicely Saunders, considered the founder of hospice, stated: "You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."
- Hospice care focuses on quality of life rather than prolonging life.
- Hospice care focuses on employing medical care that alleviates symptoms, reduces suffering and improves quality of life. It is usually utilized in the final stage of care in a serious illness.
- Hospice care emphasizes the treatment/alleviation of physical discomforts, as well as psychological and spiritual discomforts, during a time when a life nears its end - although the timeframe may be somewhat uncertain.
- Hospice care is an option for humane and compassionate care when a disease cannot be stopped and comfort is the highest priority.
- Hospice is not necessarily a place, but a type of treatment. Hospice care can be done in the home or in a skilled nursing facility. There are few hospice programs that are actual free-standing facilities.
- The focus is on the patient and the family as a unit.
- Patients are best served on hospice when they have had some time to stop invasive medical treatments, which can cause additional discomforts.



- Too often, referrals to hospice care occur just days before a death, and this is often traumatic for everyone involved. Sometimes, hospice is not brought up by families or physicians, or there is a concern that entering hospice care means you are “giving up.” Another way to frame this is that hospice care is the best care available for the phase of the disease that you are dealing with at this time.
- Hospice does not provide all the caregiving that a patient needs, but hospice does provide assistance to the family in making good decisions around pain medications and reduction of symptoms such as nausea or constipation. Hospice companies always have a 24-hour on-call nurse and a telephone number for assistance. This allows patients to stay in their own environment rather than be rushed to a hospital to address symptoms.
- It is a reasonable choice to have hospice care, even if you ultimately decide that you would like to use the aid-in-dying drug. One option does not exclude the other.

### **Physician Orders for Life-Sustaining Treatment (POLST)**

- This form, usually printed on bright pink paper, states what kind of medical treatment patients want toward the end of their lives. It is placed in your medical records and usually placed on the back of a door or at the foot of your bed in your home in the event the paramedics are called.
- Any patient with a serious disease should have a discussion with his/her physician around goals of care. A patient requesting or considering an aid-in-dying drug must discuss issues such as what quality of life is acceptable to you and what you are hoping to be able to do in the time you have left.
- The POLST form is completed and signed by both the patient and a physician. POLST gives seriously ill patients more control over their end-of-life care. It is a document you will keep with you at all times, and copies should be made for your healthcare providers so they can honor it.
- For a patient seeking an aid-in-dying drug, a POLST should be completed. This will prevent unwanted treatments or procedures if the patient is not in the hospital and a medical professional (e.g. paramedics) are present.
- A POLST communicates information about resuscitation, artificial nutrition, hydration, other treatments, and comfort care. It also indicates the name of your healthcare power of attorney.
- A POLST is very important for patients seeking an aid-in-dying drug because it also allows you and your physician to indicate that you want to die naturally or by means of the aid-in-dying drug and that you do not want anyone to attempt to bring you back when the likelihood is that you will not survive anyway.

- The POLST should indicate “Do Not Attempt Resuscitation” (DNAR). If you previously completed a POLST, but did not indicate DNAR, you should complete a new one prior to ingesting the aid-in-dying drug.
- Your patient advocate can help you prepare a POLST that you can take to your physician to discuss further and finalize.

### **What if I am not an English speaker?**

- If you are not an English speaker, you may still request the aid-in-dying drug; however, you must use a trained interpreter when your healthcare provider does not speak the same language as you do. The UCLA Health Interpreter/Translation and Deaf Services Program is available to our patients and families.
- The interpreter may not be related to you by blood, marriage, registered domestic partnership, adoption or be entitled to a portion of your estate upon your death.
- An interpreter must meet the standard put forth by the California Healthcare Interpreting Association or the National Council on Interpreting in Health Care or other standard accepted by the deemed acceptable by CDPH. The interpreter may read the Request for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form to you and verify your agreement with this document by making an additional declaration about their fluency.
- If you do not speak English, you will need an interpreter to engage in all formal counseling and attestations. This can be arranged for you with your patient advocate. Our interpreter team can also be reached at (310) 267-8001.

### **What can your physician not do under the Act?**

- Your physician cannot administer a medication through injection or IV that is intended to end your life. This act only allows the physician to prescribe a life-ending medication that you ingest yourself if you have a terminal illness and are expected to live less than six months.

### **Can I take the aid-in-dying drug while an inpatient in the hospital?**

- No, you cannot take the aid-in-dying drug in a UCLA hospital.
- At UCLA, you may make a request for the aid-in-dying drug while an inpatient, but you cannot bring the drug to the hospital and take it as an inpatient.

### **What will be listed on my death certificate as the cause of death?**

- The physician will comply with the law, which states that the cause of death on the death certificate will not be listed as suicide. No actions taken in accordance with the End of Life Option Act constitute suicide, assisted suicide, homicide or elder abuse. The physician will list the underlying disease as the cause of death, as recommended by the CDPH.

### **Will using the End of Life Option Act affect my will or insurance?**

- The End of Life Option Act specifically mandates that you should not be negatively affected by making this choice.
- The law states that wills, insurance, contracts, and annuities are not affected if a qualified individual shortens their time before dying by taking an aid-in-dying drug that was prescribed to him/her by his/her physician.

### **What is the drug that I will be prescribed?**

- There is more than one drug or combination of drugs that may be used as an aid-in-dying medication. Discuss this with your physician and pharmacist.
- Your doctor should prescribe a medication (antiemetic) that is used to reduce the likelihood of you becoming nauseated or vomiting the drug.

### **Are there other states where a law like the California End of Life Option Act has been used?**

- Yes. Oregon, Vermont and Washington have similar laws that allow for patients to ingest a prescribed drug when they have a terminal illness.
- These states have a documented history of using this process.
- Oregon and Washington have published their data and outcomes, which were reviewed here at UCLA prior to our own implementation.
- While a small number of qualified individuals have utilized these acts, there have been positive effects on end of life, including increased discussion among patients and physicians, higher use of palliative care and hospice, and fewer deaths in hospitals.

### **Informational Resources**

- To read the full law - California End of Life Option Act (ABX2-15) - visit: [leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill\\_id=201520162AB15](http://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201520162AB15)
- Compassion & Choices is an organization that has supported the passage of these bills. The organization also has educational materials on their website: [compassionandchoices.org](http://compassionandchoices.org)

### **Checklist of things to do before taking the drug**

- ☐ Complete the Final Attestation for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form 48 hours prior to ingesting the drug; this is to be returned to your physician.
- ☐ Review the step-by-step instructions for taking the drug given to you by your pharmacist and follow them precisely.
- ☐ Have someone with you when you take the drug.
- ☐ Make sure whoever is with you understands that you DO NOT WANT ANYONE TO ATTEMPT RESUSCITATION.

## **Preparing for Your Own Death: Instructions and Essential Information**

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The following topics are important for patients who are considering, and may choose to use, the aid-in-dying drug. You should share this with your family too, if they are part of this process with you. We recognize that initiating this process with your physician and the patient advocate does not necessarily mean that you will use the aid-in-dying medication. Approximately one-third of the patients in other states with a similar law who received a prescription for an aid-in-dying drug did not take the drug. They may not use the drug for a variety of reasons, including never reaching clarity about what to do, changing their minds, deciding to allow the disease process to take its course, adequate symptom control, dying from the disease, or other reasons.

Regardless, there are some important factors to know when considering the use of an aid-in-dying drug.

### **Enrollment in Hospice**

It is important to enroll in hospice. Hospice care is a type of care that focuses on quality of life rather than on prolonging life. Hospice typically helps families provide care to their loved ones in their own homes. We recommend that people with terminal illnesses enroll in hospice. Patients in hospice tend to live with better quality of care, have fewer hospitalizations and are more likely to die at home surrounded by their loved ones. Patients in hospice are likely to have more peaceful deaths with the support that they need. It is helpful to the family, too, as hospice provides help to loved ones and supports them after death. At the time of death, hospice is simpler for families because only one call is needed to the hospice, which will then help coordinate with the funeral home. Hospice is a good option even if you know that at some point you may use the aid-in-dying drug.

### **If Not Enrolled in Hospice**

If you have not enrolled in hospice and you are imminently planning on using the aid-in-dying drug, you may want to make sure that you have made arrangements in advance with a funeral home. Most funeral homes will contact the physician for your family once they have picked up your body. Your family should have contact information available for the funeral home. Your physician will likely sign the death certificate. Your family or attendants do not need to call 911 or the coroner in an expected death, although the coroner will become involved if you have not chosen a mortuary.

## **With Your Physician, Sign a POLST Form and Indicate DNR**

Make certain that you and your physician have recently completed a Physician Orders for Life Sustaining Treatment (POLST) form. The POLST is completed and signed by you, the patient, and your physician. The POLST for patients choosing to use an aid-in-dying drug should clearly indicate “do not attempt to resuscitate” (DNR).

## **Once You Have Qualified for the End of Life Option Act**

Once your physician has indicated that you have qualified to have the prescription, discuss with your physician whether you should have the prescription filled now or at a later time. Some people wait to have the prescription filled and you should discuss the pros and cons of this decision with your physician. Issues to consider include:

- Making sure you have access to it when you need it
- How long the drug will last, as you may not take it for some time
- Whether you are ready to pay for the prescription now (this may involve a consult with your insurance company about paying for the medication)
- How long it takes to get the medication once the prescription is written
- If you do not use the medication, who will have access to it and will they dispose of it properly

If you do decide to have the medication filled, please make certain you review the instructions for consuming the drug as well as all steps leading up to it. The pharmacist should consult with you and provide you with a written handout describing the medications and how they should be used.

Your physician will also prescribe anti-nausea medication to be taken prior to taking the aid-in-dying medication to ensure that you do not vomit the aid-in-dying drug after ingesting it.

## **You Must Have Ability to Ingest and Digest the Medications**

To use the California End of Life Option Act you must ingest the medication yourself. You must be able to either swallow half a cup of liquid, consume applesauce or yogurt with the drug mixed into it, or self-administer the drug into your feeding tube. The mixture containing the lethal dose of medication must be ingested within 1-2 minutes. This is very important, because typically, an individual will fall asleep within 5 minutes of taking the medication. If you have swallowing problems, this could interfere with your ability to successfully use the California End of Life Option Act.

If you have any doubts about your ability to consume/ingest this mixture in 1-2 minutes, we highly recommend that you practice swallowing half a cup of water within 2 minutes or practice self-administering half a cup of water through a feeding tube in the same amount of time before attempting to use the life-ending medication.

## **Where Can You Take the Aid-In Dying Drug?**

You are allowed to take the drugs in the privacy of your own home or yard. You are not allowed to take the drug in any public place including a beach, park or other public area. You are not allowed to take the drug while in the hospital at UCLA and likely not at other hospitals. If you are living in an assisted living facility you will be allowed to take the drug. Nursing facilities may or may not allow you to take the drug. You will have to ask.

## **Who Should Be Present At Your Death?**

This is a deeply personal decision. Some people have their close friends and family members present while others opt to have just one person. You may also choose a caregiver to be present. Whomever you choose, you should determine if the person is comfortable with being there and not someone who is likely to panic and decide to call 911.

Most people are looking for a peaceful death; therefore, the choice of which person you have present may be very important in ensuring that it is peaceful. You may ask someone from your medical team to be present; however, if they are not comfortable being present or do not support your decision, this is not a good idea. Ideally you want someone who supports your decision.

Whoever is present should be someone who wants to be helpful by creating the environment that you want. Once you have decided whom you would like to have present and tend to you during the process, you may want to have a conversation and reflect about more personal considerations and desires. Here is a checklist of things to consider and guide you through a deeper reflection and conversation:

- Whom would you want to be present?
- Would you want to be held, caressed or touched?
- What kind of atmosphere would you want?
- Are there photos, special objects or animal companions you would want nearby?
- Particular flowers, candles, or scents?
- Would you prefer silence, or a particular piece of music played?
- Would you want a particular poem or prayer read?
- Would you want loved ones to reminisce and share stories as if it were a party, or just carry on as if it were an ordinary day?

There are no right answers to any of these questions – except what you would want.

Those attending will also need to help make sure you stay awake and take the medication quickly, and help you to sit upright for the first 20 minutes after you have taken the medication.

## **The Dying Process**

Your attendants/loved ones will need to make sure you stay awake and take the medication quickly (within 1-2 minutes) to avoid falling asleep before ingesting all of the medication. Your attendants/loved ones will also need to help you to sit upright for the first 20 minutes after taking the medication.

Usually within a very few minutes you will appear to be sleeping. How long it takes an individual to die can vary and every individual is different. In other states that have used aid-in-dying medications, people tend to die quickly, but every individual is different. How much time passes before death can vary, and there have been reports of it taking from 10-to-20 minutes to hours. The factors that affect the length of time can include how sick you are (overall condition) and how easily your body absorbs the medication. Be assured that once you are in a non-responsive state (usually takes 5-10 minutes after taking the medication), you will not experience any suffering.

## **Once the Death Occurs**

In your packet you will find a companion document called, "Preparing for Death: Guidelines for Family, Loved Ones or Caregivers." There are explicit guidelines and instructions for your loved ones and caregivers on what needs to take place in a logistical way, as well as guidelines and suggestions to fulfill your requests and create the most meaningful and peaceful experience possible.

Your survivors will likely need to tend to a host of legal documents and to the settling of your estate and affairs. By law, using aid-in-dying medication is not suicide. The underlying diagnosis will be listed as the cause of death on the death certificate. Making the choice to use the aid-in-dying medication does not affect your life insurance, health insurance, accident insurance or annuity policies.

## **Disposing of Unused Medications**

Disposing of unused medications is very important and must be done safely and properly. The U.S. Drug Enforcement Agency has developed guidelines for disposing of medications. It is not uncommon for patients near end of life to have many medications left over. It is important that these medications are safely handled and they cannot be used by someone else. If you choose not to use the aid-in-dying medication, please safeguard this medication from others until you can dispose of it properly.

- The aid-in-dying medication is a controlled substance and is not accepted at every location that accepts medications.
- Never flush unused medications of any kind down a toilet or drain and do not throw it into the trash.



- The best disposal method is to use a designated drop-off facility.
- The Los Angeles County Sheriff's Department, along with the Los Angeles County Departments of Public Health and Public Works, has created the Safe Drop-Off Program. There is a handout in the patient packet that lists the Safe Drug Drop-Off locations.
- The Santa Monica Police Department has a drop-off box located outside the police station, at 333 Olympic Blvd, Santa Monica, CA 90401. For questions, call (310) 395-9931.
- Many cities have special days designated as "Take Back" days in order to safely remove old drugs and controlled substances from the street.
- To find a facility that accepts controlled substance medications, visit: **[nodrugsdownthedrain.org/NoDrugs](http://nodrugsdownthedrain.org/NoDrugs)**. Be aware that the location needs to say that it accepts "CONTROLLED SUBSTANCES," not just medications.
- A statewide recycling program called CalRecycle can also help you find a place near you. They can be reached at (800) 732-9253. Make sure that when you call, you specify that you need to dispose of a controlled substance so that they do not misdirect you. They can assist with other recycling issues as well, such as needles (sharps) or other medications.

## Preparing for Your Own Death: Personal Checklist

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There are a lot of factors to take into consideration when you make the decision to begin the process outlined in the California End of Life Option Act. Beyond the decision itself, there are many personal matters to think about and there may be some specific tasks you wish to accomplish. It can be time consuming and takes some energy ahead of time, but may be helpful to you and your family to think through these issues. There can be positive experiences in actively addressing these issues and some relief in knowing that you have taken care of some unfinished business. Many have found these to be areas to consider, in addition to our "Preparing for End of Life" checklists you'll also find in the Patient Packet.

Whether or not you receive or use the aid-in-dying drug, these steps can be helpful in preparing. We want to note that we also recognize that at the time you receive this, you may also be quite ill. This list is not a demand or meant to add additional pressure on you. If you have a small amount of energy and time, then this list can be used as an opportunity to decide what is most important for you and your family.

### Personal Communications With Your Family and Friends About Healthcare

- ☐ Have I **discussed my condition** with my family/friends in complete honesty?
- ☐ Have I told my loved ones EXACTLY what **medical interventions** that I want and do not want? Do they know at what stage of illness I would choose to forgo certain therapies or artificial life support? Share and discuss your advance directive, POLST and other important paperwork indicating your wishes with them.
- ☐ My family needs to know whom I have put in charge of my medical decisions when I can no longer make them. My **healthcare proxy or surrogate medical decision-maker** needs to understand and agree to carry out my wishes and desires regarding my end-of-life care.
- ☐ Do I need a **private discussion** with anyone, if it would help them to accept my decision?

### Personal Considerations

- ☐ What are my beliefs about death? Do I need to make peace with myself or with any spiritual figures of my faith? At UCLA, talk to your patient advocate if this is something that is important to you. He or she can direct you to spiritual resources.
- ☐ Do I need psychological, emotional, spiritual care, counseling or support? At UCLA, your patient advocate can help with appropriate referrals.
- ☐ Do I have anything amiss with my family/friends to fix? Can I fix them now?
- ☐ Do I have letters to write? Calls to make?

- ☐ Are there people that you want to make peace with before you die? It can be helpful to make a list of people that you want to have a final communication with either to express love and gratitude, or to address old grudges, enemies, etc. Attempt to settle those affairs. You may use this list as a guide:

"I'm sorry."

"Thank you."

"Goodbye."

"I forgive you."

"I love you."

- ☐ Have I created my "**bucket list**"? What am I able to accomplish with the time I have left? This may help inform your choices around when to take the aid-in-dying drug and your goals for medical care. We also know that you may not have the opportunity to do all of this; you may want to think about what is possible for you, setting smaller goals, while still listing other goals that may or may not be obtainable. Use this list to help create your "goals of medical care."
- ☐ To whom do I give my **personal belongings**? If you are married, most likely all of your belongings will **transfer to your spouse or family**. If you are single, then you must specify what you want done with these items. There may be special items that you want to designate for special people or give in advance.
- ☐ Who gets my special items, such as photos, mementos, etc.?
- ☐ Have I labeled (identified) the people in my photos? To whom do my photos (pictures, negatives, discs, etc.) go? This should not be a pressure to do more than you are capable of doing. If you go through pictures, you may want to do this with a friend or family member as you may have special photos you wish to be shared at your funeral or memorial if appropriate in your culture.
- ☐ If I am single and have children who are minors, have I set up a **guardian for my children** for the immediate time after my death? Short-term money for them?
- ☐ Have I set up the paperwork for where my children will go permanently?
- ☐ What should I **sell before my death**? House? Car? Furniture? Land?
- ☐ Have I made arrangements for the care of my **pets**?
- ☐ What **unfinished projects** around the house, at work, or in the community would I like to complete? Again, this should not be a pressure about what you can and cannot do.
- ☐ If I have young children, **have I left letters or videos** to them? Please see the enclosed article on written legacies.
- ☐ Are all my digital photos/videos in one place? What about my computer(s)? Have I left passwords my family will need after I die?

## **Personal Reflection and Communication About the Dying Process**

In addition to logistical considerations regarding the aid-in-dying drug, there remain personal considerations about your desires that require reflection and communication to your family and loved ones throughout this process. Here is a checklist of things to consider and guide you through a deeper reflection and conversation:

- ☐ Whom would you want to be present?
- ☐ Would you want to be held, caressed or touched?
- ☐ What kind of atmosphere would you want?
- ☐ Are there photos, special objects or animal companions you would want nearby? Particular flowers, candles, or scents?
- ☐ Would you prefer silence, or a particular piece of music played?
- ☐ Would you want a particular poem or prayer read?
- ☐ Would you want loved ones to reminisce and share stories as if it were a party, or just carry on as if it were an ordinary day?

There are no right answers to any of these questions – except what you would want.

## **Funeral/Memorial/Wake/Celebration of Life - Planning and Logistics**

Each person and family is different in how they treat death and if, how and where they memorialize someone who has died. It is sometimes determined by religious practices, spiritual beliefs or cultural norms. It may also be governed solely by personal preferences and choice, having no ties to other cultural or religious backgrounds. When there is no religious or cultural framework, families especially may want to know preferences. This section provides opportunities to think about what you may or may not want to help guide your friends and family.

- ☐ Where do I want my body to be taken? Which funeral home/mortuary? Do you have a preference?
- ☐ How do you want your body handled after your death? Do I want to be embalmed? Buried? Cremated? Do I want a green burial (an environmentally-friendly natural burial)? Would my family want this also?
- ☐ What are my burial/casket preferences?
- ☐ Whom do I want notified of my death?
- ☐ Do I want to write my own obituary?

- ☐ Do I have burial plot? If cremated, where should my ashes be scattered or interned?
- ☐ Do I want/need a headstone/grave marker? Have I written out what I want inscribed on it? Design?
- ☐ Do I want a ceremony of some kind, such as a funeral/wake/memorial service or celebration of life?
- ☐ Do I have special needs for my ceremony? Military? Religious? At home?
- ☐ Who will deliver the eulogy or are there several people that you would like to speak about you and your life? Ask him or her in advance.
- ☐ Should I pre-pay funeral/burial/cremation expenses? It can often be less expensive when done in advance. If this is hard for you, do you want to designate someone to make these arrangements in advance? If so, talk to them.
- ☐ Do I want to identify a charity "in lieu of flowers"? This is often very helpful to programs that are supported by philanthropic funds and can be helpful to others or causes you believe in.
- ☐ Who needs to be made aware of my death? Make a contact list for your funeral or memorial notices.

## **Preparing for Death: Guidelines for Your Family, Loved Ones or Caregivers**

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Once your loved one has chosen to take this step, and make use of the aid-in-dying drug, you may be the one — or one of several — who has been asked to tend to this process and be a witness. This is intended to briefly give you a sense of what to expect — before, during and after — as well as some practical information and guidelines.

While you have been asked or chosen to tend to this process for your loved one, it is quite possible that you may have your own hesitations or conflicts in participating as a matter of conscience. You may honor your loved one's choice and want to support him or her, but still have your own reservations or struggles. Take the time you need to reflect on your possibly competing values so that you can arrive at a plan you can live with. Upon reflection, have that conversation with your loved one. A heart-felt truth-telling may offer guidance and clarity for each of you.

We all know that death is a part of life and that each of us will likely face it at some point either as a witness, or ultimately at the end of our own physical life. Some people have no direct experience with the dying process, and may know death only through images in the media. Our cultures have moved us away from helping us process this as a part of everyday life. If we have witnessed death, depending on the circumstances, it may have been something beautiful and peaceful or something far from that.

Nothing prepares a person for being present at the death of a loved one, other than experience — and many of us do not have that history. Even if one did have a particular experience, it still wasn't with *this* loved one. Even a "planned death" will stir emotions that we may not have anticipated. After all, the disease that leads up to this moment was not planned.

We know that deaths that allow time for preparation often can be helpful for the survivors because there has been time to prepare, anticipate, talk, forgive, share, and make arrangements. Our hope is that this deeply personal choice will afford the opportunity to make such preparations, have those conversations, and ultimately find a deeper meaning and sense of peace.

Being present and tending to someone in their last moments when someone has made this personal choice is an act of courage and a demonstration of great love and service. Don't forget to breathe and go easy on yourself.



## **In Preparation for the Process**

You will likely have had a conversation with your family member or loved one about when and where the drug will be taken and what his or her wishes are with respect to many things. Remember that the drug cannot be ingested in a public place. That is against the law.

If that conversation has not happened, or has not been finished, you may want to initiate and facilitate such a conversation and these questions might help guide you:

- Whom does he/she want present?
- Would he/she want to be held, caressed or touched?
- What kind of atmosphere would he/she want?
- Are there photos, special objects or animal companions he/she would want nearby? Particular flowers, candles, or scents?
- Would he/she prefer silence, or a particular piece of music played?
- Would he/she want a particular poem or prayer read?
- Would he/she want loved ones to reminisce and share stories as if it were a party, or just carry on as if it were an ordinary day?

There are no right answers to any of these questions — except what he or she wants.

There are some additional things you need to know:

- Is your loved one enrolled in hospice? Be sure to have the name and phone number of the hospice available to you.
- Has he/she signed the Final Attestation for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form 48 hours prior to ingesting the drug?
- What is the name of the physician who wrote the prescription? This attestation needs to be returned to the physician, and the physician will then be able to sign the death certificate.

If the patient is in hospice, the decision may be made for hospice attendants to be present in the house when the patient takes the drug. If that is the case, such attendants may choose to step outside of the room. Participation in this law is voluntary, and some individuals may not be in agreement with facilitating a death with an aid-in-dying drug. That does not mean that they will not be with you or attend to your or your loved one's needs, but they may choose to be out of the room at the time the drug is ingested and return to attend to the person dying if needed. They will also help with the body once the death has occurred. It may be important to clarify with the hospice attendant just how he/she will be present.

If the patient is in hospice and a hospice attendant is not present, it may be important to discuss in advance if he or she would like to have the hospice nurse or social worker notified should there be an extended dying process. Identifying who communicates with hospice is important. It may be the patient's legal surrogate decision-maker or a family member.

## **The Dying Process**

The instructions for taking the drugs will have been provided. You will need to make sure your loved one stays awake and takes the drug quickly (within 1-2 minutes) to avoid falling asleep before ingesting the entire dose. You will also need to help your loved one sit upright for the first 20 minutes after taking the drug.

Usually within a few minutes, the person will appear to be sleeping. How long it takes an individual to die can vary and every individual is different. We have learned from other states that already have experience with this medication that people tend to die quickly, but every individual is different. How much time passes varies, and there have been reports of it taking from minutes (approximately 10-20 minutes) to hours. The factors that affect the amount of time can be how sick the person is (overall condition) and how easily his or her body absorbs the drug. Be assured that once the person is non-responsive (usually 5-10 minutes after taking the drug), he or she will not experience any suffering. If he or she does not die as soon as you expect, do not panic. Do not call 911. Do not attempt to resuscitate your loved one. This is a time of waiting, much as when someone's disease has progressed and natural death is near. It may be helpful to think about any additional time of waiting as a vigil, which often occurs during the last hours of a person's life during a natural death.

Although there is not any specific activity you need to do, this can be an important time to create the atmosphere that you have talked about with your loved one regarding his or her desires – perhaps reading a poem, saying a prayer, singing a special song, caressing a hand, stroking a forehead, sharing tender feelings, offering reassurance, or simply holding the space of calm in stillness.

Caregivers may also administer any of the medications that they have been using or may have been provided by the physician or hospice if there are any symptoms that ordinarily would be treated. For example, atropine may be used under the tongue when excessive oral fluids seem present, and morphine or other pain medications may continue to be administered if the patient seems to be in pain. Medications for pain and agitation can be taken in advance as well if these have been part of the patient's regimen of symptom management.

Those present at the death will witness some or all of the following changes that frequently occur during the natural dying process: snoring, gurgling noises, changes in rate of breathing (sometimes slower, sometimes faster), increased paleness or grayness of the skin, and coolness of the skin. One might also observe release of bowel and bladder, no response,

eyelids slightly open, pupils enlarged, eyes fixed on a certain spot, no blinking, jaw relaxed and mouth slightly open. Lowering the person to a semi-upright position and turning the person onto his or her right side, a position that may also improve absorption of the drug, may alleviate snoring and gurgling noises. Generally, there are no physical movements or signs of distress, although it is not uncommon for people to twitch or make sounds after death has occurred. Death has occurred when breathing has stopped for five minutes and no pulse or heartbeat can be felt.

As a witness, you might experience the moment of death in any number of ways. It might be an intensely meaningful or even spiritual encounter. Or it may seem surprisingly ordinary, even anti-climactic. You may feel instant grief. You may feel numb. You may feel relief. Or you may be angry. There are no correct feelings or responses — only yours.

## **After Death Occurs**

There is no hurry to notify anyone or have the body removed. Nothing has to be done right away. Some people want to stay in the room with the body; others prefer to leave. Take as long as you like to observe any cultural or spiritual traditions, gather family together, reminisce, mourn, or celebrate life. It is not unusual and can be healing for some to tend to the body in a tactile, physical way — apply lotion or fragrant oils, bathe the body, or comb the hair; others will not opt to do this. You might ask a member of your religious community or a spiritual counselor to come. If you have a list of people to notify, this is the time to call those who might want to come and see the body before it is moved. Very often the mouth will open — placing a rolled up towel under the chin can close the mouth. It is not necessary to do this, but often people are distressed by the open-mouth appearance.

We recommend that either you or others in attendance make sure the body is lying flat as the joints can become stiff after death and cannot be moved. This stiffness is called “rigor mortis” and begins sometime during the first hours after death.

If hospice is involved, a plan for what happens after death is already in place. You only need to make the one call to hospice.

If your loved one is not enrolled in hospice, please contact the funeral home with which you have pre-arranged pick up. Most funeral homes will contact the physician for you, but you may want to have that contact information available. The physician for your loved one will likely sign the death certificate. You do not need to call 911 or the coroner in an expected death, although the coroner will become involved if you have not chosen a mortuary. In the patient packet that was given, you will find resources about mortuaries, burial and cremation. Ideally, these issues will be worked out in advance of the ingestion of the drug.

## **Disposal of Aid-in-Dying Drug**

Disposing of unused drugs is very important and must be done safely and properly. The U.S. Drug Enforcement Agency has developed guidelines for disposing of medications. It is not uncommon for patients near end of life to have many medications left over. It is important that these medications are safely handled and cannot be used by someone else. If your loved one died before having the opportunity to use the aid-in-dying drug, please safeguard this drug from others until you can dispose of it properly.

- The aid-in-dying drug is a controlled substance and is not accepted at every location that takes medications.
- Never flush unused medications of any kind down a toilet or drain or throw them into the trash.
- The best disposal method is to use a designated facility:
  - The Los Angeles County Sheriff's Departments, along with the Los Angeles County Departments of Public Health and Public Works, have created the Safe Drop-Off Program. There is a handout in the patient packet that lists the Safe Drug Drop-Off locations.
  - The Santa Monica Police Department has a drop-off box located outside the police station, at 333 Olympic Blvd, Santa Monica, CA 90401. You may call them at (310) 395-9931.
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## **Next Steps**

When you witness and tend to such an event, you will experience feelings of grief and personal loss, but you may also feel disconnected from people, places or things. It can feel as if you are walking in a fog, without your bearings in the "real world." This can be especially difficult when you are thrown into the intensity of making funeral/memorial arrangements.

These are profound events — the death and the witnessing of the death. Life will never quite be the same again. How could it be? It would only make sense that you may feel disconnected or strange. It may be hard to understand your feelings yourself, let alone explain them to others, especially to those who have never witnessed a death.

Over the following weeks and months, some may experience emotional and spiritual rawness that stirs up feelings of anger as well as grief and even guilt. For others, it can be truly liberating. We only really know what we need to deal with as we move into and through our grieving process, step-by-step, day-by-day.

There are a number of ways to find support as you learn to carry this experience and loss — including bereavement groups and individual counseling. In the patient packet that was given, you will find specific resources on grief support groups. Some feel a need for solitude and retreat from everyday life for a while. It may take a false start or two. Be kind to yourself and find what serves you. You have given someone a great gift beyond measure.