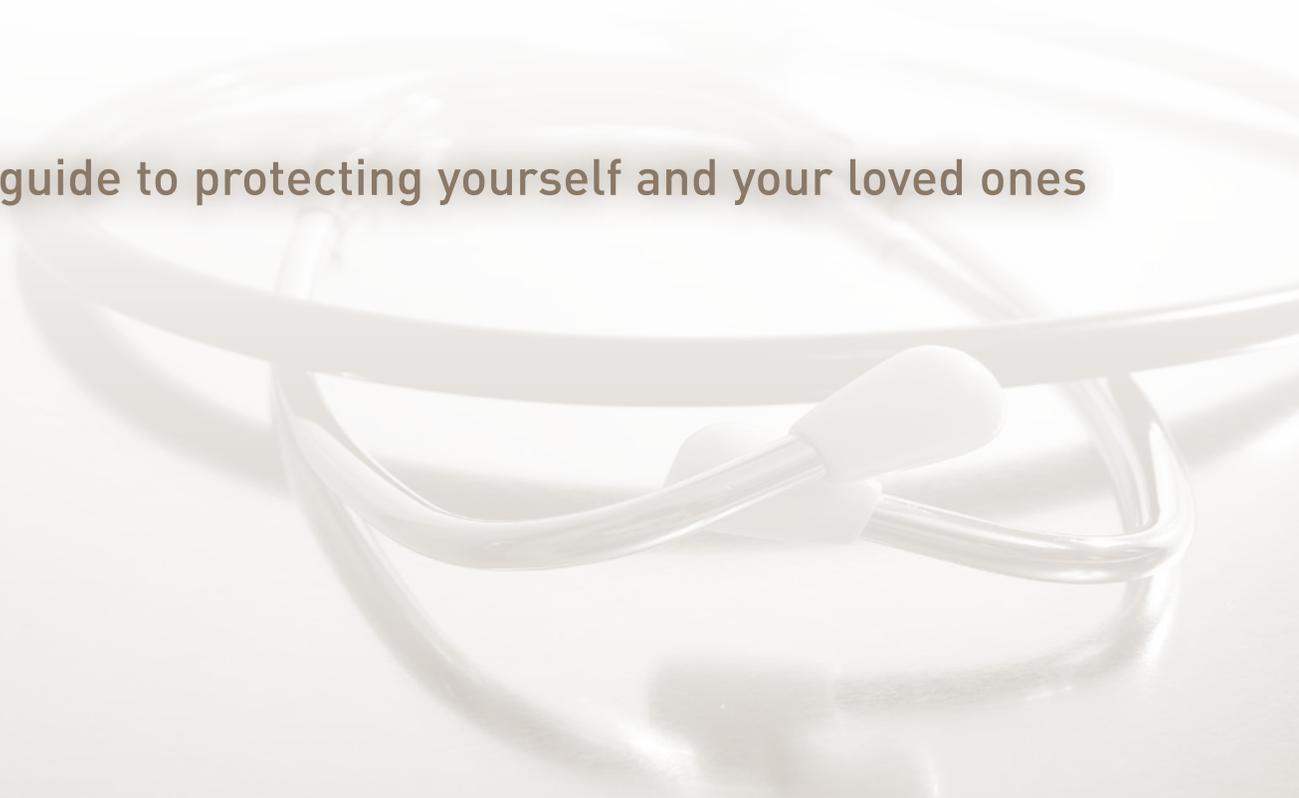


Make Your Health Care Decisions... Or They Will Be Made For You

A guide to protecting yourself and your loved ones



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Why Plan Ahead?

Far too, often people find themselves in the middle of an urgent health care crisis—before they realize that they should have taken measures to protect their rights, or the rights of their loved ones, in advance. They are faced with pressure to receive or refuse medical treatment. This pressure frequently leads to the abandonment of their wishes and sincerely held religious beliefs. Patients who are incapacitated may never realize decisions are being made on their behalf, or if they are aware of those decisions, they may be unable to communicate sufficiently to express their orders for preferred treatment. Incapacitated or unconscious patients are not necessarily unaware of their surroundings, but the incapacitated patient's beliefs and desires are no less real when they are unexpressed.

In a recent case, LLDF assisted a mother whose adult son was diagnosed as permanently unconscious. His wife wanted to discontinue all life-sustaining treatment. Hospital staff concurred while discussing the matter in the patient's room. He was invisible to them because he was unconscious. When LLDF intervened, treatment was reinstated and the patient rehabilitated. When he left the hospital, he went home with his mother—not his wife—because he was able to recall the dehumanizing conversations that took place in his presence. While this particular incident had a happy ending, many do not. Planning ahead is the only sure protection against the tragedy of having a healthcare options forced upon an unwilling recipient.



Who Decides?

Under California law there is a general admonition for hospitals to make reasonable, prompt attempts to locate family members who might reasonably have authority to make healthcare decisions. (See California Probate Code §4717.) Prior to 1999, California law provided a clear order of preferred decision-makers for an incapacitated patient. In 1999, however, California lawmakers abolished that. Practically speaking, this means that although not devoid of authority to make decisions on behalf of an incapacitated person, it is not necessarily a spouse or other family member who will be the decision-maker, even if treatment is a matter of life or death. It is still possible for a family member or interested friend to bring a petition to change an aspect of the care provided, and family members are still recognized as having an interest and legitimate authority in making these decisions, but the descending order of those who would rightfully make decisions has been removed. The net result is that healthcare providers now make these decisions based on their own policies.

For an individual with no written healthcare directive, it has been LLDF's experience that when a California healthcare provider wishes to discontinue life-sustaining treatment and a family member objects, the healthcare provider can easily seek out another family member willing to agree to end the treatment. Considering that there are often extremely divergent values and personal preferences present even within a family, this leads to serious risk of not adhering to the true desires of the patient. Thus, the best and surest way to protect your personal wishes and values is to put them in writing, and to entrust decision-making authority to a person who will enforce your directives.



What Treatment?

Healthcare and medical treatment are not always what you might assume. In some instances, simple provision of nutrition and hydration (food and fluids) can be considered a form of extreme medical treatment. Most hospitals have ethics committees or a "hospitalist" whose job is to determine when treatment should be provided or withheld. The interests of a hospital employee or a committee of hospital employees do not always match the wishes of the patient, especially when the monetary cost associated with care is taken into consideration. One hospital, via its legal counsel, told an LLDF attorney that it did not make decisions based on the family's wishes, or even the patient's wishes, but rather based on hospital policies. When it comes to choosing what type of healthcare you receive, you need to take steps to ensure that you are the one making the decisions and to ensure that if you are incapacitated your directives are followed.



SUGGESTED STEPS

The purpose of this document is to give you practical steps to ensure that you and your loved ones are able to make decisions based upon your most deeply held beliefs, even during an urgent healthcare crisis. Please be aware that the information offered here is not intended to be legal advice, and that you should consult your attorney or contact LLDF if you have questions with regard to specific legal issues. Further, you should understand that most of the laws discussed and steps suggested are recommended for California residents. There may be significant differences in the appropriate steps to be taken depending on your state of residence, although many of the same steps will apply. Again, it is imperative for you to consult your personal attorney with your questions.

1. Execute an Advance Directive

Advance healthcare directives are legal instruments that provide you with the ability to express your wishes with regard to health care. An advance directive is the best way to protect any person who later becomes incapacitated or physically unable to express his or her wishes. To this end, you should consider executing the following documents:

(A.) An Advance Health Care Directive

Executing this document allows you to specify your instructions with regard to essential parts of your health care, including the provision of life-sustaining measures. A good advance health care directive will include a power of attorney for health care by which you can give authority to a person of your choice to make health care decisions for you. Choose this person with care as they will be largely responsible for carrying out your instructions in the event that you become incapacitated. A sample form and instructions for executing an advance health care directive are provided in the California Probate Code.

(California Probate Code §4701, available at <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=prob&group=04001-05000&file=4700-4701>)

Although this model form is available, you are not limited to using it. You are free to write your own directive or to use a different form. As long as your form complies with the statutory guidelines, it will be enforced and you will be protected. One reason to consider using a different form is that some of the language in the model form could

be interpreted to justify premature removal of nutrition and hydration in addition to other forms of life-sustaining treatment before giving the patient a sufficient chance to recover. If you are not comfortable with this ambiguity in your advance directive, LLDF suggests that you use a form designed to more closely adhere to your personal convictions, such as those forms recommended through LLDF's website at <http://lldf.org/pmdd-info.html>.

Once you have created your advance health care directive, be sure that you execute it properly: sign and date it at the end, and then have it signed by two qualified witnesses or have it notarized.

(B.) A Request Regarding Resuscitative Measures

You should consider executing a request regarding resuscitative measures, which may be one of two documents: either a "do not resuscitate" order, or a "physician's orders for life sustaining treatment." (See California Probate Code §4780.) Both of these documents are designed to act as fully executed medical orders and require your physician's signature.

"Do Not Resuscitate" (DNR) order forms are available at <http://www.emsa.ca.gov/pubs/pdf/DNRForm.pdf>. This form states that you do not wish to have resuscitative measures undertaken on your behalf by emergency medical personnel. It is possible to obtain a medallion to wear that will indicate you have executed a DNR order. Once a DNR form is executed, it will be enforced, so it is important that the document expresses your wishes. If you are not comfortable with using a DNR order, you are not required to do so.

Physician Orders for Life Sustaining Treatment (POLST) forms are available at <http://www.emsa.ca.gov/pubs/pdf/ApprovedPOLSTForm.pdf>, and allow you to specify your wishes with regard to provision of nutrition and hydration, comfort measures, and resuscitation. Again, you are not required to execute this document, but it can be a good way to express your wishes. As always, make sure that you understand the implications of the choices you make with this type of medical directive. Once the order is executed, health care staff will follow the order without further consulting you or your designated agent, so it is important to be sure that your directives are clearly expressed.

Of the three documents discussed above, it is most important to have an advance healthcare directive with a clear indication of the person you designate to act as your health care agent.

This will be the best guarantee you have that your wishes will be protected. To the extent possible, make sure that every doctor who treats you has a copy of your directive and understands your wishes. Discuss the directive with your doctor to be sure he or she is willing to abide by your wishes (if not, it may be in your best interest to find another doctor). The goal is, as always, to communicate your preferences effectively.

2. Educate about the Available Options and Alternatives

Educating yourself and evaluating available options is one of the best ways to protect yourself and your loved ones because it allows you to make truly informed decisions.

An example of an important area of healthcare which you should know about is pain management. The health care decision-maker should understand that there is a difference between pain management and palliative care (comfort care). Palliative care can mean two things: First, it can mean medical or comfort care that reduces the severity of a disease or slows its progress rather than providing a cure. Second, in a negative sense, palliative care may mean the provision of perfunctory health care even though a cure is possible. In cases of incurable diseases, or in cases where the patient does not wish to pursue a cure, palliative care becomes the focus of treatment targeting pain and symptom management.¹

Pain management, on the other hand, refers to the process of providing medical care that alleviates or reduces pain. Pain management is an extremely important part of health care, as patients forced to remain in severe pain often become agitated or depressed and have noticeably poorer treatment outcomes.² Mild to moderate pain can usually be treated with analgesic medications, such as aspirin or Ibuprofen. For chronic or severe pain, opiates and other narcotics are used, sometimes in concert with analgesics. Pain can be treated with steroids or non-steroidal anti-inflammatory drugs when the pain is related to inflammation, or with anti-depressants, which can accentuate some pain medications without raising the actual dose of the drug, and which also affect the patient's perception of pain.² Hospitalized patients with severe pain can frequently now use devices for self-administration of narcotics. Other simple procedures can be useful in pain management programs. For bedridden patients, simply changing position regularly or using pillows to support a more comfortable position can be effective. Massage, acupuncture, acupressure,

and biofeedback have also shown some validity for increased pain control in some patients.² Knowing the options that are available for pain management will enable the decision-maker to have more freedom in making determinations since it will be possible to provide continuing pain relief for the patient.

Once you are satisfied that you have received information on all available options for both care and treatment, you will be in a good position to make the best decision possible. California law requires health care providers to give their patients comprehensive information and counseling regarding care options. (See California Health and Safety Code §442.5.) If you are not comfortable with the medical advice you are receiving, or if you feel that you need to be given more options, you should ask for a second opinion.

3. Document and Monitor the Treatment Administered

When you are making health care decisions for someone else, documenting the treatment received becomes an imperative part of ensuring proper care. You have to know both the patient's medical history as well as the current treatments in order to make informed health care decisions.

Medical records provide ongoing communication between physicians, nurses, and the greater health care team, but for the patient's decision-maker, medical records are not always easily accessible, and may be difficult to understand for one who is not a medical professional. Asking to review medical records is appropriate whenever you need to make an informed medical decision. Healthcare staff should provide clear explanations to any documentation that you do not understand; this means explaining medical jargon in lay terms if needed.

Another option for the health care decision-maker is to keep a record of discussions with the physician and steps taken during treatment. Keep a log of tests, treatments, medications and responses to medications and procedures administered by keeping detailed notes of what actually occurs. This can be done by making detailed notes of what actually occurs. Tracking the treatments given in this manner will protect your ability to recall what has actually occurred with respect to treatment and may improve the quality of care that is provided. Referring to documentation of treatment will protect your ability to make informed decisions and will increase your ability to communicate effectively with health care providers.

4. Don't be Afraid to Report Problems

If it ever becomes apparent to you that health care providers are giving sub-standard care, or if any other problem arises that cannot be resolved by discussion with the caregiver, it may be appropriate to appeal to a higher authority. One of the situations in which inappropriate health care most commonly arises is when the patient is being cared for in a long-term care facility. Professional medical standards often fall victim to competing interests in this type of care situation. When attempts to resolve issues fail, there is no need to hesitate to report problems to the California Ombudsman's office, of the California Department of Public Health. The Ombudsman's office can be reached by phone at 1(800) 231-4024, or on the web at <http://www.aging.ca.gov/programs/ombudsman.asp>. Information for contacting local offices can also be obtained at http://www.cdss.ca.gov/agedblinddisabled/res/pdf/APS_Co_Agencies_Public_Info.pdf. Further information can be obtained through the California Department of Social Services <http://www.cdss.ca.gov/agedblinddisabled/PG1298.htm>, or through the California Department of Aging, <http://www.aging.ca.gov/>.

Additionally, there are several available ways to find applicable care standards: one way is to ask the treating physician, another is to contact the California Department of Health through their website at <http://www.cdph.ca.gov/programs/Pages/LnCCContact.aspx>, or by phone at (916) 558-1784. Your knowledge of the applicable care standards will allow you to insist on accountability from caregivers as needed to ensure that proper care is given.

The importance of caregivers following both applicable care standards and the wishes and best interests of the patients cannot be overestimated, so do not be afraid to take the steps necessary to ensure the best care possible.

1. <http://www.medterms.com/script/main/art.asp?articlekey=11867>.
2. <http://www.medterms.com/script/main/art.asp?articlekey=10513>.

As the experience of many people facing health care crises has demonstrated, careful planning and commitment to do what is best for your loved ones and for yourself will pay off through the freedom you will experience—freedom to make the decisions that best comport with your personal convictions and most deeply held beliefs.

For current link, information and document downloads, go to: <http://lldf.org/pmdd-info.html>.

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