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What Matters Most?

Advance health care directive and values exploration workshop

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About This Packet

THIS packet is a resource as you go through the process of creating a meaningful Advance Directive for Healthcare. There are pages that discuss patient advocacy, pages that are samples of writing that others have used, and pages that are samples of different types of Advance Directive documents. We prefer the Prepare for Your Care document, but you are free to explore the options.

There is also information about other resources on the topics of palliative and end of life care, as well as a suggested reading list.

Thank you for taking this step in considering a difficult but essential part of life and doing what you can to ensure that your wishes may be followed.

Table of Contents

Patient Advocacy Information

Advance Care Planning Documents

CPR

Resources

OTHERWISE

I got out of bed
on two strong legs.
It might have been
otherwise. I ate
cereal, sweet
milk, ripe, flawless
peach. It might
have been otherwise.
I took the dog uphill
to the birch wood.
All morning I did
the work I love.

At noon I lay down
with my mate. It might
have been otherwise.
We ate dinner together
at a table with silver
candlesticks. It might
have been otherwise.
I slept in a bed
in a room with paintings
on the walls, and
planned another day
just like this day.
But one day, I know,
it will be otherwise.

Jane Kenyon

Being a Patient Advocate For Yourself, Family, or a Friend

AT THE DOCTOR'S OFFICE

- Do not be afraid to ask questions.
- Write down questions for the doctor or healthcare practitioner. At the appointment, write down the answers.
- If you do not understand what a doctor is saying, ask for clarification.
- Make sure that the patient's goals for treatment or care are the same as the healthcare provider's goals.
- Ask about side effects of drugs and treatments, and how to manage them.
- Find out if there are new treatments that should be considered.
- Ask if there are any lifestyle changes that might better support your loved one's health goals.
- Find out if there are any products or services that would be helpful.
- If you use "complementary" or "integrative" healing modalities, let your doctor know about this.
- If a medication is not working (for pain or symptoms), ask for a different one, or request a consultation.
- Second opinions are usually covered by insurance.

IN THE HOSPITAL

- Most hospitals have Palliative Care teams. You need a doctor's referral to access this team. Anyone with a serious illness can get a referral, either as an inpatient or in some cases as an outpatient (UCSF, CPMC, and Kaiser). These teams are incredibly valuable.
- Have a copy of your DPOA/Advance Directive with you in the hospital.
- If your loved one or friend is in the hospital, it is beneficial to have someone present at most times, who can advocate by asking questions, getting the nurse, make sure the right medications are given at the right time, etc. A squeaky wheel gets the grease! There is no point in being a "good and quiet patient," if it means suffering.

- In the hospital, things fall through cracks easily. You may need to remind someone about a consult or test, or you may need to speak with a doctor.
- If you do not understand what is happening, ask to speak with the charge nurse, doctor, or case manager.
- DO NOT allow for a discharge to home without a solid plan.
- If you believe that the patient has needs that are not being addressed, you must help address them. If you are not the medical power of attorney for healthcare, make sure that whoever is, can be contacted easily.
- Sometimes you must request to see the doctor who is in charge, and not a resident.

AT HOME

- ◆ If you believe that your friend/loved one is near the end of life, but no one is discussing it, ask. Ask the physician about a hospice referral. That often opens up a different level of conversation.
- ◆ Find out how much your friend does or does not want to know about their illness and treatment.
- ◆ Some hospice teams have an outpatient palliative care department that can assist you.

IMPORTANT INFO FOR PERSONAL HEALTH BINDER

USE A 3-RING TYPE BINDER WITH TABS

TABS SHOULD INCLUDE:

- Health history
  - Complete medical history updated regularly
  - Dates of any major diagnoses or surgeries
- Medications
  - Both current and any recently stopped.
  - Any complementary medications/supplements, etc
  - Name of pharmacy
- Doctors
  - List of all doctors with contact info
  - emergency contact information
- Recent visits
  - Summaries of recent MD visits
  - List of upcoming appointments

UCSF Health

DATE:

PATIENT NAME:

BIRTHDATE:

ID VERIFICATION (TYPE):

ID VERIFIED BY:

AUTHORIZATION FOR RELEASE OF HEALTH INFORMATION

I authorize: ______________________________
(Name of person or facility which has information - example: UCSF/Mt. Zion)

to release health information to: ______________________________
(Name of person or facility to receive health information and full address)

Street address	City	State	Zip Code

☐ Check this box to authorize exchange between the persons/organizations listed above.

The purpose of this release is for (check one or more):

☐ Continuity of care or discharge planning ☐ Billing and payment of bill

☐ At the request of the patient/patient representative ☐ Other (state reason): ____________________

Please specify the health information you authorize to be released. Please check all that apply.

For dates of service: ______________________________

☐ **Emergency Room Visit** (e.g. ED provider notes, radiology reports, lab and diagnostic, consults and procedure notes)

☐ **Entire Hospital Record** (e.g. History and physical, consult, operative report, discharge summary, lab, radiology reports, nursing notes, progress notes)

☐ **Clinic or Office Visit** (e.g. Progress notes, office notes, procedure notes, operative notes, lab, diagnostic and radiology reports)

☐ **Billing Records** ☐ **Radiology Images (only)** ☐ **Dental Clinics** ☐ **Reproductive Health Clinic**

☐ **Other Records** (*not listed above, please specify type*): ______________________________

Delivery Method (*please select one*): ○ Mail ○ Pick-up ○ Online Portal (Medical Records Only)

The following information will not be released unless you specifically authorize it by marking the relevant box(es) below:

☐ Information pertaining to drug and alcohol abuse, diagnosis or treatment (42 C.F.R. §§2.34 and 2.35).

☐ Information pertaining to mental health diagnosis or treatment (Welfare and Institutions Code §§5328, *et seq.*)

☐ Release of HIV/AIDS test results (Health and Safety Code §120980(g)).

☐ Release of genetic testing information (Health and Safety Code §124980(j)).

EXPIRATION OF AUTHORIZATION

Unless otherwise revoked, this Authorization expires____________________(insert applicable date or event). If no date is indicated, the Authorization will expire 12 months after the date of my signing this form.

Print Name	Signature (Patient, Parent, Guardian)
Patient Phone Number	Patient Email
Date Time	Relationship to Patient (Parent, Guardian, Conservator, Patient Representative)

Requested format: ☐ Paper ☐ CD

756-020ZI (Rev. 04/22) MEDICAL RECORD COPY

Advance Health Care Directives
Frequently Asked Questions for Consumers

What is an Advance Health Care Directive?

An Advance Health Care Directive (AHCD) is a way to appoint someone to make your healthcare decisions when you can't and make your healthcare wishes known if you are unable to speak for yourself. You can use an AHCD to do one or both of the following:

- Appoint a Power of Attorney for Health Care (or "healthcare agent")
- Write down Instructions for Health Care (to indicate your wishes, especially related to end-of-life care)

Why should I complete an AHCD?

People of all ages may unexpectedly need medical treatment when they cannot speak for themselves, such as an accident or severe illness. In these situations, your AHCD lets your doctor and your loved ones know your wishes about the kind of treatment you want and don't want and/or the person you want to make decisions on your behalf. Without an AHCD, your doctors and your loved ones might have to guess what you want.

Is the AHCD different from a Durable Power of Attorney for Healthcare?

California legislation enacted in July 2000 replaced the Durable Power of Attorney for Health Care and the Natural Death Act Declaration with the Advance Health Care Directive. Durable Power of Attorney forms completed prior to July 1, 2000, are still considered valid; however, if you have such a form, it would be a good idea to update it.

Does this mean only one person can decide for me? What if I want others involved too?

Legally, when you can't speak for yourself, someone else must be empowered to make decisions for you. Often many family members are involved in decision making, but one person should have legal authority to speak for you. Occasionally, loved ones will disagree about the best course of action, so the person named as your official healthcare agent has the final say. You can also appoint a back-up or alternate agent if the first person you name is not available or can't serve for any reason. You may also indicate if there is someone whom you do NOT want to make your decisions for you.

I thought the doctors make all those life-and-death decisions – don't they?

Doctors tell you about your medical condition, the different treatment options that are available to you, and what may happen with each type of treatment. Though doctors provide guidance, you or your designated decision maker makes the decision to have a treatment, refuse a treatment, or stop a treatment.

What if something happens to me and no form has been completed?

If you suddenly become ill or injured but are still able to speak for yourself, you can tell your doctor if there is someone else you want to make decisions for you. This oral instruction is just as legal as a written one, though this decision maker is formally called a "surrogate" instead of a "healthcare agent."

The surrogate has all the authority of a healthcare agent for the time that you are ill, staying in a healthcare facility, or 60 days, whichever is shorter.

If you are not able to speak for yourself, the doctor and healthcare team will choose a decision maker from among your family members or friends. Unlike many other states, California does not dictate the order in which these people must be chosen. Your healthcare providers must try to select the person who knows you best, has a close, caring relationship with you, is aware of your values and beliefs, and is willing and able to make the needed decisions.

This can be hard for healthcare providers to do, especially in a situation that needs important decisions to be made quickly. It’s best to make and document your choice for decision maker in an AHCD well ahead of the crisis.

Why is it important to talk about my values and beliefs? Aren’t we talking about medical treatment here?

The particular medical treatments that you might need or the decisions that might need to be made are impossible to predict. If your decision maker and your other family members and close friends know what is important to you regarding quality of life, how you want to be cared for during serious illness, and where you would want to spend your last days, they can make decisions based on your values and beliefs.

What if I don't want to appoint a healthcare agent? Or don't have one to appoint?

You do not have to appoint a healthcare agent. You can still complete the Instructions for Health Care, and this will provide your doctors with some basic information to guide your care.

What kinds of things can I write in my Instructions for Health Care?

You can, if you wish, write your preferences about accepting or refusing life-sustaining treatment (like CPR, feeding tubes, breathing machines), receiving pain medication, and making organ donations. You can indicate your main doctor for providing your care, and nominate a person who should be appointed as your conservator if you might need one. You can also express other wishes and values.

If you have a chronic or serious illness, you may also want to talk with your doctor about specific treatments that you could face and ask them to help you document your decisions on a POLST form.

Do my doctors have to follow the instructions in my AHCD?

Unfortunately, there is nothing in the law that says a doctor MUST follow your instructions in your AHCD. However, doctors generally want to know what their patients would want, and if they have an AHCD with clear instructions, they are very likely to follow them. If your AHCD also appoints a healthcare agent who can, in person, state your preferences and make decisions according to your values, there’s a very high likelihood your choices will be honored. Without any statement of your wishes, or a healthcare agent to speak for you, the chances are very slim that you’ll get the care you want and not get the care you don’t want.

What is a POLST form?

POLST stands for Physician Orders for Life-Sustaining Treatment. Adopted in California in 2009, it is a voluntary form, which must be signed by you (or your healthcare agent) and your physician, nurse practitioner, or physician assistant. It indicates the types of life-sustaining treatment you do or do not want if you are seriously ill, specifically your preferences for CPR and feeding tubes, and lets you choose your overall goals for care – to maximize comfort, extend life by any medical means, or something in between.

POLST doesn't replace your AHCD, but when you are seriously ill, it converts key choices into medical orders. Unlike the instructions in your AHCD, the choices on your POLST are orders that, according to the law, must be followed in all healthcare settings.

If I appoint a Healthcare Agent, what can that person do?

Your healthcare agent can make all decisions for you, just like you would if you could. Your healthcare agent can choose your doctor and where you will receive your care, speak with your healthcare team, review your medical record and authorize its release, accept or refuse medical treatments, and make arrangements for your funeral or what you want done with your body. You should instruct your healthcare agent on these matters, so they know how to decide for you. The more you tell your healthcare agent, the better they will be able to make those decisions on your behalf.

When does my Healthcare Agent make decisions for me?

Usually, the healthcare agent makes decisions only if you are unable to make them yourself – such as when you can't understand things or communicate clearly enough to make medical decisions. A doctor may have to formally judge whether you are able to make the decisions needed.

However, if you want, your healthcare agent can speak on your behalf at any time, even when you are still capable of making your own decisions. You just have to specifically state that in your AHCD.

You can also appoint a temporary agent or "surrogate decision maker" – for example, if you suddenly become ill, you can tell your doctor if there is someone else you want to make decisions for you. This oral instruction is just as legal as a written one.

Are there other oral instructions that don't involve a written form?

Yes. You can state your treatment and care preferences to any person at any time. All healthcare providers must document your wishes in your medical record. But there may be times when you aren't able to speak up for yourself, so written instructions are very helpful.

Can I make up my own form or use one from another state?

Yes. Any type of form is legal in California as long as it has at least three things:

1. Your signature and date,
2. The signature of two qualified witnesses with their witness statements (see below) or a notary signature, and
3. If you reside in a skilled nursing facility, the signature of the patient advocate or ombudsman.

What is a Witness Statement?

Witnesses must sign a statement on the AHCD indicating that they (a) know who you are or have been shown proof of your identity, (b) are 18 years old or more, (c) are not your healthcare provider or working for your provider, (d) are not your healthcare agent, and (e) are not employed in the place where you live.

One of the two witnesses must sign a statement indicating that they are not related to you by blood, marriage, or adoption and will not receive any property or money from you after your death.

Do I need an attorney to help with this?

No. Completing an AHCD isn't difficult, and an attorney is not necessary. See below for where to find the forms. The most important part of this is talking to your loved ones about your choices and what is most important to you. Without that conversation, the best form in the world may not be helpful!

What should I do with the form after I complete it?

Make copies for all those who are close to you. Take one to your doctor to discuss and ask that it be included in your medical record. Photocopied forms are just as valid as the original. Be sure to keep a copy for yourself in a visible, easy-to-find location – not locked in a file cabinet or safe deposit box!

What if I change my mind?

You can revoke your form or your oral instructions at any time. Also, it's a good idea to review and update your AHCD every few years, especially if there's a change in your family, your choice for healthcare agent, or your health.

Can doctors or hospitals require a patient to have an AHCD?

No, they cannot require you to complete one. But doctors and hospitals should have information available to you and your family about the form and your right to make healthcare decisions.

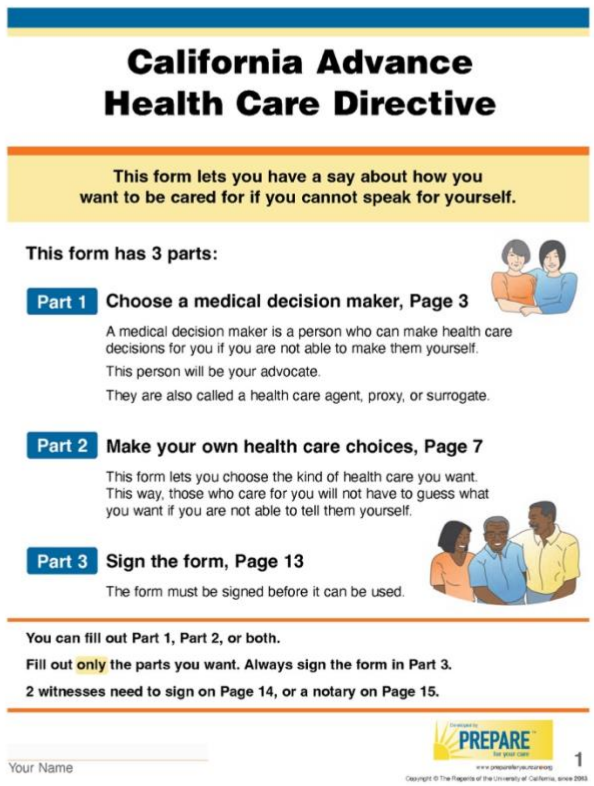
Resources

- The CCCC offers a selection of AHCD forms at **Coalitionccc.org**. Click on Resources/Advance Care Planning Resources.
- Forms are often available at no charge from your local hospital – call the Social Services or Patient Education department or ask your doctor.
- The California Medical Association has an Advance Healthcare Directive Kit available in English or Spanish that includes a form, wallet card, and answers to commonly asked questions about advance directives. To order single copies, visit https://www.cmadocs.org/store.
- Caring Connections has state-specific forms that can be downloaded at https://www.caringinfo.org/planning/advance-directives/by-state/.
- Prepare for Your Care has easy-to-read forms for each state in multiple languages that can be downloaded at https://prepareforyourcare.org/en/advance-directive.
- ***Finding Your Way: Medical Decisions When They Count Most.*** This 14-page, easy-to-read booklet helps those who are starting the advance care planning process. Also available in Spanish.

PREPARE for Your Care^{TM} Advance Directive Form

Our preferred Advance Directive for Health Care is **PREPARE for Your Care^{TM}** . PREPARE is an online resource that helps people begin the important process of planning for medical decision-making. Using video stories, PREPARE helps people explore their personal wishes and learn how to discuss them with family, friends, and medical providers.

PREPARE is updated frequently and we recommend that you download their most up-to-date form for your state at their website: prepareforyourcare.org



California Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

This form has 3 parts:

Part 1 **Choose a medical decision maker, Page 3**

A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself.

This person will be your advocate.

They are also called a health care agent, proxy, or surrogate.

Part 2 **Make your own health care choices, Page 7**

This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are not able to tell them yourself.

Part 3 **Sign the form, Page 13**

The form must be signed before it can be used.

You can fill out Part 1, Part 2, or both.

Fill out only the parts you want. Always sign the form in Part 3.

2 witnesses need to sign on Page 14, or a notary on Page 15.

Your Name

1

Why PREPARE?

Evidence-Based. PREPARE's advance care planning (ACP) programs are based on over two decades of research. In randomized trials, they have proven to empower patients and caregivers, decrease health disparities in ACP, prime patients for clinical visits, and help people get the medical care that is right for them.

National. PREPARE includes advance directives for US states and Washington, D.C.

Multilingual. PREPARE advance directives are available in English and Spanish. They are also available in Arabic, Armenian, Chinese, Farsi, Hmong, Khmer, Korean, Russian, Somali, Tagalog, and Vietnamese for some states.

Accessible. PREPARE is designed to address limited health and digital literacy and visual, hearing, and cognitive impairment.

Legally Compliant. PREPARE advance directives are reviewed yearly by UC Law San Francisco (formally UC Hastings) to ensure compliance with state laws and regulations.

Letter to My Future Doctor

FAITH FITZGERALD, MD, *Sacramento, California*

Everyone is talking. Physicians, politicians, newspaper columnists, patients, families, authors, talk show hosts, all are debating our right to decide how and when we will die. It is necessary and wise to obtain a medical directive. One question we must ask ourselves as physicians is, Can we *do what we ask our* patients *to do? Here is one physician's medical directive.*

We are in an era of ethical conundrums, especially in the distinction between what we *can* do and what we *ought* to do regarding the continuation of life. I admit that, knowing as much as I do, I fear your enthusiasms and your doubts. Because I do not know you yet, I want to take this chance to make myself clear to you.

I believe that my body is a vehicle for my brain, no more than a machine that allows my mind to function. So long as my brain works, that is, receives and sends coherent messages, I would wish to live.

If my brain fails—by trauma, a residual of metabolic disarray, degenerative process, tumor, ischemia, infection, or other chronic or acute event—let me die.

If I am in a chronic vegetative state, irreversible coma, or dementia to the point where I require help in basic functions—let me die.

It can be argued that you won't be sure of the permanence of such a state of cerebral dysfunction, but I don't require absolutes.

If in your best opinion the strong likelihood is for continued brain dysfunction—let me die.

I cannot make decisions now about dismemberment, physical limitations, chronic pain, "terminal" disease, and the like, since the circumstances of these may vary greatly. I would want to make a decision at the time, after talking with you.

If I am incapable and unlikely, because of the nature of my illness, ever to be capable of making such a decision, I will be by definition in the category of projected cerebral dysfunction already discussed—let me die.

What do I mean by "Let me die"? I mean let me die without vacillation: no antibiotics, fluids, enteral or parenteral sustenance, electrolyte manipulations, supportive machinery, or emergency interventions other than are necessary to relieve pain. Don't let your fear of the law, or the strident desires of others, override your common sense. Should someone accuse you of "playing God," tell them that I said that death is a natural end; it is the futile prolongation of severely damaged life that is "playing God." Moreover, I now also give you permission to take organs from me that might benefit others—eyes, kidneys, heart, skin, liver . . . whatever.

I was not for millions of years, the time before my birth; I will not be for all of subsequent time beyond my death; the one is no different to me from the other. Neither terrifies. I will die. Let it be when the mind I have defined as myself has ceased to allow me to function as a sentient being, interacting with others in a creative and independent way.

I'll make a bargain with you: I will, by this declaration, release you from your doubts about what to do, and you, in turn, will allow me to escape from a future threatened by senseless animation. Let this be our final act as colleagues.

FAITH FITZGERALD, MD
Sacramento, California

Have you written your own declarations of intent and have you notified your own physician or family about them? We challenge you, the readers of THE WESTERN JOURNAL OF MEDICINE, *to send us your comments. A public declaration will reveal varieties of opinion. It will put in writing your easy-to-say claims; it will give you an idea of the challenges involved in constructing these directives. This should be interesting!*

THE EDITORS

(Fitzgerald F: Letter to my future doctor. West J Med 1992 Mar; 156:313)

From the Department of Internal Medicine, Housestaff Affairs, University of California, Davis, School of Medicine, Sacramento.

Reprint requests to Faith Fitzgerald, MD, Department of Internal Medicine, Housestaff Affairs, University of California, Davis, Medical Center, 2315 Stockton Blvd, Rm 6305, Sacramento, CA 95817.

FIVE WISHES®

THE FIVE WISHES is another advance directive document that asks people to consider 5 questions that are important to think about and talk about and ultimately to put the answers in writing.

The following pages in this packet are samples of a “Five Wishes” document that a person wrote with very detailed wishes, simply to highlight that one can put all of their thoughts in writing, OR it is fine to keep the answers as simple as possible!

However, the conversations about these questions are important either way!

Here is a link to the document: https://www.fivewishes.org

WISH #1

The person I want to make healthcare decisions for me when I can’t make them for myself

WISH #2

My wish for the kind of medical treatment I want or don’t want

WISH #3

My wish for how comfortable I want to be

WISH #4

My wish for how I want people to treat me

WISH #5

My wish for what I want my loved ones to know

Sample

'Five Wishes' 1
0/16/2014 rev. 10/25/2016

l choose as my Health Care ________________

I understand that my Health Care Agent can make health care decisions for me, ifand when I am unable to. I want my Agent to be able to do following: Make choices about medical care, services, tests, drugs, surgery. This care or service could be to find out what my health problem is (but only if such information could be actionable) or how to treat it. It can also include care to keep me alive. If the treatment. or care has already started, my Health Care Agent can keep it going or have it stopped.

My Health Care Agent may do the following

Interpret any instructions I have given in this document or in other discussions, according to my Health Care Agent's understanding of my wishes and values.

Consent to admission to an assisted living facility, hospital, hospice, or nursing home for me, if such becomes advisable.

Hire any kind of health care worker I may need to help me or take care ofme. My Agent may also fire a health care worker, if needed.

Make the decision to request, take away or not give medical treatments, including artificially-provided food and water, and any other treatments to keep me alive.

See and approve release of my medical records and personal files. If I need to sign my name to get any ofthese files, my HCA can sign it for me.

Authorize any medication or procedure needed to help with pain, not authorize routine procedures such as X-Rays, that do not yield information needed for my care.

Take any legal action needed to carry out my wishes.

Medical Care

I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means that I will be drowsy or sleep more than I would otherwise, and even if, when there is no prospect of any degree of recovery that would enable me to resume being my own decision maker, the medicine risks ending my life.

I want to be offered food and fluids by mouth and kept clean and warm.

The kind of medical treatment that I want or don't want, in the four situations below:

I want my Health Care Agent, my family, my doctors and other health care providers to know these directions.

Note: "life-support" refers to any medical procedure, device or medication to keep me alive, including but not limited to tube feeding, CPR, major surgery, dialysis, antibiotics

Situation: Close to death

If my doctor and another health care professional both decide that I am likely to die within a short period of time, and life-support treatment would only delay the moment of my death, I do not want life-support treatment. If it has been started, I want it stopped.

Situation: In a coma and not expected to wake up or recover

If my doctor and another health care professional both decide that I am in a coma from which I am not expected to wake up or recover, and life-support treatment would only delay the moment of my death, I do not want life-support treatment. If it has been started, I want it stopped.

Situation: Permanent and severe brain damage and not expected to recover

e.g., I can open my eyes, but I cannot speak or show any evidence of understanding and I am not expected to get better.

I want to have life-support treatment if my doctor believes it could help.

I want to be confident that even if I cannot speak or write, my communication will be paid attention to. The means of communication could be as simple as having someone recite the alphabet and writing down the letters at which I blink or give whatever signal I am capable of.

I want my Health Care Agent or someone she designates to establish whether I can communicate despite inability to speak, write, or move a limb.

If it is established that I am unable to communicate by any means, and if the problem is not reversible, I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

The following deal with my personal, spiritual and emotional wishes.

I want to be treated with dignity near the end of my life, so I would like people to do the things written below when they can be done. I understand that my family, my doctors and other health care providers, my friends, and others may not be able to do these things or are not required by law to do these things. I do not expect the following wishes to place new or added legal duties on my doctors or other health care providers.

I wish for my family to know about options for hospice care to provide emotional support for them and guidance in how to talk to my grandsons and how to deal with my disabled son.

In regard to how I want people to treat me

I wish to be cared for with kindness and cheerfulness, and not sadness.

I wish my daughter (and of course my grandsons) not to be exposed to sights or situations which could be disturbing to them. This may require asking them to wait outside the room during personal hygiene care. It might require asking them to wait outside the room until any severe behavioral difficulties are resolved (agitation, hallucinations, anxiety).

If I show signs of depression, anxiety, nausea, shortness of breath, agitation or hallucinations, I want my caregivers to do whatever they can to help me.

I want my lips and mouth kept moist to stop dryness.

I do not wish to be touched other than in the course of medical care, personal hygiene care, or any care deemed necessary by my doctors and health care providers, with the exception of the following people:

my daughter, my grandsons and the following friends, should any of them be present: xxxxxxxxxxx My Health Care Agent can use her judgment to add someone to the list above if she deems it appropriate.

I do not wish to have anyone else use touch to comfort me. This includes hold my hand, smooth my hair, put their hand on my shoulder, offer kisses, fix my blankets or perform any related activities.

I specifically do not wish to have "healing touch" or stroking or related practices, nor Reiki or related practices used on me. I do not wish to have informal or formal practices involving transmission or summoning of "energy". I do not wish to have objects considered to have magical powers placed in my presence.

I wish there to be no praying, no reference to gods, nor any chanting or singing in my presence or hearing. Exception: a Sh'ma, if someone comes by who can recite those few words.

I want to hear the human voices of the people present in the room, and music only when there is no one to talk to me. I wish to be talked to when possible, even if I don't appear to respond to others' voices.

In the event music is played, I would prefer Mozart, or Bach, played quietly. I do not wish to hear any music that is interrupted by ads for products or donor organizations. I don't want to hear a television set.

I wish to have large pictures of my daughter and grandsons placed where they are visible to me despite my positioning and any limitations of movement I may have.

I wish to be in a room with a window that can be opened, and that the window be kept open as possible

I wish to be placed so that I can look out the window, despite my positioning and any limitations of movement I may have, and be able to see a tree, or trees in the distance or some other aspect of nature.

I wish to have people with me when possible. I want someone to be with me when it seems that death may come at any time.

I wish to have the following personal care procedures as long as they do not cause me pain or discomfort: nail clipping, teeth brushing, slight, natural-looking enhancement of my eyebrows. I wish to be kept fresh and clean at all times.

My wishes for what I want my loved ones to know

I wish to have my family and friends know that I love them.

I wish to be forgiven for the times I have hurt my family, friends and others.

I wish to have my family, friends and others know that I forgive them for when they may have hurt me. "Family, friends (and others)" does not include my third husband.

I wish my family to commit to loving and supporting each other, especially my disabled son, Benjamin.

I wish for my family to remember what I was like when I was not ill.

I wish for my family and friends and caregivers to respect my wishes even if they don't agree with them.

I wish for my family and friends to look at my dying as a valid part of my life and of theirs. This will help me live a meaningful life in my final days.

I wish for my family to seek counseling if they experience emotional distress. I wish for them to know that hospice is a good source of counseling, and also of guidance for how to talk about my death with my grandsons.

I wish to donate my remains to UCSF for medical teaching and research.

I can accept the reality of my death. My death is not the end of the world. The accelerating destruction of a liveable habitat, however does risk ending a world in which human beings can live.

If anyone wishes to honor my memory, I ask them to do all they can to bring Climate Change into the minds and conversations of the people they connect with, so that it becomes socially acceptable to talk and think about it; and to make personal choices and political choices that are in the interests of our children and grandchildren, with the goal that they will enjoy nature as we have enjoyed it, will breathe fresh air, will have an adequate water supply, and will be nurtured by delicious produce.

If anyone wishes to make a charitable donation in my memory I welcome them to donate to the charity of their choice.

I do not wish to have a funeral.
If my daughter or if a friend wishes to hold a gathering to remember me, I would like it to be done with a minimum of fuss. I do not want anyone to fly, or to drive a major distance, to attend. My wish is that this gathering be of comfort to those of my family who are capable of receiving comfort from it, and to my friends. It can take place anytime, within a year of my death. I specifically do not want it to be a "celebration of life". I want people to share whatever memories and emotions they experience.

I wish there to be food and drink available at or after this gathering, expenses to come from my estate. I would like it to include plain cake [sponge cake if obtainable) and red wine. I would prefer nothing more elaborate.

If it does not take place at my daughter's home, I would like it to take place at a space at the Jewish Home on Silver Avenue, San Francisco. This should not be interpreted as a request for prayers or references to religion. Fee or donation expenses should also come from my estate.

It may be that the university holds periodic memorials for people who bodies have been donated. They would presumably inform you.

I wish for death notices to be published in the primary newspapers of---------------

What is a POLST?

Key Facts About POLST for Individuals and Family Members

Physician Orders for Life Sustaining Treatment (POLST) is a medical order that helps give people with serious illness more control over their care during a medical emergency. POLST can help make sure you get the care you want, and also protect you from getting medical treatments you DO NOT want.

- **POLST is voluntary.** Nursing homes and assisted living facilities may include POLST in their admission papers, but can't require you to complete a POLST if you do not wish to.

- **POLST is for people who are seriously ill or have advanced frailty**. If you are healthy, an advance directive is for you.

- **A POLST does NOT replace an advance directive,** which is still the best way to appoint someone you trust to act as your medical decisionmaker. A POLST works together with your advance directive, providing more specific detail regarding medical wishes and goals of care during a serious illness or at the end of life.

- **The POLST form should be completed by your doctor or another trained medical provider** after you've had a good conversation about the form's medical terms and options. This conversation is very important and should cover your overall health, your personal values, goals for your care, and treatment wishes. It can be helpful to include your family in the talk so they know and understand your treatment wishes.

- **The POLST form is not valid until it is signed by both you (or your designated decisionmaker) *AND* your physician, nurse practitioner, or physician assistant.**

- **Once completed and signed, a copy goes in your medical record and you keep the original bright pink POLST**. Wherever you go for medical care, the signed pink form should go with you. At home, keep your POLST in an easy to find place, like on your refrigerator, in case of a medical emergency.

- **POLST does not expire, but it should be reviewed regularly to make sure your wishes haven't changed.** You do not need to fill out a new POLST if you move from one facility to another, or change doctors. You only have to complete a new POLST if your treatment wishes change.

- **POLST is a medical order, which means licensed medical providers are required to follow its instructions** regarding CPR and other emergency medical care. The POLST form is printed on bright pink paper so it is easy to recognize, but photocopies are also considered valid.

- **You can void your POLST form at any time, verbally or in writing.** If you have changes, it is best to complete a new POLST. To void a POLST form, draw a line through sections A through D, write "VOID" in large letters, then sign and date the line.

Please go to: http://www.capolst.org/ or call (916) 489-2222 for more information.

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

UCSF
The MERI Center for Humanity in Healthcare

EMSA #111 B
(Effective 4/1/2017)*

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 — CARDIOPULMONARY RESUSCITATION (CPR):

Check One

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 — MEDICAL INTERVENTIONS:

Check One

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 — ARTIFICIALLY ADMINISTERED NUTRITION:

Check One

Offer food by mouth if feasible and desired.

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

Additional Orders: ______________________________
____
____

D — INFORMATION AND SIGNATURES:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _______, available and reviewed →
☐ Advance Directive not available
☐ No Advance Directive

Health Care Agent if named in Advance Directive:
Name: ______________________________
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:	Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011,10/1/2014 or 01/01/2016 are also valid

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

Patient Information

Name (last, first, middle):	Date of Birth:	Gender: **M F**

NP/PA's Supervising Physician	**Preparer Name** (if other than signing Physician/NP/PA)	
Name:	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**.

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

Metta is a Pali word that means loving kindness. This is a meditation of compassion for caregivers.

Metta for Caregivers

(from Joan Halifax, *Being with Dying* teachers' manual)

The emphasis in these practices is on balance—the balance between opening one's heart endlessly, and accepting the limits of what one can do. The balance between compassion and equanimity. Compassion is the trembling or the quivering of the heart in response to suffering. Equanimity is a spacious stillness that can accept things as they are. The balance of compassion and equanimity allow us to care, and yet not get overwhelmed and unable to cope because of that caring.

The phrases we use reflect this balance. Choose some phrases that are personally meaningful to you. You can alter them in any way, or use one that you have created out of your unique personal significance.

To begin the practice, take as comfortable a position as possible, sitting or lying down. Take a few deep soft breaths to let your body settle. Bring your attention to your breath, and begin to silently say your chosen phrases in rhythm with the breath…you can also experiment with just having your attention settle in the phrases, without using the anchor of the breath. Feel the meaning of what you are saying, yet without trying to force anything…let the practice carry you along.

May I offer my care and presence unconditionally, knowing it may be met by gratitude, indifference, anger or anguish.

May I find the inner resources to truly be able to give

May I offer love, knowing I cannot control the course of life, suffering or death

May I remain in peace, and let go of expectations

I care about your pain, yet cannot control it

I wish you happiness and peace, but I cannot make your choices for you

May this experience be a heavenly messenger for me, helping me open to the tru nature of life

May I see my limits compassionately, just as I view the suffering of others

May I, and all beings, live and die in ease

Information for Patients and Families About CPR

What is CPR?

CPR stands for cardiopulmonary resuscitation. It is sometimes used in an emergency when someone’s heart has stopped beating adequately. Cardiac arrest is another term for when the heart stops beating.

If you are in cardiac arrest, blood stops flowing through your body.

This means that oxygen cannot get to your brain. Your brain can survive without oxygen for only about five minutes. After that point, you would have permanent brain damage, even if your heart started again.

CPR can help blood and oxygen flow to your brain while medical staff try to get your heart to beat normally again. This may help prevent brain damage.

CPR may include:

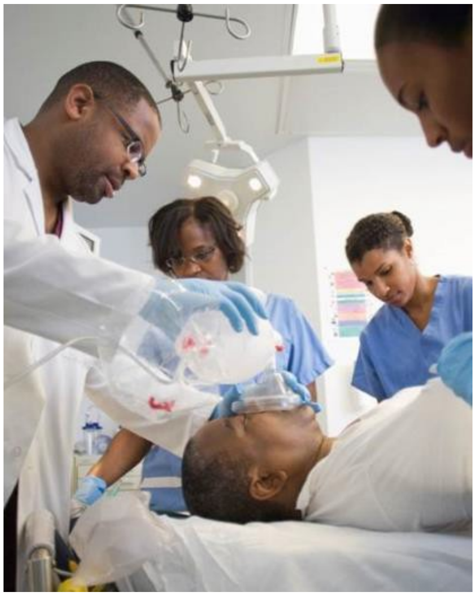
- Someone pushing on your chest with their hands (chest compressions)
- Artificial breathing. This might mean that someone breathes from their mouth into yours (mouth-to-mouth), or uses a small bag attached to a mask to push air into your lungs.
- Someone giving you medications to stimulate your heart
- A machine giving you one or more quick electrical shocks to your chest (defibrillation)
- Someone putting a tube into your windpipe to help air reach your lungs

When might CPR be used?

You would only get CPR if your heart stopped beating (cardiac arrest). Cardiac arrest can be expected or unexpected. It is a normal part of the dying process. Cardiac arrest could happen unexpectedly because of a sudden severe illness or injury, or due to a heart problem that the person may or may not know about.

Health care staff would automatically do CPR if you went into cardiac arrest, unless you have a Do Not Attempt Resuscitation (DNAR) order. A DNAR order tells health care staff not to do CPR if you go into cardiac arrest. In some places, this order is called a Do Not Resuscitate (DNR) order.

You have a choice about whether or not you would get CPR when your heart stops beating. Your choice about CPR does not affect the care you will receive or your decisions about other treatments.



Benefits and Risks

What are some possible benefits of CPR?

CPR can save lives, especially when given to a young, relatively healthy person right after their heart stops. In some cases, CPR may return the person to the same health they were in before their heart stopped. This is more likely if the person does not have serious health problems, and if CPR is started quickly after their heart stops.

CPR might or might not work to re-start your heart. It is more likely to work if you are relatively healthy before a cardiac arrest. The chances of surviving are a little better if CPR is started quickly after the heart stops and if you receive CPR in the hospital. About one in six people who get CPR while in the hospital survives their hospital stay, and five in six people die. Survival chances for you may be more or less, depending on your health problems.

What are some possible risks of CPR?

CPR often does not work to re-start the heart, especially when given to someone who has more than one illness or a very serious disease.

If you survive after CPR, you will have a sore chest and may have broken ribs because of the chest compressions. You may have a collapsed lung.

If you do not get enough blood to your vital organs during cardiac arrest and you survive after CPR, you might have serious problems afterward. You might be dependent on others to care for you, have brain damage, or need a breathing machine. Depending on the health problems you have after CPR, you may not be able to live at home.

What to Expect

What if my heart stops?

If you had a cardiac arrest, you would lose consciousness and pass out quickly. Once you passed out, you would not feel anything.

If you do not receive CPR, or if CPR does not work to restart your heart, you would die. If CPR works to restart your heart but you do not start breathing on your own, you would be put on a breathing machine (ventilator) unless you have a doctor's order stating that you do not want to be on a breathing machine. If CPR works to restart your heart, you would receive medical care to treat any problems caused by CPR. Some possible risks of CPR are listed on the page before.

Your health care team can tell you if you are at increased risk for cardiopulmonary arrest. Talk with them about treatment options that support your goals and preferences.

CPR Outcomes

Most patients get information about CPR from TV. Depictions of CPR on TV create overly-optimistic impressions about CPR's effectiveness. A study[1] reviewing outcomes after CPR as portrayed on *ER*, *Chicago Hope*, & *Rescue 911* found the following across 60 episodes of CPR:

- 77% of patients resuscitated on these TV shows survived the immediate arrest;
- Most cases implied long term survival; and
- Only one survivor incurred any obvious disability after CPR.

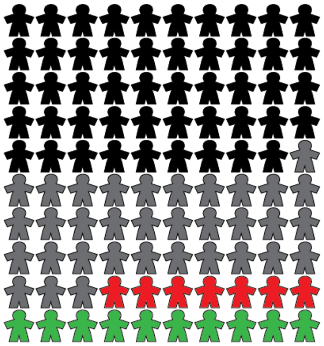
Real-life outcomes are not as positive.

Among adults who received CPR in the hospital[2,3]:

- 56% died during resuscitation
- 27% died before hospital discharge
- 17% survived to discharge

Among patients 65 and older who received CPR in the hospital[4]:

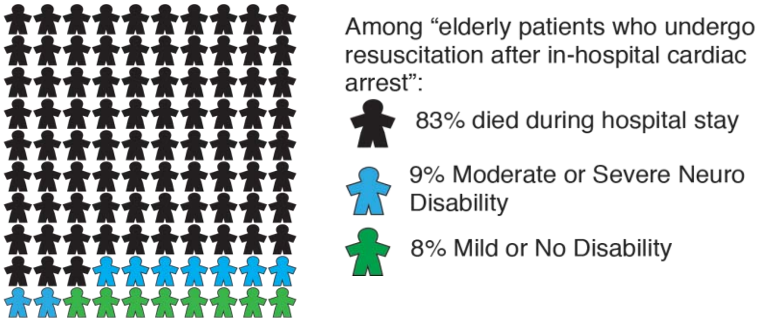
- 49% died during resuscitation (black figures, below)
- 34% died before hospital discharge (gray figures)
- 17% survived to discharge (red and green figures)
- 10% were alive one year after discharge (green figures)



Source of images:
http://www.geripal.org/2013/09/outcomes-of-in-hospital-cpr-not-as-rosy.html

Keep in mind that these numbers are averages. Survival rates after CPR are lower for some patient groups, higher for other.

This figure illustrates the risk of experiencing cognitive disability after CPR for patients age 65+.



Among those who survived after CPR and had good cognitive performance before their arrest, most (86%) had good cognitive performance after CPR; some (14%) had at least moderate cognitive impairment.[2]

There is also a risk of not being able to return home, or being unable to care for oneself after surviving CPR. In a recent large study, 83% died during CPR or prior to discharge, 9% were discharged to an inpatient facility, 7% were discharged home, and 1% were discharged to hospice.[4]

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[1] Diem SJ, Lantos JD, Tulsky JA. Cardiopulmonary resuscitation on television: Miracles and misinformation. N Eng J Med 1996;334: 1578-82.

[2] Peberdy MA, Kaye W, Ornato JP, Larkin GL, Nadkarni V, Mancini ME, Berg RA, Nichol G, Lane-Trultt T. Cardiopulmonary resuscitation of adults in the hospital: a report of 14720 cardiac arrests from the National Registry of Cardiopulmonary Resuscitation. Resuscitation 2003:58;297-308.

[3] Girotra S, Nallamothu BK, Spertus JA, Li Y, Krumholz HM, Chan PS. Trends in survival after in-hospital cardiac arrest. N Engl J Med 2012:367(20):1912-20.

[4] Chan PS, Nallamothu BK, Krumholz HM, et al. Long-term outcomes in elderly survivors of in-hospital cardiac arrest. N Engl J Med 2013; 368:1019-1026.

End of Life Doulas

An End-of-Life Doula (also called a Death Doula) is a trained, non-medical support person who provides education, guidance, emotional support, and logistical and practical assistance to people facing serious illness and death. EOL doulas enhance medical care; they don't replace it. They complement and supplement the work of family and other caregivers.

Every end-of-life journey is unique. A doula's role depends on the needs and values of the people they are supporting, and care is guided by the client's individual circumstances, values, and wishes. Doulas focus on compassionate care that honors the dying person's wishes and supports their loved ones through this important journey.

Some of the services that may be offered by an EOL Doula:

- Guidance and support for completing advance health care directives
- Facilitation for a life review or legacy project
- Planning for how someone wants the last days of life to look, sound, and feel
- Providing comfort and support during the final days of life and post death
- Explaining the nature of the dying process and coordinating with care providers, including hospice
- Advocating for the dying person's wishes to be honored and respected
- Education and guidance about end-of-life options, including Medical Aid in Dying
- Information about body disposition
- Assistance with after death care, memorial planning and grief and bereavement support

Doulas are privately compensated for their services, depending on the specific services provided. At this time, there is no third-party reimbursement for EOL doula care.

How to find a doula

It is important to find a doula that meets your needs and desires. Doulas from various backgrounds and trainings may have different skills and communication styles. It is beneficial to find the best match for your personality, beliefs, and types of care.

- Ask your medical team for referrals to doulas with whom they have trust and familiarity.
- Many doulas have websites that can be found via an internet search.
    - It is important to assess the level of training and experience that a doula has, before entering into an agreement.
- Doula directories are available at:
    - National End of Life Doula Alliance https://nedalliance.org/directories/find-a-doula/
    - International End of Life Doula Association https://inelda.org/find-a-doula/

Suggested Reading List for books on Palliative and End of Life Care

1. **Last Acts of Kindness: Lessons for the Living from the Bedside of the Dying**, by Judith Redwing Keyssar RN, Createspace 2010.
2. **A Beginner's Guide to the End: How to Live Life to the Full and Die a Good Death** ;BJ Miller, MD and Shoshana Berger; 2019, Simon and Shuster
3. **Life After the Diagnosis**; Steven Pantilat, MD, 2017, Da Capo Press
4. **Dying Well**, by Ira Byock, MD, Riverhead Trade, 1998
5. **The Four Things that Matter Most (2004) and The Best Care Possible** (2012) by Ira Byock
6. **The Wild Edge of Sorrow; Rituals of Renewal and the Sacred Work of Grief;** Francis Weller; 2015,Random House
7. **Elderhood: Redefining Aging, Transforming Medicine, Reimagining Life;** Louise Aronson, MD; 2019; Bloomsbury Pub
8. **Extreme Measures**, Jessica Zitter, MD, 2017, Avery Press
9. **Being with Dying: Cultivating Compassion and Fearlessness in the Presence of Death**; Joan Halifax, 2009;
10. **The Four-fold Way: Walking the Paths of the Warrior, Teacher, Healer and Visionary,** by Angeles Arrien, HarperOne 1993
11. **When Breath Becomes Air**, Paul Kalanithi, MD; 2016, Random House
12. **Being Mortal**, by Atul Gawande, Henry Holt and Company, 2014.
13. **The Grace in Dying**, by Kathleen Dowling Singh, HarperOne, 1998.
14. **Who Dies**, by Stephen Levine, Anchor Books, 1982.
15. **A Year to Live: How to Live This Year as If It Were Your Last**, Three Rivers Press, 1998 (any of Stephen Levine's books)
16. **The Way of Council** by Jack Zimmerman and Virginia Coyle, Bramble Books, 1996.
17. **Mortally Wounded**, by Michael Kearney, MD, Scribner, 1996.
18. **Rituals of Healing, Using Imagery for Health and Wellness,** by Jeanne Achterberg, Barbara Dossey, Leslie Kolkmeier, Bantam New Age Books, 1994.
19. **How We Die, Reflections on Life's Final Chapter**, by Sherwin B. Nuland, MD, Alfred A. Knopf, 1994.
20. **Caring for the Dying,** The Doula Approach to a Meaningful Death, Henry Fersko-Weiss, Conari Press, 2019
21. **Tuesdays with Morri**e, by Mitch Albom, Doubleday, 1997.
22. **Kitchen Table Wisdom and My Grandfather's Blessings**, by Rachel Naomi Remen, MD; Riverhead Books, 1997/2000.
23. **The Tibetan Book of Living and Dying**, by Sogyal Rinpoche; Harper, 1993.
24. **The Dying Time; Practical Wisdom for the Dying and Their Caregivers,** by Joan Furman and David McNabb, Bell Tower, 1997
25. **The Good Death**, by Marilyn Webb, Bantam, 1997.
26. **Caring for Your Dead**, by Lisa Carlson, Upper Access, 1998.
27. **How Then, Shall We Live?: Four Simple Questions that Reveal the Beauty and Meaning of Our Lives**, by Wayne Mueller, Bantam, 1997.
28. **Start Where You Are: A Guide to Compassionate Living and When Things Fall Apart**, by Pema Chodron, Shambhala, 2004/2001
29. **Hope for the Best, Plan for the Rest,** by Dr. Sammy Winemaker and Dr. Hsien Seo, Page Two, 2023

RESOURCES AND WEBSITES

UCSF MERI Center Advance Care Planning Resource Page
Website: https://meri.ucsf.edu/advance-care-planning

Prepare for Your Care
Advance directive forms
Website: https://prepareforyourcare.org/

Advanced Directive for Dementia
Website: https://dementia-directive.org/

Advance Directive for Voluntary Stopping of Eating and Drinking
Website:
https://www.washingtonlawhelp.org/en/VSED

Coalition for Compassionate Care of California
Phone: 916-552-7678
Website: https://coalitionccc.org/

California Department of Aging
Assistance for seniors and functionally impaired adults locate legal services in their community.
Phone: 800-510-2020
Website: https://aging.ca.gov/

California Medical Association
CMA's Advance Health Care Directive Kit in English or Spanish can be ordered for a fee.
Phone: 415-541-0900
Website: www.cmanet.org

CaringInfo
Information about digital and video advance directives
Website:
https://www.caringinfo.org/planning/advance-directives/digital-video-advance-directives/

Academy of Aid-in-Dying Medicine
Website: https://www.aadm.org/

Compassion & Choices
Information about End-of-Life Options
Phone: 800-247-7421
Website:
https://compassionandchoices.org/

End of Life Choices California
Information and support to navigate legal EOL options and bereavement support after Medical Aid in Dying
Phone: 760-636-8009
Website: info@endoflifechoicesca.org

ALS Association
Website: https://www.als.org/

Alzheimer's Association
Northern California & Nevada
Phone: 408.372.9900
Website: https://www.alz.org/

American Cancer Society
Phone: 415-394-7100
Website: www.cancer.org

American Heart Association
San Francisco Division
Phone: 415-433-2273
Website: www.americanheart.org

Donate Life California
Organ donation registry information
Website: https://donatelifecalifornia.org/

Go Wish Cards
To Purchase decks:
https://codaalliance.org/go-wish/
To play online:
https://codaalliance.org/go-wish-game/

End of Life Doulas and Caregiver Resources

Bay Area End of Life Doula Alliance
Website: https://www.endoflifedoulaalliance.com/

End of Life Journeys
Website: www.endoflifejourneys.com

National End of Life Doula Alliance
Website: https://nedalliance.org/directories/find-a-doula/

International End of Life Doula Association
Website: https://inelda.org/find-a-doula/

Family Caregiver Alliance
Phone: 415-434-3388
Toll-free: 800-445-8106
Website: www.caregiver.org
E-mail: info@caregiver.org

Body Donation Resources

University of California, San Francisco Willed Body Program
Phone: 415-476-1981
Fax: 415-502-1460
Website: https://meded.ucsf.edu/willed-body-program

Loma Linda University Bodies for Science Program
Phone: 909-558-4301
Website: https://medicine.llu.edu/research/department-pathology-and-human-anatomy/division-anatomy/bodies-science-willed-body-program

UCLA Donated Body Program David Geffen School of Medicine
Phone: 310-794-0372
Fax: 310-794-0334
Website: https://www.uclahealth.org/programs/donatedbody

UC Davis, Body Donation Program
Phone: 916-734-9560
Fax: 916-734-9563
Website: https://health.ucdavis.edu/bodydonation/

UC San Diego Body Donation Program
Phone: 858-534-4536
Website: http://bodydonation.ucsd.edu

UC Irvine Willed Body Program
Phone: 949-824-6061
Website: https://medschool.uci.edu/community/willed-body-program

Los Angeles College of Chiropractic Medicine
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USC Anatomical Gift Program
Phone: 323-442-1229
Fax: 323-442-3145
Website: https://agp.usc.edu/

Stanford University School of Medicine
Phone: 650-723-2404
Website: http://med.stanford.edu/anatomy/donate/

Western University of Health Sciences College of Osteopathic Medicine of the Pacific
Body Donation Program
Phone: 909-469-5431
Website: https://www.westernu.edu/osteopathic/body-donation-program/

Go Wish Cards

Go Wish gives you an easy, even entertaining way to talk about what is most important to you. The cards help you find words to talk about what is important if you were to be living a life that may be shortened by serious illness. Playing the game with your relatives or best friends can help you learn how you can best comfort your loved ones when they need you most. Go Wish can be played by one, two or more people.

Each deck has 36 cards. Thirty-five of the cards describe things that people often say are important when they are very sick or dying. The cards describe how people want to be treated, who they want near them, and what matters to them. One card is a "wild card." You can use this card to stand for something you want that isn't on any of the other cards.

Ways to Play:

Go Wish Solitare

This is a good way to figure out what is important to you and why.

1. Read through all 36 cards. Sort them into three piles:

- Very important to me
- Somewhat important to me
- Not important to me

NOTE: Putting a card in the "Not important to me" pile does not necessarily mean that you don't care about what is written on the card. It could simply mean that this is something that you have already taken care of. For example, if all of your financial affairs are competely in order, taking care of your financial affairs is no longer one of your top ten concerns.

2. You can use the wild card to stand for something you want that is not on any of the other cards. For example: "To live in my own home." or "To be able to recognize my family and friends." That card can go into any of the three piles.

3. When you have three piles, sort through your "very important" pile. Choose the 10 wishes that mean the most to you. If you don't have 10 cards in your "very important" pile, choose some from your "somewhat important" pile. If you have more than 10 in your "very important" pile, sort through them and put some of the cards into the "somewhat important" or "not important" piles until you only have 10 cards in your "very important" pile.

4. Rank your 10 "very important" cards, putting the most important ones at the top of the pile. This is your Top 10.

5. Think about how you would explain to your family or friends why those things are your Top 10 wishes. Think about your "not important" pile and how you would explain to your family or friends why those things are not important to you. Then make time to talk to them about your choices.

Make time to talk to your loved ones about your choices.

Playing Solitaire On-Line

Playing the solitaire version on-line is exactly like playing with the actual cards. We've added sound so that you can hear the contents of each card. By default the sound is turned on. If you'd like to turn the sound off, mute (turn off) your speakers.

As you view (and hear) each card from the main pile, you can click to put each card in the "Very Important," "Somewhat Important," or "Not Important" stacks below. Move your mouse over any card in any stack and you can view it again and move it to another stack or back to the main pile.

When you have completed your sorting, you can save your stacks by clicking "save." You'll be asked to pick a file name for your stack (no spaces allowed). Pick something you'll remember! Plus, you'll be able to email the name of your sorted stacks to yourself or others.

Think about how you would explain to your family or friends why those things are your Top 10 wishes. Think about your "not important" pile and how you would explain to your family or friends why those things are not important to you. Then make time to talk to them about your choices.

Your stacks will remain here at Go Wish for years to come so that you can revisit them to remind yourself of your saved wishes. Plus, you can resort them and save them as a different name as time moves on and your desires change. There is NO personal information stored with these stacks so your privacy remains intact! Share your file name only with those you wish to know about your wishes.

Go Wish Pairs

This can be a good game to play with someone who might become your health care agent. It is especially important for that person to understand your wishes. It is best to play with two decks of cards.

If you are playing with the actual printed cards, you will need two decks. If you are playing on-line, each of you should play on your own computer connected to the Internet. You don't have to be in the same room or even the same time-zone to play on-line!

Each play reads through all 36 cards. Each play divides them into three piles.

Player A sorts the cards into three piles:

- Very important to me
- Somewhat important to me
- Not important to me

Player B sorts the cards into three piles:

- Very important to Player A
- Somewhat important to Player A
- Not important to Player A

Go Wish was developed by **Coda Alliance**, made possible in part by a grant from the **Archstone Foundation**. For more information about Coda Alliance, a community-based, not-for-profit organization helping individuals and their families plan and prepare for end-of-life issues, go to http://www.codaalliance.org

To be free from pain

To be free from anxiety

Not being short of breath

To be kept clean

To have human touch

To have my financial affairs in order

To have my family prepared for my death

To die at home

To know how my body will change

To feel that my life is complete

To say goodbye to important people in my life

To remember personal accomplishments

To take care of unfinished business with family and friends

To prevent arguments by making sure my family knows what I want

To have an advocate who knows my values and priorities

To be treated the way I want

To maintain my dignity

To keep my sense of humor

To have
a doctor
who knows
me as a
whole person

To have
close friends
near

Not
dying
alone

To have
someone
who will
listen to me

To trust
my doctor

To have
a nurse
I feel
comfortable
with

To be
mentally
aware

To have
my funeral
arrangements
made

Not being
a burden to
my family

To be
able to help
others

To be
at peace
with God

To pray

To be
able to talk
about what
scares me

Not being
connected
to machines

To meet
with clergy
or a chaplain

To be
able to talk
about what
death means

To have
my family
with me

WILD
CARD

I Will Not Die an Unlived Life

By Dawna Markova

I will not die an unlived life
I will not live in fear
of falling or catching fire.
I choose to inhabit my days,
to allow my living to open me,
to make me less afraid,
more accessible,
to loosen my heart
until it becomes a wing,
a torch, a promise.
I choose to risk my significance;
to live so that which came to me as seed
goes to the next as blossom
and that which came to me as blossom,
goes on as fruit.