


End of Life Decisions Guide and Toolkit – Advance Health Care Planning
David R. Grube MD
National Medical Director
Compassion and Choices
 National Healthcare Decisions Day 2020



(take a moment ...)

Why ACP is more important than ever!

News > Health

The COVID-19 talk families need to have now


Health care experts say all adults should think about their end-of-life wishes to make things easier on themselves, their families and doctors and nurses who might see them in the E.R.



#AloneTogether

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“Life is meaningful because it is a story ...



... and in stories, endings matter.”

–Atul Gawande, *Being Mortal*


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As I see it

Make choices about health care now

By David R. Grube

Nearly 50 percent of deaths in the United States occur in hospitals, nursing homes and other health care facilities. About 70 to 80 percent of those deaths are preventable. This is a tragedy. It is a tragedy because, as a society, we have the ability to prevent these deaths. We can do this by making choices about our health care now.



David R. Grube is a family physician in PSID and chairman of Good Samaritan Hospital's Ethics Committee.

Corvallis Gazette-Times, October 1990
 Patient Self-Determination Act (PSDA)

“A friend of mine has a T-shirt which reads, “DENIAL IS NOT A RIVER IN EGYPT!”


Please decide what medical treatment possibilities you want for yourself and complete an Advance Directive. Then, hope that the forms will never be necessary.”

Before the 20th C. ...



health care was palliative care

In the 20th C.



health care became what we know as 'modern medicine'

It has become complicated to die...

"MODERN SCIENTIFIC CAPABILITY has profoundly altered the course of human life. People live longer and better than at any other time in history. But scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals. And we in the medical world have proved alarmingly unprepared for it."

Being Mortal: ATUL GAWANDE MD

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In 2020, end of life care (and palliative care) can resemble this...

The Default in US medicine:

- 1) Do everything,
- 2) For everybody,
- 3) Every time

Treatment Options:

- Pursuing Treatment
- Refusing Treatment
- Discontinuing Treatment
- Hospice
- Voluntarily Stopping Eating and Drinking (VSED)
- Continuous Deep Sedation
- Medical Aid in Dying*

(* 9 States and DC)

Advance Health Care Planning — where to begin?

Your personal beliefs and values: *What kinds of things are most important to you? What makes you happy?*

Quality of life concerns: *What basic abilities are important to you in order to feel you would want to continue living?*

Types of life sustaining treatments: *Are there specific procedures or treatments you would want or definitely not want if you were diagnosed with a terminal condition?*

Your support network: *Connect with your health care team! Is there anyone you do not want involved in your health care decisions?*

Advance Health Care Planning

Institute of Medicine *Dying in America* Study, 2014




Effective Approaches:

- Acknowledge and address barriers to engaging in advance planning process
 - “Not important” / “too many other things to worry about right now”
 - “Don’t want to think about death”
 - “Loved ones don’t want to discuss it”

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Advance HC Planning

Institute of Medicine *Dying in America* Study, 2014



Effective Approaches:

- Shift the focus of end-of-life decision making away from document completion and toward **facilitating conversations and discussions of values and preferences**
 - Do not stress importance of making choices about every possible intervention
 - Provide guidelines for how to make decisions
 - (Especially important in COVID-19 pandemic)

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Advance Health Care Planning

Institute of Medicine *Dying in America* Study, 2014

Effective Approaches:

- Treat advance care planning as an **ongoing process**, not as a one time event designed to produce a product.
 - Revisit plans, upon change of health conditions, upon change of social situations
 - Make choices based on current health conditions
 - Promote ongoing conversations with loved ones and healthcare providers

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Advance Health Care Planning



Benefits of ongoing advance healthcare planning conversations:

- A better chance that your loved ones and health care providers will honor your health care wishes
- Less confusion and family conflict
- A ‘gift of love’ for those who will need to make decisions
- Modeling for children and parents and friends

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Advance HC Planning Documents

- **Living Will**
- **Healthcare Proxy**
- **Addenda**

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Advance HC Planning Documents

- Advance directives combine both pieces, the what and the who
- Documents and regulations change from state to state
 - Some states have multiple documents, others just have one
 - Compassion & Choices End of Life Information Center links to the state pages for the state approved forms
 - People can use forms other than the state forms, but the state forms will include instructions about state specific regulations so they are recommended

C&C End of Life Decisions Guide and Dementia Values & Priorities Tool documents can be used as addenda to the health care proxy, living will or advance directive to further specify wishes

Advance HC Planning Documents – Living Will

- What medical care you would want if you had a sudden, unexpected event in which you did not know yourself or others, and were unlikely to recover? What are your healthcare wishes? (different names in different states):
 - Living will
 - Declaration of wishes
- Would you want life prolonging treatment to continue?
- Would you want life prolonging treatment to stop?
- How could you help your loved ones make this decision?

Advance HC Planning Documents - Health Care Proxy

- Who would make medical decisions for you?
- Person(s) appointed to make health care decisions for you if you can no longer make decisions for yourself (different names in different states):
 - Healthcare Proxy
 - Durable Power of Attorney for Healthcare Decisions
 - Surrogate
- Someone you trust to speak on your behalf and who knows your wishes
- Primary and alternates (not a group of people)
- Does not have to be family member or someone nearby, just someone available if needed
- Cannot be healthcare provider or anyone under 18
- You can specify who you "DO NOT" want to make decisions as well

Your Health Care Representative

Will this person:

- Speak for you in case you cannot?
- Act on your wishes and separate their own feelings from yours?
- Live close by or could easily travel to be with you?
- Know you well and understand what you want?
- Be someone you trust with your life and, more importantly, with your death?
- Talk with you about sensitive issues?
- Be available long-term?
- Be able to handle conflicting opinions between family, friends and medical team?
- Be a strong advocate in the face of an unresponsive doctor or institution?

The Decisions a Health Care Proxy will make on your behalf

- Choices about medical tests, medicine, or surgery
- The right to request or decline life-support treatments such as medical devices to aid breathing, medical devices to provide food and water, CPR, blood transfusions, dialysis, and antibiotics
- Choices about pain management, including authorization or refusal of medication or procedures
- Admission to an assisted living facility, hospital, hospice, or nursing home
- Choices about where to seek medical treatment, including the right to move you to another facility, hospital, or state
- The right to see and approve release of your medical records
- The option to take legal action on your behalf in order to advocate for your health care rights and wishes
- The right to apply for Medicare, Medicaid, or other programs

Advance HC Planning Documents

- Documents must be signed to be authorized per state regulation:
 - Two witnesses – witnesses cannot be the primary or surrogate decision maker
 - Notary public
- Documents must be signed in front of witnesses / notary
- An attorney is not needed to complete advance healthcare planning documents (but is needed for POA for finances and final wills).

Advance HC Planning Documents

- Keep the original and any working papers in your place of residence in a location that can easily be found, and that your family know about
 - POLST on refrigerator door
- Give a copy and any working notes to your proxy
- Give your health care provider a copy
- Have an ACP wallet card
- Keep a copy in the glove box of your car?
- Have a copy entered in to your hospital medical record
- Church/Synagogue/e-Registry

Advance HC Planning Documents - Language

- General language is not recommended:
 - “No heroic measures”
 - “No extraordinary treatments”
 - “Don’t want to be a vegetable”
 (*These statements are not specific and open to interpretation*)
- Discuss what “living well” means to you (talk with family, eat foods, etc.)
- Use C&C addenda documents to make your wishes clear and specific

Not a option...



ACP Documents should be reviewed whenever one of the 5 “D’s” occur:

- Decade** - when you start each decade of your life
- Death** - whenever you experience the death of a loved one (including proxy)
- Divorce** - when you experience a divorce or other major family change
- Diagnosis** - when you are newly diagnosed with a serious health condition
- Decline** - when you experience a significant deterioration of an existing health condition, especially when it diminishes your ability to live independently

ABA

Advance HC Planning Documents - Limitations

- Advance directives go into effect when a person loses decisional capacity for any reason
 - If they regain capacity, they can make their own decisions
- Advance directives and living wills DO NOT go into effect in emergency situations. (If someone indicates they do not want CPR in the living will only, they WILL receive CPR if found unresponsive by EMS)
- Decisions by healthcare agents are often honored even if they disagree with instructions in living will
 - Need to choose agents carefully
- Healthcare instructions may not be honored if there is family conflict, threats of lawsuits, in some religiously affiliated facilities, etc.

Advance HC Planning Documents

**ADVANCE HEALTH CARE DIRECTIVES
DO NOT APPLY IN AN EMERGENCY**

What does apply? (state specific)

Who will decide?

- **The Pre-Hospital Do Not Resuscitate form**
- **Portable Orders for Life Sustaining Treatment (POLST)**
- **Medic-Alert bracelet or medallion**

Cardiopulmonary Resuscitation CPR

Cardiopulmonary resuscitation is an emergency procedure that combines chest compressions often with artificial ventilation in an effort to manually preserve intact brain function until further measures are taken to restore spontaneous blood circulation and breathing in a person who is in cardiac arrest.

CPR (cardiopulmonary resuscitation) DNR (do not resuscitate)

CPR in emergency automatically performed:

- unless DNR form or POLST completed & evidenced
- unless DNR ordered in hospital
- unless not indicated, not intended in an inevitable arrest at end-of-life
- During surgery and hospital procedures

Hospital: It is important to recognize the low rate of success of CPR resulting in discharge of patients, especially those who are elderly or who have end-stage cancer, renal failure, sepsis, multi-organ failure, etc.

CPR / DNR

Out-of-hospital CPR Success: what does success mean?

- Public perception 45-85% success for CPR
 - > 90% on TV dramas
- In general population, 2-17% survival from CPR to discharge from hospital
 - **Of these, very few with neurologic function intact**
- In long term care, 3% survival to discharge from hospital
- Of those surviving to discharge, long-term survival 5-10%

CPR / DNR

If someone has a DNR, paramedics WILL NOT:

- Initiate CPR or continue if already started
- Administer chest compressions
- Intubate
- Initiate cardiac monitoring
- Administer cardiac resuscitation drugs
- Defibrillate
- Provide ventilator assistance

CPR / DNR

DNR does not mean forgoing all treatment.

If someone has a DNR, paramedics will:

- Suction the airway
- Administer oxygen
- Position for comfort
- Splint
- Control bleeding
- Provide pain medication (Advanced Life Support only)
- Provide emotional support
- Contact hospice, home health agency, attending physician or hospital as appropriate

CPR / DNR

Pre-Hospital or Non-Hospital DNR Order

- Different names in different states (Comfort One, etc.)
- "Request to forgo resuscitative measures"
- Written document, signed by
 - a) person or healthcare agent
 - b) a physician
- Designed to spare people the trauma of a CPR attempt if that attempt is not medically appropriate
- Can be evidenced by Medic-Alert bracelet or medallion engraved "do not resuscitate" or "DNR" ("DNAR") (states have different rules and protocols for obtaining bracelets, **getting a DNR bracelet without the DNR order MAY NOT WORK!**)
- Info about DNR forms by state and bracelets: <http://www.americanmedical-id.com/extras/dnr.php>

POLST

PORTALBLE Orders for Life Sustaining Treatment (POLST)
(Physician Orders for Life Sustaining Treatment)

- Program in different stages of development in different states
 - <http://www.polst.org/>
- Not readily available in all states
- Different names used (POLST, MOLST, MOST, POST, COLST)
- Standardized form in bright pink/yellow/green
- Physician's orders, guides treatment immediately (not an advance directive)
- Can be completed by the person or their healthcare agent with the physician
- Addresses multiple options including goals of care, resuscitation, intubation, artificial nutrition / hydration, antibiotics, hospitalization, etc.

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POLST

Particularly useful for:

- Frail elderly, especially those in any facility
- Anyone with one or more chronic, progressive diseases
- Anyone with a terminal illness (hospice patients)
- Anyone whose "death within the next 12 months would not be a surprise"
- Others interested in defining their end-of-life care

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POLST

- A). Cardiopulmonary Resuscitation Orders (Yes / No)
- B). Initial Treatment Orders
Full / Selective / Comfort Focused
- C). Additional Orders or Instructions
- D). Medically Assisted Nutrition

Signature of Patient (or HC Proxy)
Signature of Clinician (State Dependent)

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<https://compassionandchoices.org/end-of-life-planning/>

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Plan Your Care Resource Center

Compassion & Choices is committed to empowering people to get the care they want during a serious illness or at the end of life. One way we do that is by helping people plan well and become good advocates for themselves and their loved ones.

- End-of-Life Decisions Guide & Toolkit**
Download our thorough end-of-life planning guide and toolkit to help you navigate your end-of-life choices.
- Take Control of Your Care with Tools to Finish Strong**
Explore our Tools to Finish Strong, including the new Dementia Values & Priorities Tool and Dementia Decoder.
- Doc2Doc Consultation Program**
Doc2Doc offers practicing physicians free, confidential telephone consultation with one of our seasoned medical directors.

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About Us Plan Your Care Take Action Resources Q Donate

My End-of-Life Decisions: An Advance Planning Guide and Toolkit

Death finds us all eventually. We can't prevent that. But we can direct how we'd like our final days to unfold. Advance planning is key — making thoughtful choices now, putting them into a written advance directive and discussing those choices with others. Advance planning helps ensure that we get the care we want and avoid what we don't want, even if we're unable to speak for ourselves.

About the Advance Planning Guide
Like many people, you may have put off making decisions about your end-of-life care. [Download and explore](#) our end-of-life care...

Download This Resource

Donate to Compassion & Choices

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Advance Planning Guide

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- [What I Want: Other Documents That Spell Out Your Choices](#)
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C&C Dementia Values and Priorities Tool

compassion & choices | Dementia Values and Priorities Tool | My Account

Stay in Control of Your Life and Care During a Dementia Diagnosis

Identify your personal values and provide clear care instructions to your loved ones as you deal with a dementia diagnosis.

START

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COVID - 19

Original Investigation ONLINE FIRST FREE

April 6, 2020

Baseline Characteristics and Outcomes of 1591 Patients Infected With SARS-CoV-2 Admitted to ICUs of the Lombardy Region, Italy

Giacomo Grasselli, MD^{1,2}; Alberto Zangrillo, MD^{3,4}; Alberto Zanella, MD^{1,2}; et al

> [Author Affiliations](#) | [Article Information](#)

JAMA. Published online April 6, 2020. doi:10.1001/jama.2020.5394

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JAMA, Graselli et. al.

- ~ 1,600 patients (Feb 20 – March 18) in ICU's
- 83% male; med. Age 63 yo;
- 70% with at least one co-morbid condition

88% need intubation / ventilation

At 5 weeks 58% still in ICU

26% had died, 16% discharged

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COVID-19: Advance Care Planning

The COVID-19 (coronavirus) pandemic has brought a keen awareness of our own mortality into clear focus. Regardless of your age or health status, now is the time to make sure you have clearly outlined your preferences for end-of-life care.

Compassion & Choices offers a comprehensive bilingual end-of-life planning guide, End of Life Decision Guide Toolkit in English and Spanish. These guides help you think through your values and priorities, choose a health care proxy and document your care preferences for life's end.

However, a traditional advanced directive does not go into the level of specificity necessary to address the possible progression of the coronavirus. Therefore, in addition to filling out an advance directive and identifying your healthcare proxy, we encourage you to create a COVID-19-specific addendum to your advanced directive using the attached form.

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Compassion and Choices Fact Sheets COVID-19

- <https://compassionandchoices.org/resource/covid-19-advance-care-planning/>
- <https://compassionandchoices.org/resource/covid-19-dying-in-the-age-of-the-pandemic/>
- <https://compassionandchoices.org/resource/covid-19-understanding-your-options/>
- <https://compassionandchoices.org/resource/covid-19-using-telehealth-to-reduce-your-risk/>

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C&C - COVID ACP Addendum

If your oxygen levels are dropping, do you want to go to the hospital or would you prefer to try to get non-invasive respiratory care at home?

If you are not able to receive non-invasive respiratory care at home, do you want to go to the hospital?

If the care that is available to you at home can keep you comfortable, but cannot save your life, is your preference to stay at home? Or do you want to go to the hospital?

When you get to the hospital, do you want healthcare providers to only treat you with noninvasive options that could still save your life (such as oxygen through a face mask or nasal mask) and anything necessary to keep you comfortable and control your symptoms? Or do you want to be put on a ventilator if that becomes necessary to safe your life?

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COVID ACP Addendum (cont'd)

When you get to the hospital, do you want healthcare providers to only treat you with noninvasive options that could still save your life (such as oxygen through a face mask or nasal mask) and anything necessary to keep you comfortable and control your symptoms? Or do you want to be put on a ventilator if that becomes necessary to safe your life?

If you would like to be ventilated, are there any guidelines around how long you want to stay on the ventilator?

Do you want to stay on the ventilator if your kidneys also shut down and you need dialysis?

Do you want to stay on the ventilator if you are also going to need tubes to feed you to keep you alive?

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COVID ACP Addendum (cont'd)

Is there a length of time that you want to stay on the ventilator? Days? Weeks? Months?

If your heart stops, do you want to be resuscitated via CPR?

Do you want your healthcare proxy to have the ability to override any of these orders if he or she believes you have a reasonable chance of living a life consistent with your values and priorities based on the information provided by the doctor? Or, do you want these orders followed no matter what?

Attach this form to your advance directive. Sign and date it. Then have it signed by witnesses in accordance with witness signature requirements for your state's Advanced Directives.

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POLST and COVID-19

National POLST Resources

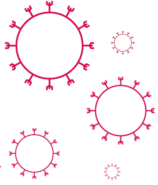
Basics about POLST:

- Intended Population & Guidance for Health Care Professionals
- Appropriate POLST Form Use Policy

For Health Care Professionals and Facilities:

- Completing POLST Forms in Crisis Standards of Care
- COVID-19 & POLST Statement
- Long Term Care Facility Guidance
- Advance Care Planning: Reimbursable under Medicare (Coalition for Compassionate Care of California)
 - Summary of CMS Interim Final Rule provisions (Healthspieren)

For Patients:



Frequently Asked Questions

How can I ensure my healthcare wishes will be followed?

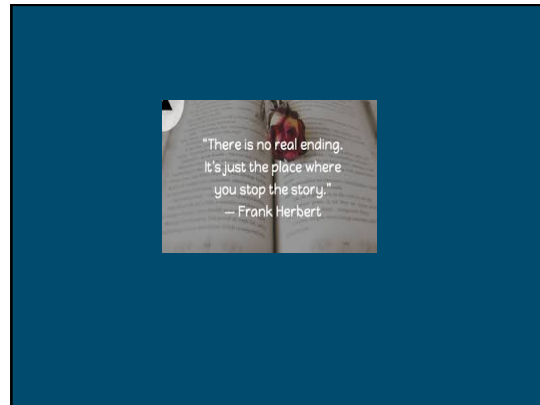
- Recognize advance planning as an ongoing, dynamic process
- Identify someone you trust as a healthcare agent to follow your wishes
- Use C&C values worksheets (located in the End of Life Decisions Guide) to clarify your wishes and what living well means to you
- Have ongoing conversations with your doctors, healthcare agents and other healthcare providers about your wishes.
- Use the addenda documents to specify your wishes

- VIDEO ON A DEVICE (iPhone, iPad, Laptop)

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Advance Directives and POLST



www.compassionandchoices.org/end-of-life/planning

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- End-of-Life Decisions Guide & Toolkit**
 - Download our thorough and easy-to-use planning guide and toolkit to help you prepare your end-of-life choices.
- Take Control of Your Care with Tools to Finish Strong**
 - Empower your family with strong end-of-life care. Use our Video, Checklist, and Planning Worksheet.
- Doc2Doc Consultation Program**
 - Doc2Doc offers practical guidance from our end-of-life care specialists. Consultation with one of our team's end-of-life doctors.

COVID-19 Toolkit

COVID-19 Toolkit	COVID-19: How to Stay Safe	COVID-19: How to Stay Safe
Learn	COVID-19: How to Stay Safe	COVID-19: How to Stay Safe

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Upcoming Webinars

Diane Rehm on Charting Your Personal Journey From Life to Death
(Hosted by the Raben Group)
Monday, April 20 at 3 p.m. ET

Living and Dying With Dementia: Taking Charge of Your Personal Values
(Hosted by the American Society on Aging)
Tuesday, April 21 at 2 p.m. ET

Learn More and Register at:
www.CompassionAndChoices.org/take-action/staying-stronger-together/

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Compassionandchoices.org/give-now

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