



## My Plan to Decide, Document, and Communicate My Own End Of Life Terms

Congratulations on your foresight and for your consideration to your Proxy and your loved ones! A solid plan will help you maximize your chances of having your specific desires respected, and will minimize the emotional burden on your loved ones.

Go to <http://chooselivewell.com/preparing/> for active links to the resources within this checklist, including links to state specific forms to document your Advance Directive.

Let's break our preparation down into some simple steps – below you will find both a short 'Overview' and as well as a 'Detailed' Form.

### Overview Form:

*Step 1: Understand what goes on near typical end of life situations, and what treatment decisions might be likely.*

*Step 2: Explore your own feelings and thoughts in advance regarding various treatment options, and consciously apply your own values and beliefs to define your desires.*

*Step 3: Draft your definition of your specific desires.*

*Step 4: Discuss your desires with your selected Proxy and your Primary Care Physician, and finalize your desires.*

*Step 5: Finalize and document your desires in valid [state specific forms](#) .*

*Step 6: Distribute copies of your documents.*

*Step 7: Consider sharing your planning and/or your specific desires with a broader circle of loved ones, so that if a decision falls on your Proxy, they will have broad support.*

*Later - Repeat this cycle and update or reaffirm your desires.*



*Be sure you understand our Disclaimer –*

We coach, support, educate, and empower. We illuminate options you may not have known you had. But we don't decide what's right for you in your unique circumstances; only you can do that. And we don't provide medical, financial, or legal advice; nor do we replace the valuable counsel of those who do.

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Detailed Form:

*Step 1: Understand what goes on near typical end of life situations, and what treatment decisions might be likely.*

Talk to your friends and family. Ask them what their experiences have been with other friends and loved ones who have gone through the final stages of their lives. What have they learned? How do they want their own future treatment to be shaped by those experiences? Spend a few moments checking out other's experiences at social media sites, such as The Conversation Project's [Your Stories](#), the comments (>700) after the article [How Doctors Die](#), or [POLST Stories](#). Seek to understand the realities of the potential benefits and adverse effects on quality and length of life for the likely end of life procedures.

People I want to make a point to talk to:

_____	_____
(person)	(date discussed)
_____	_____
(person)	(date discussed)
_____	_____
(person)	(date discussed)
_____	_____
(person)	(date discussed)

*Step 2: Explore your own feelings and thoughts in advance regarding various treatment options, and consciously apply your own values and beliefs to define your desires.*

Talk to your religious mentors, if appropriate. Are there other beliefs or values based on your nationality or upbringing? Is there general guidance I want to provide to describe my own definition of the point at which natural life has ended? Are there specific treatments that I wish to rule out (for example, narcotic pain medications)?

After thinking about it, I've decided that there are some things that are important to me:

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I've decided that there are some things that I would like to see done to and for me:

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I've also decided that there are some things that I am afraid of, or that I do not want done to or for me:

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*Step 3: Draft your definition of your specific desires.*

This includes guidance as it pertains to various quality of life thresholds, such as:

If I have no pulse and am not breathing, my desire is;



- \_\_\_\_\_ Use all available means to resuscitate me.
- \_\_\_\_\_ Do Not attempt Resuscitation (DNR/no CPR). Allow Natural Death.

If I am permanently unconscious (am unaware of the people and surroundings around me and have little chance of recovering consciousness), my desire is;

- \_\_\_\_\_ Withhold medical care and allow me to die a natural death.
- \_\_\_\_\_ Only provide me with comfort measures. This generally means to relieve pain and suffering through the use of medication by any route (oral, IV, etc), positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. DO NOT (or DO) transfer me to a hospital or higher acuity setting for life-sustaining treatment. OR Transfer me to a hospital only if comfort needs cannot be met in my current location. Treatment Plan = maximize comfort through symptom management.
- \_\_\_\_\_ Provide me with Limited Additional Interventions. In addition to providing me with comfort measures, use medical treatment such as antibiotics, IV fluids and cardiac monitoring as indicated. No intubation, advanced airway interventions, or medical ventilation. May consider less invasive airway support (such as CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the ICU. Treatment Plan = basic medical treatment.
- \_\_\_\_\_ Provide me with Full Treatment. In addition to comfort measures and limited additional interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and/or ICU if indicated. Treatment Plan: Full available treatment.

If I develop new conditions while permanently unconscious (such as a heart attack or stroke);

- \_\_\_\_\_ Treat the new conditions consistent with my choice of comfort care, limited additional interventions, or full treatment above.
- \_\_\_\_\_ Do not treat the new conditions.

Specifics: \_\_\_\_\_

If I am suffering from permanent confusion and am unable to remember, understand, make decisions, recognize loved ones or have a clear conversation with them (this includes diagnosis of Alzheimer's and dementia), my desire is;



- ☐ Withhold medical care and allow me to die a natural death.
- ☐ Only provide me with comfort measures.
- ☐ Provide me with Limited Additional Interventions.
- ☐ Provide me with Full Treatment.

If I develop new conditions while suffering from permanent confusion (such as a heart attack or stroke);

- ☐ Treat the new conditions consistent with my choice of comfort care, limited additional interventions, or full treatment above.
- ☐ Do not treat the new conditions.

Specifics: \_\_\_\_\_

If I am dependent on others in all activities of daily living (ADL's) and am no longer able to talk or communicate clearly or move by myself; and I depend on others for feeding, bathing, dressing and walking; and rehabilitation or other treatment will not help, my desire is;

- ☐ Withhold medical care and allow me to die a natural death.
- ☐ Only provide me with comfort measures.
- ☐ Provide me with Limited Additional Interventions.
- ☐ Provide me with Full Treatment.

If I develop new conditions while dependent in all ADL's (such as a heart attack or stroke);

- ☐ Treat the new conditions consistent with my choice of comfort care, limited additional interventions, or full treatment above.
- ☐ Do not treat the new conditions.

Specifics: \_\_\_\_\_

If I have an End State Illness that has reached it's final stages and no longer responds to treatment, my desire is;

- ☐ Withhold medical care and allow me to die a natural death.
- ☐ Only provide me with comfort measures.



\_\_\_\_\_ Provide me with Limited Additional Interventions.

\_\_\_\_\_ Provide me with Full Treatment.

If I develop new conditions while experiencing an End State Illness (such as a heart attack or stroke);

\_\_\_\_\_ Treat the new conditions consistent with my choice of comfort care, limited additional interventions, or full treatment above.

\_\_\_\_\_ Do not treat the new conditions.

Specifics: \_\_\_\_\_

If I cannot eat or drink naturally, my desire is;

\_\_\_\_\_ No artificial nutrition by IV or other means.

\_\_\_\_\_ Defined trial period of artificial nutrition by IV or other means. If after \_\_\_\_\_ days I have not resumed the ability to eat and drink naturally, then cease artificial nutrition.

\_\_\_\_\_ Long term artificial nutrition by IV or other means. Continue indefinitely. OR If after \_\_\_\_\_ days/weeks/months I have not resumed the ability to eat and drink naturally, then cease artificial nutrition.

If, in accordance with my wishes for comfort measures, limited additional interventions, or full treatment above, my physicians recommend experimental treatment or other treatments or procedures that my insurance (or Medicare) consider excluded benefits, my desire is;

\_\_\_\_\_ No excluded benefits under any circumstances.

\_\_\_\_\_ Apply any treatments that have any chance of restoring me to mental competence.

\_\_\_\_\_ Apply any treatments that my physician can demonstrate have a better than \_\_\_\_\_% chance of restoring me to mental competence, and cost less than \$\_\_\_\_\_ (or any amount).

\_\_\_\_\_ Apply any treatments that have any chance of prolonging my life.

\_\_\_\_\_ Apply any treatments that my physician can demonstrate have a better than \_\_\_\_\_% chance of prolonging my life, and cost less than \$\_\_\_\_\_ (or any amount).



Upon my death;

\_\_\_\_\_ I would like to donate my organs and/or tissue.

\_\_\_\_\_ I do not wish to donate my organs and/or tissue.

Specifics: \_\_\_\_\_

Other things I want my providers and Proxy to understand about me when making decisions on my behalf:

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*Step 4: Discuss your desires with your selected Proxy and your Primary Care Physician, and finalize your desires.*

The reason Step 3 resulted in a draft is that your conversations with your primary care physician and your Proxy may result in clarifying your understanding or modifying how you express your desires. Your goal in discussing with your PCP should be to benefit from their experiences to help you make the most informed decisions possible. But recognize that many doctors may not be ready to have this conversation, and even when ready, [it may be uncomfortable for them as well](#). Specifically ask your PCP to help you understand the realities of the potential benefits and adverse effects on quality and length of life for the likely end of life procedures. As part of your preparation for this conversation, you may benefit from the [‘Talking to your Doctor’](#) (less than 4min) video provided by Advanced Care Planning (ACP). ACP also offers a wide range of resources for physicians to prepare for their side of end of life planning with their patients, including [videos](#) on specific procedures or disease states. These resources require advanced registration on the part of your physician, so you may want to alert your doctor to their availability in advance.





\_\_\_\_\_ If possible, discuss your desires with your PCP and your Proxy together. If that's not possible, the next best option is to discuss with your PCP first since they'll have the most practical experience on which to base their 'what if xxx happens' questions. Recognize that there is no formal way to reimburse your PCP for this council. As of this writing, legislation had been proposed to allow Medicare to reimburse for this time, but that legislation has not yet passed. Reimbursed or not, respect your PCP's time and come prepared with your draft and any specific questions you may have. It's often helpful to ask some open ended questions like the examples below.

Questions for my PCP:

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May I ask if you have an Advance Directive of your own? (if their answer is no, they may not have spent much time thinking about these topics. Give them this planning guide!)

What scenarios have you had experience with that I could benefit from in shaping my Advance Directive?

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What scenarios have you experienced where things went either really well because a good AD was in place; or that went really poorly for the individual or their family because an AD wasn't in place or wasn't specific enough?

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What scenarios have I not thought of that I should consider?

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\_\_\_\_\_ If you have one or more chronic conditions, discuss with your PCP the applicability of a POLST based on [your state's POLST program](#). You're welcome to explore your state's details in advance, but in most states, your PCP will actually have to create the document. Each state that has a program offers a document template via the link above.

\_\_\_\_\_ In your discussion with your Proxy, make sure they really get you. What's important to you. The more detail you discuss the more comfortable they'll be if they're ever called on to make a decision on your behalf about something that's not explicit in your Advance Directive.

*Step 5: Document your desires in valid forms specific to your state.*

Each state has different formatting and content requirements. Try to be as comprehensive as possible in documenting your desires, but if the document template you're working with doesn't allow you to fully express your desires, and you can't add an appendix or some other attachment, then provide the additional guidance to your Proxy so they have a clear understanding. Based on your state, in addition to your own signature your documents may require signatures from witnesses, your PCP, or a notary public.

\_\_\_\_\_ Navigate to Caringinfo for [your state specific forms](#) in pdf format, print, and fill them out. Or go to Appendix X – [Guidance on State Specific Legal Forms](#) for guidance specific to your state, including some state forms that can be filled out on line. You want to come out with some combination of Advance Directive, Living Will, and an assigned Proxy (either from within the Advance Directive or from a separate Durable Healthcare Power of Attorney). If there is content from your draft that you can't seem to get into the form, consider trying to include your finalized detailed desires from Step 3 as an attachment or exhibit. If not, make sure your Proxy has a copy.



*Step 6: Distribute copies of your documents.*

Your originals should remain either in yours or your Proxy's possession, but should be readily available when needed. At a minimum, you, your Proxy, your Primary Care Physician should all have copies, and your PCP should make your copies part of their EHR/EMR. Scan the documents to create electronic copies if desired, and consider storing electronic copies somewhere where you, your Proxy, and selected family members can access them quickly on demand so they can quickly be made available to a hospital or emergency care provider.

Possible storage options include the [US Living Will Registry](#), which offers personal accounts that allow you to upload and store your documents in a secure database that your providers can later access once you've given them permission. Registration includes an annual update reminder to encourage you to keep your documents current, and a wallet card with your registration # for later reference. There is a fee for a 5 year membership, with discounted extensions.

Alternatively, you could consider mainstream cloud-based storage such as iCloud, Box, DropBox, etc. Consider creating a separate account used only for these documents, but recognize that would mean having a unique UserID and password, which must accessible to you and at least your Proxy when needed. Keep in mind that you are accepting personal responsibility for the security of your documents and the personal information they contain, but also understand that you are not violating HIPAA in any way. Your providers are obligated to certified and audited [secure storage locations](#) for protected health information, but you can put documents any place you choose as long as you are satisfied that they are secure enough for your personal standards.

Optimally, electronic copies would also be part of your Personal Health Record.

Delivered to my primary Proxy \_\_\_\_\_ on \_\_\_\_\_  
(name) (date)

Delivered to my alternate Proxy \_\_\_\_\_ on \_\_\_\_\_  
(name) (date)

Delivered to my PCP \_\_\_\_\_ on \_\_\_\_\_  
(name) (date)

Delivered to \_\_\_\_\_ on \_\_\_\_\_  
(name) (date)



Delivered to \_\_\_\_\_ on \_\_\_\_\_  
(name) (date)

Delivered to \_\_\_\_\_ on \_\_\_\_\_  
(name) (date)

Electronically stored in \_\_\_\_\_ on \_\_\_\_\_, which  
(cloud based location) (date)

can be accessed with the User ID of \_\_\_\_\_ and password  
\_\_\_\_\_.

*Step 7: Consider sharing your planning and/or your specific desires with a broader circle of loved ones, so that if a decision falls on your Proxy, they will have broad support.*

This is, of course, highly dependent on your personal circumstances. But recognize that being a Proxy is a difficult job, especially when all of your loved ones are in distress over your condition. Absent advanced communication of your desires, some (or most, or all) of your loved ones will likely be biased toward aggressive measures to prolong your life. If your desires are anything less than that, you may be able to make it easier on everyone by communicating in advance to the broader audience.

Excellent guidance, including videos, can be found at the National Hospice and Palliative Care Organization's CaringInfo website at the ['Communicate with Your Loved Ones'](#) page. They also include tips on dealing with [loved ones you can predict may make things difficult](#) on your Proxy.

Examples of what you might consider sharing include any combination of:

'I've been doing some planning about how I'd like to be cared for near the end of my life. I've appointed \_\_\_\_\_ as my Proxy, and have communicated to him/her as well as my PCP \_\_\_\_\_ what my specific desires are if I'm not able to make my own decisions. If those unfortunate events unfold, please understand that I've placed my full trust in them and I ask that you give them your full support.'

Or, the above, plus; 'In general, my guidance to them is \_\_\_\_\_'. This could include things like 'I'd prefer to die at home if possible', or 'If I get permanent dementia like Grandma had, I want ...'



Or provide them with full copies of all or a selected subset of your documents.

If you do choose to share this information with loved ones, family events or holidays can be a convenient time. Choose one now and resolve to have your pitch ready by then.

Consider having someone videotape you talking about the decisions and desires you've documented in your Advance Directive. This can either be the actual conversation you have with your loved ones present, or it can be separate, but it's important that the message you deliver be consistent in detail with your Advance Directive. The advantage of a video is that it captures your tone, inflection, and body language that can help your Proxy and loved ones really understand the meaning behind your words. It can also be an extremely helpful reminder of what you communicate in person. From the position of a loved one, the message you're communicating during this conversation can be very hard to hear and absorb. If you were to quiz three of your loved ones one hour after the conversation, it wouldn't be surprising to find major discrepancies in what each of the three thought they heard. Imagine how those discrepancies could lead to misunderstandings years later. A video that can be revisited later, especially when your desires most need to be clearly understood. This can be extremely helpful to your Proxy and can help prevent misunderstandings amongst the rest of your loved ones. Any hand held smartphone or tablet can make a video of adequate quality.

*Later - Repeat this cycle and update or reaffirm your desires.*

Keep in mind that state laws and the formats and content of the documents in question, specifically including POLST's in states that are less than 'Mature', are changing rapidly. While young, this review might be every 3-5 years, or if you acquire a chronic condition or wish to change your Proxy. As you grow elderly, it makes sense to review annually or more often if your personal conditions or desires change. Consider that if many years (or many life events) go by without an update by you, your Proxy, loved ones, and attending physician are more likely to question whether your Advance Directive really represents your current desires. Make it easier for everyone and keep it current.

While our focus here is on documents pertaining to your healthcare and treatment, the same updates may also be appropriate (based on the passing of time or on life events) to update your Will, Life Insurance, etc.



Each time you update:

\_\_\_\_\_ I plan on doing my next review on \_\_\_\_\_ (date) and have set a tickler in my own calendar and/or asked my Proxy to remind me.

\_\_\_\_\_ Having done my review, I have either added a brief addendum to my existing Advance Directive and Durable Power of Attorney stating that I have reviewed on that date and am reaffirming my desires; OR I have created new documents with the current date that include my reaffirmed or updated desires. Note that creating new documents from state specific templates, even if they reflect your exact same desires, will allow you to take advantage of any changes in language or terms of the most current documents. If I chose to have a videotaped copy of my desires, I have updated that to be consistent with my most current legal documents.

\_\_\_\_\_ Having updated my legal documents, I have either provided updated copies to everyone who had prior copies; OR I have updated whomever I choose and have notified the others that my old copies are now null and void.

\_\_\_\_\_ Having redistributed my updated legal documents, I have considered updating my loved ones verbally and have done so.

### ***Congratulations. You did it!***

You have just significantly increased the likelihood that your desires will be followed, and you have likely made a very difficult situation – your passing – just a bit less distressful for your Proxy and loved ones by making your desires known.

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