

Matters of Life & Death

An Investigation of Living Wills & Other Advance Directives

BY CAROLINE JARRETT

Earlier this year, we learned of the bitter legal battles over Terri Schiavo. The case centered on the different interpretations of her wishes by her husband and parents. Like Terri, I have no living will. So I thought it would be a good idea to find out about them, with the usability of the forms in mind.

In 1996, a study of living wills showed that 41 percent of the patients filled in the form inconsistently, giving contradictory instructions, and up to 45 percent filled in the form in a way that did not match their intentions.

So are today's forms any better? Can we learn some general lessons about usability from them?

Picking Some Forms

Living wills are legal documents. To get a sample of documents, I looked to the U.S. where they are governed by state law. I chose six U.S. states: Alabama, Georgia, Maryland, New Mexico, South Carolina, and Wyoming. I thought they would give me a good spread of approaches. For each state, I hunted for a state government source for the appropriate forms for creating a living will in that state.

The Structure of the Task

Creating a living will is a complex task. You need to:

1 Understand the various terms used and their meaning in your state. (Comprehension—or "understanding the task")

2 Decide what your wishes are with respect to the health care treatment you receive if you become unable to express those wishes at the time. (Decision—or "finding the answer")

3 Communicate the decisions, preferably by appointing a person whom you trust to act on your behalf and discussing your wishes with them. (Communication—or "discussing the answer")

4 Repeat the process from time to time, so that your expressed decisions continue to align with your current wishes. (Revision—or "keep it up to date")

These four steps—comprehension, decision, communication, and revision—are implicit in many types of long-term form tasks such as deciding what to do with your retirement fund, pension, or superannuation. But they are outside most people's everyday experience of forms.

Living wills are especially problematic because they require people to make decisions about the unpleasant topic of serious illness.

Comprehension—Understanding the Task

A quick quiz: What are these, and how are they used?



BBC News, 31st March 2005 *Brain-damaged Terri Schiavo Dies*

"Terri Schiavo, the brain-damaged Florida woman at the heart of a bitter legal dispute, has died. ... The case galvanised activists from both sides of the euthanasia debate. It also highlighted the issue of living wills, since Terri Schiavo had left no written instructions about what action she wanted taken if she became disabled."

(<http://news.bbc.co.uk/1/hi/world/americas/4398131.stm>)

- Advance directive
- Living will
- Healthcare proxy
- Durable power of attorney
- Do not resuscitate order

Not quite sure? Well, try this explanation from South Carolina:
"Entry of a Do Not Resuscitate Order is, however, one means of effectuating a patient's Advance Directive for the withholding of

life-sustaining procedures when the conditions set forth in the Advance Directive are met.” (South Carolina <http://www.state.sc.us/dmh/804-97.htm>)

Although the point was not obvious to the South Carolina legislature, I think that as usability professionals we can agree that these legal terms require plain language explanations.

The most confused example I found was from Georgia’s guidance. Someone in Georgia must have realized that their form was tough going, and therefore attempted to write a “friendly” guide to it. Unfortunately, they chose to use first person plural (“we”) rather than writing to the user as “you.” So it contains passages such as this:

“When Does a Living Will Work?

If we are in a Persistent Comatose Condition (Coma);

or

If we are in a Persistent Vegetative State...”

(Georgia- http://aging.dhr.georgia.gov/DHR-DAS/DHR-DAS_Publications/LivingWill.pdf)

Although “we” seems intended to be approachable, the effect is the opposite—particularly when they give up and mix “you” and “we” in the same sentence:

“As long as your Living Will was signed after 1987, it is good until you revoke it, which means you indicate that we no longer wish to have one.” (Georgia - http://aging.dhr.georgia.gov/DHR-DAS/DHR-DAS_Publications/LivingWill.pdf)

Usability Lesson: Do not try to reinvent plain language. Follow accepted principles such as writing to the reader as “you.” (More information on plain language is available at <http://www.plainlanguage.gov/howto/index.php>)

Decision—Finding the Answer

Let’s think about an ordinary web transaction—maybe buying a book. Think about the different levels of effort required for finding the answer to these typical questions:

- choice of book
- delivery address
- method of payment

It’s all somewhat trivial, isn’t it? Now let’s think about finding an answer to this typical question in a living will form:

“(2) AGENT’S AUTHORITY: My agent is authorized to obtain and review medical

records, reports and information about me and to make all health-care decisions for me, including decisions to provide, withhold or withdraw artificial nutrition, hydration and all other forms of health care to keep me alive, except as I state here...” (New Mexico Uniform Health-Care Decisions Act [24-7A-1 to 24-7A-17 NMSA 1978])

To answer this question, a user has to think about complex medical procedures such as artificial nutrition and then think about whether or not he or she wishes to have those procedures in unpleasant medical circumstances. It’s a far more challenging task than the book purchase. My view is that many people will require some help, preferably a structure that takes them through the steps that may be involved in the decision.

All of the forms that I reviewed offer some wording that I interpreted as an attempt to offer some help to users.

Help with the Mechanics

I found several examples of mechanical help—instructions that tell you about the mechanics of getting around the form and how to write on it.

Write your initials next to the statement that says what you want. Don’t use checkmarks or X’s. Then draw lines all the way through other statements that do not say what you want. Please don’t make inconsistent choices. For example, if you initial any or all of items 1, 2, and 3 on Part B of the advance directive, do not initial item 5. Draw lines through it instead. Also, be very careful about item 4. Draw lines through it if you want to make sure that you get pain relief medication. (Maryland Advance Directives, http://www.oag.state.md.us/Healthpol/advance_directive.pdf)

Although these instructions are well-intentioned, the user’s best strategy would be to ignore them and to concentrate instead on the underlying, more important task of decision. Therefore, these instructions need to be reworked so that each question is self-contained: the rules about how to place marks and about routing should be right there in the question.

What most people will need is decision help—something that guides them through the thought processes to come to an answer.

Usability Lesson: When providing help to users, are you offering mechanical help or decision help?

Blame Your Attorney

The American Bar Association offers a toolkit for helping people through the process of creating a living will, and one of its most helpful parts is “Tool 6: Conversation Scripts: Getting Past the Resistance.” This offers a selection of advice about ways to start and conduct the conversation, including this unusual piece of advice from a lawyers’ professional association: “Blame it on your attorney.”

Communication—Telling Other People about the Decision

Compare this paragraph from the Wyoming Living Will:

“This document has significant medical, legal and possible ethical implications and effects. Before you sign this document, you should become completely familiar with these implications and effects. The operation, effects and implications of this document may be discussed with a physician, a lawyer and a clergyman of your choice.” (Wyoming Living Will, <http://www.finance.cch.com/tools/downloads/wyominglivingwill.rtf>)

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What is a living will?

A living will is used to write down ahead of time what kind of care you do or do not want if you are too sick to speak for yourself.

What is a proxy?

A proxy can be part of a living will. You can pick a proxy to speak for you and make the choices you would make if you could. If you pick a proxy, you should talk to that person ahead of time. Be sure that your proxy knows how you feel about different kinds of medical treatments.

What is a durable power of attorney for healthcare?

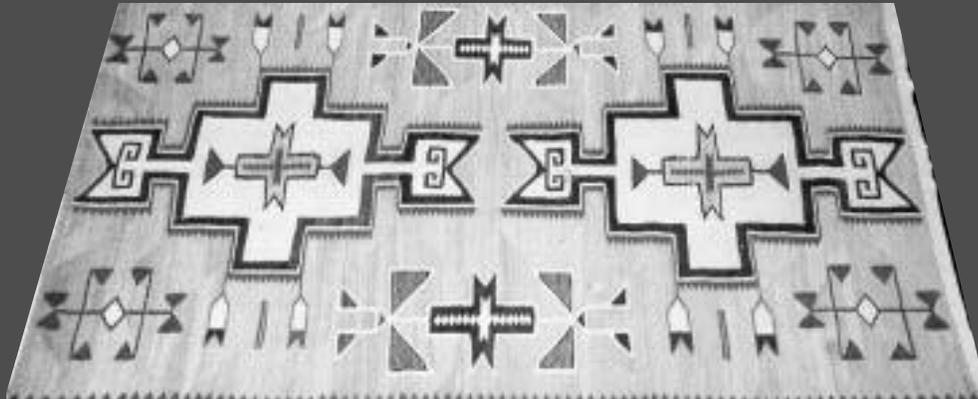
Another way to pick a proxy is to sign a durable power of attorney for health care. The person you pick does not need to be a lawyer. See the information on the Alabama website, http://www.alaha.org/advance_directive.html.

Six States Compared

	Alabama	Georgia	Maryland	New Mexico	South Carolina	Wyoming
Finding the form and guidance	Easy if you know "advance directives"	Throws you directly into the raw law	First page of an Adobe Acrobat PDF	Puts you onto a Presbyterian website	Nearly raw law—at least you can see it's South Carolina—plus a small amount of plain language guidance	Puts you directly into a Word rich-text format (rtf) document—nearly raw law
Search for further guidance	Not needed	Found PDF in "Seniors" (eventually)	Not needed	Quite difficult. Found it eventually.	Some guidance on their website (hard to find)	Not found
Explains difference between "living will," "health proxy/durable power of attorney" and "DNR"	Uses "proxy" and "durable power of attorney" (but a bit unclear on the difference)	No. Uses the term "durable power of attorney" without explanation	Yes. Uses the term "health care agent"	Form uses the term "power of attorney for healthcare," and later "guardian of my person." Guidance uses "surrogate decision maker," "agent," and "attorney-in-fact"	Yes. Uses term "declaration of a desire for a natural death"	No
Help for thinking through the issues	No	Some, but in peculiar language	No	Have to recognize that "Values History" will help you.	No	No
Encouraged to get professional advice (legal, medical, or spiritual)	Yes, legal and medical	Some (mostly spiritual)	Yes (legal and medical)	No	No	Yes
Encouraged to discuss with the proxy	Yes	Yes	Yes	Yes, in "Values History"	Told to "inform" your chosen proxy	No
Allows for different types of living will	Yes	No	Yes	Yes	Yes (limited)	No—single "do not prolong life" choice
Allows for optional proxy and replacement proxy	Yes	No mention of proxy in form	Yes	Yes	Yes. Also appoints one proxy to revoke and one proxy to enforce. Not clear what happens if they disagree	No—single (apparently required) proxy
Allows for DNR request	No	No	Yes, with some difficulty	No	Yes	No
Allows for organ/tissue donation	No	No	Yes	Yes	Yes	No
Type of language used	Plain legal language	A weird type of plain language in guidance. Legalese in the form	Guidance: plain language in general, but some tricky bits of wording. Form: a relatively clear version of legalese	Legalese and small print	A relatively clear version of legalese	Legalese
Declaration	Reasonably clear	Legalese	Reasonably clear	Reasonably clear	Legalese	Legalese
Encouragement to review and update	No	No, only a note "can be revoked at any time"	Yes	No	No	No
Signatures	Declarant, two witnesses, proxy/proxies	Declarant, two witnesses, extra witness if signed in a medical facility, (proxy's signature not required)	Declarant, two witnesses (proxy's signature not required)	Optional—two witnesses and optional—notary	Declarant, two witnesses (proxy's signature not required)	Declarant, two witnesses (proxy's signature not required)
Signing is not a condition of treatment	Mentions that you can be moved to another hospital for treatment	Yes	Yes	Not mentioned	Mentioned for state treatment only	No

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As usability professionals, we weave stories together that have been harvested from our user communities. They tell us of their frustrations and joyous discoveries while using products we are helping to develop. As we observe and analyze the users and their tasks we begin to create stories that will bring the user community alive in the minds of others. We tell these stories in ways that can be understood and acted upon by designers, business owners, and technical teams.

As usability gains acceptance, there are still times when we must ascend treacherous peaks and cross chasmic valleys. As a professional community, we can use our stories in this journey to create a world of better user experiences.

In 2006, UPA goes to Colorado, a land where the stories of hardship and challenge in the quest to succeed in a new world mingle with even older stories in the ancient tradition of Native American tribes. In this mountain setting, we will explore the role of storytelling in establishing new traditions in usability.

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