


A Couples Advance Directives Interview Using the Five Wishes Questionnaire

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Abstract

This article provides couples an opportunity to consider personal wishes for end-of-life decision making. There is brief overview of some of the issues and organizations addressing advanced directives. A portion of the *Five Wishes*¹ questionnaire, presented with permission of the Aging with Dignity organization, will be presented as a resource for the interviewing process. A sample case study is presented.

Keywords

five wishes, advanced directives, couple's problem solving, end-of-life decisions

In a *New York Times* article entitled "Why Do We Avoid Advance Directives?" Paula Span (2009) explores resistance from individuals and couples as they complete what is commonly known as living wills. She notes that a 2006 Pew Research Center study found that only 29% of the people surveyed had a living will. The study indicated that public attitudes on these and many other end-of-life issues are unchanged from 1990, despite advances in lifesaving technology, the aging of the population, and the controversy associated with the Terri Schiavo case. Although most Americans believe it should be up to the individual to ultimately determine end-of-life decisions, too few actually make any provisions to make their own personal wishes known.

The Pew Research Center's survey also found that although overall attitudes are largely stable, people are increasingly thinking about and planning for their own medical treatment in the event of a terminal illness or incapacitating medical condition. Public awareness of living wills, already widespread in 1990, is now virtually universal. People reporting they have a living will have more than doubled from just 12% in 1990 to 29% today. Sixty-nine percent who are married say they have had a conversation with their husband or wife about their spouse's wishes for end-of-life medical care; only 51% reported doing so in 1990 (Bryant, 2009).

The purpose of this article is in providing couples an opportunity to individually consider and then to interview each other regarding their personal wishes. The article will be organized as follows: there will be a brief overview of some of the issues and organizations addressing advanced directives. A portion of the *Five Wishes* questionnaire will be presented to complete and discuss with each other. A sample case study will then be presented.

In a Harris Interactive study, Byrne (2009) reported 55% Americans report having no will or medical directives. The study also indicated significant cultural differences. For

example, only 33% of African Americans and 25% of Hispanics reported having any type of advance directives.

Advance directives are also known as living wills. These are formal legal documents specifically authorized by state laws that allow patients to continue their personal autonomy by providing instructions for care in case they become incapacitated and cannot make decisions. An advance directive may also be one form of a durable power of attorney in some states. Check with each legal mandates for state or country laws before assuming such documents will be recognized.

A durable power of attorney is also known as a health care proxy. This document allows the patient to designate a surrogate, a person who will make treatment decisions for the patient if the patient becomes too incapacitated to make such decisions (Byrne, 2009).

The Agency for Healthcare Research and Quality (AHRQ) has published a pamphlet citing research relative to patient wishes for care at the end of life (Kass-Bartelmes & Hughes, 2009). They report that many patients have not participated in effective advance care planning. Although the Patient Self-Determination Act guarantees patients the right to accept or refuse treatment and to complete advance medical directives, AHRQ research reveals that

less than 50% of the severely or terminally ill patients studied had an advance directive in their medical record;

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only 12% of patients with an advance directive had received input from their physician in its development; between 65% and 76% of physicians whose patients had an advance directive were not aware that their patients had the directive; physicians were only about 65% accurate in predicting patient preferences and tended to make errors of under-treatment, even after reviewing the patient's advance directive.

Aging With Dignity and Five Wishes

Aging with Dignity is a national nonprofit organization with a mission to affirm and safeguard the human dignity of individuals as they age and to promote better care for those near the end of life. The work of Mother Teresa of Calcutta served as the inspirational foundation of Aging with Dignity.

Aging with Dignity founder Jim Towey served as Mother Teresa's friend and legal counsel for 12 years and was a full-time volunteer in her home for people with AIDS. It was her care and concern for all people's medical, emotional, and spiritual needs, which provided the inspiration in 1997 for *Five Wishes*. Called by some "the living will with a heart and soul," *Five Wishes* today meets the legal requirements in 40 states. The document is available in 23 languages and in Braille (Aging with Dignity, 2009).

Five Wishes Couple Interview

Here is a chance to personalize this for you as a couple. What follows is an interview you both are encouraged to complete with each other. If your partner is not available you can complete this on your own. In addition, consider writing your own answers in the *Five Wishes* format available from the Web page below. The *Five Wishes*¹ document itself is both an advance directive and conversation starter/structure. <http://www.aging-withdignity.org/forms/5wishes.pdf> is the read-only address. Check there for the complete document including additional written directives, which are necessary to make the document legal in all but 10 U.S. states. There is additional information on their Web site for complete directions.

The following interview has been summarized from the *Five Wishes* document with permission of the publisher. Each of you is invited to interview each other relative to personal preferences. If your partner is not willing or able to complete an interview, consider completing the document and discussing your responses with your family, friends, spiritual mentor, and/or a trusted counselor. That is one concrete way of making your own personal wishes known to them.

Basic respect for your partner's wishes means you listen and respect his or her wishes rather than imposing your own beliefs and opinions. Although it is important for the two of you to discuss each of your own preferences, existentially each of you has your own personal requests that are best respected in your partnership.

Here are the five questions for the two of you to discuss:

1. The person I choose to make health care decisions when I can't make them for myself is:

(a) First choice _____; (b) Second choice if the first is not available _____

The following two conditions must both be met for your designated health care agent (or comparable term in some states) to be legally recognized to make health care decisions on your behalf. The two conditions include:

Your attending or treating doctor finds you are no longer able to make your own health care decisions, AND Another health care professional agrees such an assessment is true.

Here are some additional considerations relative to your choices:

While your spouse or other family member may be your first choice, they may be too emotionally involved to make the best choices on your care.

You may also want someone who is geographically close to your primary residence.

While the *Five Wishes* form itself has specific directives for a designated health care agent, for your interview with each other, discuss if each of you would like such an individual to make such decisions as medical care or services like tests, medicine, and/or surgery; admission to an assisted living facility or other residential care; any life-saving or life-ending procedures; approve release of medical records; donate any organs or tissues as allowed by law; be allowed access to financial records; and/or to apply for any public or private insurance programs that might be available.

Be sure this person first knows your wishes and also agrees to follow them.

If you change your mind on your written form you can simply write "REVOKED."

2. My wish for the kind of medical care I want or do not want is:

Here are some of the kinds of directives you want to let your designated health care agent know: what to do when you're in pain; issues of your doctors doing anything to facilitate your death; and food, drink and comfort issues should they be necessary.

Discuss with your partner your desires relative to life-support issues, including such medical issues as tube feeding, cardiopulmonary resuscitation (CPR), major surgery, blood transfusions, dialysis; antibiotics; and/or related medical interventions that might keep you alive.

Discuss with your partner any spiritual, religious, and/or personal beliefs you have on this matter.

You may wish to purchase a “do not resuscitate” bracelet if that is your wish.

Some specific conditions for which you want to provide specific written instructions include issues such as when you are close to death, when you are in a coma and not expected to recover; when you have permanent brain damage and not expected to recover; and when you have any other condition under which you would not want to be kept alive.

3. My wish for how comfortable I want to be is

Discuss with your partner your wishes relative to your care including such issues as: when you are in pain, if you show signs of depression or nausea; any favorite music you would like played; religious readings or poems you would like read if you are near death; and any specific spiritual or religious persons you would like to be present with you if possible.

4. My wish for how I wish people to treat me is

Some examples include you desire to have other people with you; having your hand held and talked to even when you do not appear to be conscious; having prayers and/or members of your faith with you; pictures of loved ones in your room; and dying at home if that is possible.

5. My wish for what I want my loved ones to know is

Some topics to discuss here would include forgiveness from and to others; requesting your family to respect your wishes even if they do not agree with you; encouraging your family to seek counseling for grief; issues of burial or cremation; where you would like to be buried; who best knows your funeral wishes; any particular requests of a memorial service; and any other wishes you may have such as organ donation.

Five Wishes Couples Case Study

Jack and Debra, not their real names, were 60 and 58 years old, respectively. They first met in 1989, shortly after both had been through long and painful divorces from their spouses. They each had two grown children from their previous marriages but fell in love and married when it became obvious to them that they were soul mates and were destined to spend the rest of their lives together. Although they had talked around the issue of a living will, or advance directive, in the past, this couple’s interview gave them the structure necessary to quantify their wishes into a single document.

Jack was a highly successful man, having retired from a military career and many years as a commercial airline pilot. He is currently pursuing his dream of becoming a professional counselor. Debra spends her time with domestic duties and taking care of the couple’s home and their seven dogs. Due to recent

medical issues for both, they decided to make their final wishes known to each other and their families.

“The person I choose to make health care decisions when I can’t make them for myself” was easily answered by Jack. He put Debra as his primary choice and his daughter, Rebecca, as his secondary choice. Debra had acted in this role in the past when Jack was battling an alcohol addiction, so she was not opposed to the idea of doing it again for end-of-life decisions. She was well aware of his wishes and vowed to carry them out should the need arise without letting emotion cloud her judgment. Debra asked Jack to be her primary decision maker should the need arise, and then wanted her son, Matthew, to act as secondary in the event Jack could not serve. She had seen her mother refuse to intervene in her dying father’s life long after she should have let him go. Debra vowed she would not go through that again either with herself or with Jack. They agreed to get the necessary legal forms and accomplish them as soon as possible.

“My wish for the kind of medical care I want or do not want” was again easily answered and discussed by both partners. Jack prioritized this subject by saying “I want to be kept out of pain to the maximum extent possible, but I do not want life support measures to be employed past the point that I am unable to comprehend what is happening. In other words, do not resuscitate when my body ceases to function. If I am not expected to recover, based upon sound medical advice, and then let me go in peace.” Debra was in complete agreement with this approach and both felt this was in line with their spiritual beliefs and would be acceptable to their families. They agreed to put this information on “do not resuscitate” bracelets that they would purchase.

“My wish for how comfortable I want to be” was the one area that Debra was adamant about. She had seen her father suffer in the terminal stage of his life, and she made Jack promise that would not be the case for her. Jack had seen virtually the same thing with his father, had seen the pain and panic in his eyes, and swore that he would comply with her wishes, and vice versa. Although they were not religious people in the sense of being members of a specific church, they both had deeply-held spiritual beliefs that influenced their decisions. Debra had certain songs that she would like playing in her room if possible, and Jack had a short list as well. They both stated that if the pain was not controllable by medication, then bringing the situation to a conclusion by any means possible was an option, including euthanasia.

“My wish for how I wish people to treat me” produced the most powerful emotional response of the entire interview. Both partners have been in situations where the family had to maintain the vigil; that is, interspersed with the wailing and gnashing of teeth was the overriding question of “when will this finally be over?” Jack expressed the opinion that he felt that when the time came to go, it was the correct time, and to try to prolong it was an affront to his Maker. Debra added that it would be selfish to keep someone alive just because the partner could not let them go. Both voiced the hope that people, including family, would celebrate their lives rather than mourn their

deaths. Both agreed that dying at home would be preferable to passing in a hospital room.

“My wish for what I want my loved ones to know” was the one question where the partners differed in their desires. Jack wished to be cremated, with his ashes being spread from an airplane over land in the Hill Country of Texas that he loves so well. Debra desires to be buried next to her father, and later her mother, at a small cemetery on the coast of Texas. The commonality came when they asked that their wishes be followed even if there was disagreement among family members. Jack has already written his obituary and an outline for the memorial service that will follow his death. Debra stated that she would sit down and do the same thing, both of which would be included in the paperwork given to the primary and secondary agents. Both partners also agree to update their driver’s licenses designating their desire to be organ donors.

This exercise was a powerful and emotional experience for both partners. It provided answers to questions most couples often do not, or will not, ask of each other. However, by clarifying these issues in advance of a crisis, the decisions have already been made and it greatly reduces the pressure on the family in a time of desperation or mourning.

It is highly recommended that every couple complete this inventory for their own sakes and for the sake of those left behind. It takes but a little time to complete but will pay for itself and reap benefits far into the future.

Your Own Summary

In the space below write a summarizing paragraph or two relative to some of the key points of each of your interviews. In addition, consider going to <http://www.agingwithdignity.org/forms/5wishes.pdf> where each of you will be able to complete the official form which is what will be recognized in many states.

Partner One:

Partner Two:

Conclusion

The *Five Wishes* is one of the most widely used methods for communicating one’s advanced directives. The purpose of the present article has been to encourage both individual consideration and then an interview between you and your partner regarding each of your advanced directives desires. You might want to discuss these issues with other family members, with trusted spiritual leaders, and/or with a counselor. It is important that you respect each other’s wishes. It is also suggested that from time to time, the five wishes be revisited and updated as appropriate.

Note

1. From *Five Wishes* by Aging with Dignity Web site www.agingwithdignity.org. adapted with permission.

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References

- Aging with Dignity. (2009). Retrieved November 11, 2009, from <http://www.agingwithdignity.org/forms/5wishes.pdf>
- Bryne, L. (2009) Strong public support for right to die. Retrieved November 11, 2009, from <http://people-press.org/report/266/strong-public-support-for-right-to-die>
- Kass-Bartelmes, B., & Hughes, R. (2009). Advance care planning preferences for care at the end of life, Issue 12, Retrieved November 11, 2009, from <http://www.ahrq.gov/research/endliferia/endria.htm>
- Span, P. (2009, October 27). Why do we avoid advance directives? *The New York Times*.