

# Death, Taxes and Advance Directives

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Health information exchange, end of life, advance directive

## Summary

Suboptimal care at the end-of-life can be due to lack of access or knowledge of patient wishes. Ambiguity is often the result of non-standardized formats. Borrowing digital technology from other industries and using existing health information infrastructure can greatly improve the completion, storage, and distribution of advance directives. We believe several simple, low-cost adaptations to regional and federal programs can raise the standard of end-of-life care.

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According to Benjamin Franklin,

**“... in this world nothing can be said to be certain, except death and taxes.”**

Unfortunately, modern Americans are better equipped for taxation than death. While a majority of patients in long term care would decline intubation and CPR at the end-of-life, practice does not reflect this [1]. In good part, this is because established methods for communicating patients' wishes to their physicians leave much undone. Surveys find less than half of Americans middle age or older have a living will or healthcare power of attorney, even if they have a terminal illness [2]. Worse, up to three quarters of doctors do not know their patients' wishes even if a document exists [3]. Patients, their families and society suffer from the lack of effective advance directives. We argue that the completion of advance directives should be as routine, transmissible, and accessible as tax returns.

When care providers are uninformed about end-of-life elections, they tend towards unwanted medical intervention relying heavily on surrogates. Many of these surrogates later regret their choices which often overestimate a patient's wishes regarding the duration of life-extending measures [4–6]. On average, less aggressive care accrues to those who prepare advanced directives [7]. Physicians, arguably the most medically informed, complete advance directives far more frequently than their patients [8].

To be effective, end-of-life wishes must be accessible in a medical crisis. While patients are asked for advanced directives when hospitalized, an estimated 35 percent of existing advance directives cannot be located when needed [2, 9]. Paper elections stored in safe deposit and shoe boxes are less likely to be acted upon than those digitally available [10]. Non-standard formats and vocabularies cause further ambiguity in what interventions are desired.

Advance directive initiatives to date, both private and government, have not solved these problems. Private registry endeavors attempting to commercialize such services have floundered for lack of participation while states have been unable to maintain services due to budget cuts [2]. Clearly, there is much room for improvement in the completion, storage, and distribution of advance directives. Other industries have streamlined more complicated processes and health care should borrow these best practices.

Recent improvements in tax preparation software have ushered in a digital age where 80% of federal returns are filed electronically, fostered by a sizeable industry of certified tax preparers and consumer software. Authenticated by a universal identifier, such as social security number (SSN) or taxpayer identifier number (TIN), returns are matched to individuals with a high level of assurance [11]. The Internal Revenue Service (IRS) provides line-by-line instruction for all forms, free tax preparation software for nearly 70% of taxpayers, as well as YouTube videos and assistance by phone to simplify compliance. The same level of documentation, tools and consistency, as advocated by patient-centered organizations, can be extended to advance directives.

Five Wishes, the most common living will format and legally valid in 42 of 50 states, is a balance of simple check-boxes and patient narrative [12]. An analogous initiative, Physician Orders for Life Sustaining Treatment (POLST) is widely available but not uniform across states [13]. While both Five Wishes and POLST are straightforward advance directives, they are not structured digital documents and lack the health data exchange capabilities promoted by federal programs. We have created a model form that is even more “tax-like” in order to provoke a comparison as shown in ► Figure 1. Just as the IRS is the go-to source for tax forms and support, Medicare, as the insurance provider to 80 percent of all persons who die each year, could provide access to a digital equivalent of ► Figure 1 [14]. Medicare should encourage beneficiaries to complete this form while relatively healthy and mentally competent [15]. In conjunction with its regulations for electronic health record (EHR) adoption, Medicare could require access to a digital advance directive.

Like routine transmission of tax information to the government, advance directives must be transmitted where they are needed – to healthcare providers. Patient advocacy organizations often suggest patients “store advance directives in a safe place” but a more effective policy would be to “post to your social network.” Facebook recently added organ donation status to their online profiles, so extending to other end-of-life elections isn't far-fetched. A new social norm may have been created when this feature was launched, underscored by the nearly 100,000 people who signed up as

an organ donor in the first week after launch [16]. In 2013, 43% of adults over 65 were already using a social network [17]. While there is no legal precedent to bind such information to the end-of-life decisions as documented in EHRs, family members and surrogates would be better informed of their loved one's wishes. Updating an advance directive could be as simple as a status update and a lot easier to find than a document in a shoe box.

Linking advance directives to the EHR is the most feasible way to ensure access and provider compliance. *Respecting Choices*, an advance care program evaluated through clinical trials, demonstrated that electronic availability of standardized advance directives is critical to ensuring patient care consistent with their wishes [1]. As a sponsor for EHR adoption, Medicare can streamline advance directive exchange through interoperability standards that have already been established, such as the Consolidated Clinical Document Architecture. This could be done through existing programs without congressional action, such as pairing with BlueButton, a federal initiative to increase patient access to medical data and available on myMedicare.gov [18]. Aligning advance directives with existing medical data standards safeguards them by providing the same level of access authorization. However, neither Medicare nor social networks can rationally become legal registries for advance directives or develop last-mile connectivity to provider EHRs.

Regional Health Information Exchanges (HIEs) should be the ultimate hub for advance directive storage. The mission of most HIEs is to provide connectivity and multi-directional information flow to improve patient health within a region, a mission that encompasses advance directive storage and retrieval [19]. Although individual participation is voluntary, one of the more successful HIEs in up-state New York has already incorporated advance directives into its functionality, and others are following suit. Emergency rooms commonly access HIEs for medical history and could simultaneously access advanced directives in time of crisis [20]. HIE infrastructure can accelerate amendment of an advance directive as health status changes and allow patients to verify the contents of their advance directive through EHR or HIE patient portals. Limited adoption of patient portals and health information technology pose a short-term barrier to the digital advance directives, although none of our recommendations invalidate existing paper forms.

In 2012, the National Quality Forum adopted advance directive completion rates as a quality measurement [21]. Initiatives that tie financial reimbursement to quality performance should include this metric, since choices around end-of-life care may reduce medical costs and are critical to delivering care aligned with a patient's wishes. We believe several simple, low-cost adaptations to current federal and regional programs would substantially improve the collection, storage and effective use of advance directives. Together, these can support a culture where end-of-life decision making is as routine and accessible as IRS filings. The alternative is to remain a nation better equipped to face the inevitabilities of taxes than death.

### Conflicts of Interest

The authors declare that they have no conflicts of interest in the research.

### Protection of human subjects

Neither human nor animal subjects were used in this project.

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**Form 419** Department of Health and Human Services  
**U.S. Individual Advance Directive** **2013**  
 For the year Jan. 1–Dec. 31, 2013, or other year beginning \_\_\_\_\_, 2013, ending \_\_\_\_\_, 20.

Your first name and initial \_\_\_\_\_ Last name \_\_\_\_\_  
 if married, spouse's first name and initial \_\_\_\_\_ Last name \_\_\_\_\_ Apt. no. \_\_\_\_\_  
 Home address (number and street). If you have a P.O. box, see instructions. \_\_\_\_\_  
 City, town or post office, state, and ZIP code. \_\_\_\_\_

**Elections**  
 Here are my desires about my health care if my doctor and another knowledgeable doctor confirm that I am in a medical condition described below:  
**Close to Death.** If I am close to death and life support would only postpone that moment of my death:  
 1  I want to receive tube feeding and life support.  
 2  I want tube feeding and life support only as my physician recommends. } Check only one box.  
 3  I DO NOT WANT tube feeding or life support.

**Elections**  
 Here are my desires about my health care if my doctor and another knowledgeable doctor confirm that I am in a medical condition described below:  
**Close to Death.** If I am close to death and life support would only postpone that moment of my death:  
 1  I want to receive tube feeding and life support.  
 2  I want tube feeding and life support only as my physician recommends. } Check only one box.  
 3  I DO NOT WANT tube feeding or life support.

**Life Support**  
 I want to receive life support if I am close to death and life support would only postpone that moment of my death:  
 1  I want to receive tube feeding and life support.  
 2  I want tube feeding and life support only as my physician recommends.  
 3  I DO NOT WANT tube feeding or life support.

**Appointment**  
 I want to receive life support if I am close to death and life support would only postpone that moment of my death:  
 1  I want to receive tube feeding and life support.  
 2  I want tube feeding and life support only as my physician recommends.  
 3  I DO NOT WANT tube feeding or life support.

**Organ Donation**  
 I want to receive life support if I am close to death and life support would only postpone that moment of my death:  
 1  I want to receive tube feeding and life support.  
 2  I want tube feeding and life support only as my physician recommends.  
 3  I DO NOT WANT tube feeding or life support.

**Signature**  
 I want to receive life support if I am close to death and life support would only postpone that moment of my death:  
 1  I want to receive tube feeding and life support.  
 2  I want tube feeding and life support only as my physician recommends.  
 3  I DO NOT WANT tube feeding or life support.

Fig. 1 Model US Individual Advance Directive Claim Form

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