Video Advance Directives: Growth and Benefits of Audiovisual Recording

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VIDEO ADVANCE DIRECTIVES:
GROWTH AND BENEFITS OF AUDIOVISUAL RECORDING

Thaddeus Mason Pope*

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I. INTRODUCTION

THIS special symposium issue of the SMU Law Review commemo-
rates the thirtieth anniversary of the U.S. Supreme Court’s deci-
sion in Cruzan v. Director, Missouri Department of Health.1 In that
famous and seminal decision, the Court held that the U.S. Constitution

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permits states to require clear and convincing evidence of an incapacitated patient’s preferences before allowing that patient’s family to direct the withholding or withdrawing of life-sustaining medical treatment.2

The key question in Cruzan was one of substantiation and evidence: how can the incapacitated patient’s surrogate decision maker prove that the health care decisions she makes on the patient’s behalf are the same health care decisions that the patient would have made for herself?3 Answering this question, the Court observed that an advance directive would constitute adequate proof because an advance directive constitutes clear and convincing evidence of a patient’s wishes.4

Today, clinicians and policymakers no longer focus on the constitutional question of how much evidence state law may require from a patient’s surrogate. Instead, the current relevant question is more practical than legal: how can people best assure that their health care wishes are known and respected after they lose decision-making capacity? Thirty years ago, the Cruzan Court identified advance directives as a paradigm solution to this problem.5 And that is how policymakers have understood the lesson of the case.6 But if advance directives are a good way to communicate one’s wishes, then video advance directives are even better.

Addressing both the questions presented in Cruzan and the theme of this special symposium issue, this article makes the case for video advance directives as a valuable, additional way for individuals to record their health care treatment preferences. Supplementing a traditional advance directive with a video advance directive increases the likelihood that surrogates and clinicians will understand and follow the patient’s recorded wishes in the way the patient intended.

The primary purpose of advance directives is to assure that incapacitated patients get both the medical treatment they want and avoid the medical treatment they do not want.7 These objectives are more likely to be achieved by supplementing a cold and sterile paper document with an audiovisual recording of the patient’s own voice, body language, and fa-

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2. Id. at 286-87.
3. Id. at 280 (framing the central issue as whether a state may establish “a procedural safeguard to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent”).
4. See id. at 289 (O’Connor, J., concurring) (noting that while the patient’s own oral or written instructions are sufficient, other evidence might also be sufficient); id. at 323 (Brennan, J., dissenting) (“The court did not specifically define what kind of evidence it would consider clear and convincing, but its general discussion suggests that only a living will or equivalently formal directive from the patient when competent would meet this standard.”).
5. See supra note 4 and accompanying text.
cial expressions. In short, video advance directives offer material advantages over traditional written advance directives.

Part II describes two persistent problems with traditional advance directives: uncertainty regarding their validity and uncertainty regarding their meaning. Part III explains how video advance directives avoid or mitigate these problems. The benefits of video advance directives are demonstrated by analogous experience with video wills, as well as by new research on video advance directives. Given this evidence base, it is no surprise that the use of video advance directives has been growing. Part IV describes seven companies that offer video advance directive services. Finally, Part V concludes that stakeholders promoting advance directives should also promote audiovisual recording.

II. PROBLEMS WITH TRADITIONAL ADVANCE DIRECTIVES

The promise of advance directives is to assure that patients get the treatments they want and avoid the treatments they do not want. But that promise has never been completely fulfilled. Authors have identified a wide range of persistent challenges. For example, few individuals complete advance directives. Even when they are completed, many advance directives are unknown or unavailable when needed.

Furthermore, there are substantive, persistent problems with traditional advance directives. First, some family members challenge the validity of advance directives, contending that the patient lacked capacity at the time of completion. Second, some families and clinicians misinterpret advance directives or dispute what the patient intended.

A. VALIDITY OF THE DIRECTIVE: DID THE PATIENT HAVE CAPACITY WHEN SHE COMPLETED IT?

Clinicians and surrogates should generally follow the patient’s advance directive. But they may not (and perhaps should not) follow an advance directive if they doubt its validity. One common reason for questioning the validity of an advance directive is uncertainty whether the patient had capacity when she completed it. For example, the Ontario Health Care Consent Act invites surrogates and clinicians to apply to a special adjudicative tribunal (the Consent and Capacity Board) when the incapacitated patient has “expressed a wish with respect to the treatment” but “it is not
clear whether the wish was expressed while the incapable person was capable.” U.S. jurisdictions have similar laws.

For example, in one recent case, the Supreme Court of Nebraska set aside an advance directive because the patient executed it while she lacked capacity. Several of the patient’s eleven children brought actions contesting which of several amended directives was the operative one. The patient executed her most recent directive after being diagnosed with moderate dementia. Four months earlier, a clinical neuropsychologist had examined the patient and found that she was unable to “make complex medical decisions” or “define the concept of power of attorney.” The court ruled that the directive was invalid.

B. MEANING OF THE DIRECTIVE: WHAT DID THE PATIENT INTEND?

Uncertainty regarding an advance directive’s validity is not the only problem. Clinicians and surrogates also fail to follow an advance directive because they are not sure what it says. Accordingly, the Ontario Health Care Consent Act invites applications for tribunal review when the meaning of an advance directive is in question. A surrogate or clinician may apply to the Consent and Capacity Board when the incapacitated patient has “expressed a wish with respect to the treatment” but either (1) “the wish is not clear” or (2) “it is not clear whether the wish is applicable to the circumstances.”

Such challenges are common in Canadian and U.S. jurisdictions because the language used in advance directives is notoriously vague. For example, the patient may check a box indicating that she declines “heroic measures” or “extraordinary treatment.” But it remains unclear what exactly a patient intends with broad, ambiguous language. Below are two case examples.

“I WISH TO LIVE.” In 2009, S.S. completed an advance directive, writing “I wish to live” in the “Optional Instructions” section. It is unclear whether the patient meant this language to indicate some sort of vitalism.

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17. Id. at 556–58.
18. Id. at 556.
19. Id. at 556, 563.
20. Id. at 553.
22. Id. (emphasis added).
statement or something else. Just weeks after the patient completed the directive, he suffered “a heart attack and severe neurological damage to his brain.”

Thereafter, a dispute erupted between S.S.’s wife and his siblings over how to apply the advance directive. The parties asked the court to interpret the “I wish to live” language. After reviewing extensive testimony and other evidence, the court found that it simply meant that “S.S. wanted to live life to the fullest, not to merely exist, unable to communicate and interact with his family and friends.”

“NO NOURISHMENT OR LIQUIDS.” In 1991, Margot Bentley executed an advance directive requesting that if “there [was] no reasonable expectation of [her] recovery from extreme physical or mental disability,” then she wanted “[n]o nourishment or liquids.” In 2012, when Bentley’s Alzheimer’s disease reached a late stage of advanced dementia, her family directed her facility caregivers to stop feeding her. When they refused, the family brought the matter to court. But the court found the relevant language “so unclear that . . . this instruction could not be taken as consent” to stop providing assistance with eating with a spoon or drinking with a glass. Typically, “nutrition and hydration” refers to clinically assisted measures with feeding tubes. Therefore, the court found this was the “most likely interpretation” of the language in Bentley’s advance directive.

In S.I. v. R.S. and Bentley v. Maplewood Seniors Care Society, it was unclear what interventions the patients wanted to receive and what interventions they wanted to avoid. In contrast, in other cases, it can be clear what interventions the patients wanted. But it may still be unclear whether the patients wanted them under their present (unanticipated) circumstances. In other words, even if the patients’ wishes are known, it may still be uncertain whether the wishes are “applicable” to the patients’ current situations.

For example, Paul Conway had a “prior capable wish” not to receive

25. Id. at 866.
26. Id. at 864–66.
27. Id.
28. Id. at 866.
29. Bentley v. Maplewood Seniors Care Soc’y, 2014 BCSC 165, para. 5 (Can.), aff’d, 2015 BCCA 91 (Can.).
30. Id. at para. 1.
31. Id. at paras. 2–3.
32. Id. at para. 112.
33. Id. at para. 111.
35. Bentley, 2014 BCSC. 165 at para. 111. Generally, as the patient makes more unusual requests, they should ensure their surrogates have correspondingly better evidence to establish that the patient understood and really wanted those interventions.
anti-psychotic medications. But after Conway was found incapable of consenting to psychiatric treatment, a question arose whether that wish applied only to traditional medications or also to atypical anti-psychotics. The case was decided differently by more than five different courts over a period of more than six years. Neither the parties nor the courts could agree on whether Conway’s prior capable wish was applicable to his then-current circumstances.

III. BENEFITS OF VIDEO ADVANCE DIRECTIVES

The previous section shows that traditional advance directives often suffer from uncertainty regarding both their validity and meaning. This section shows that supplementing a traditional advance directive with a video advance directive potentially alleviates these problems.

Over the past five years, both legal and medical commentators have increasingly discussed video advance directives. These and other commentators not only discuss but also recommend using video advance directives. Fortunately, there is substantial evidence to support these recommendations. First, Section A details evidence from decades of using videos to supplement wills. Second, Section B discusses growing evidence of the benefits of video advance directives.


38. Conway, 59 O.R. 3d at 739.

39. Id. at 744–45.

40. See, e.g., Conway, 250 D.L.R. 4th 178, paras. 9–18.


A. Benefits of Video Wills

Individuals have been supplementing their wills with videos since the 1980s.45 Even the now-infamous pornographic actress and stripper Stormy Daniels has a video will.46 This makes sense. First, scores of elder law attorneys recommend that their clients create video wills.47 Second, it is sound advice, supported by well-reasoned literature,48 law commission recommendations,49 and demonstrated success in the courts.50 Indeed, several state statutes specifically invite using video to “probate a testament.”51


50. See infra notes 56–65. Of course, the more important benefit of video is not winning a will contest but deterring the will challenge in the first place. Cf. Buckley, The Case for the Videotaped Living Will, supra note 48, at 31.

51. See, e.g., LA. CODE CIV. PROC. ANN. art. 2904 (2005); IND. CODE § 29-1-21-5 (2018).
All this experience is probative because wills are analogous to advance directives. Both instruments are ways for individuals to leave instructions to guide third parties managing the individuals’ affairs. The main reasons to supplement a will with a video will are much the same as the reasons to supplement a traditional advance directive with a video advance directive. First, a video shows that the individual had capacity. Second, a video shows that the individual signed the will voluntarily. Third, a video clarifies the individual’s intent.

1. Video Shows the Individual Had Capacity at Signature

Video has helped many courts conclude that a decedent had decision-making capacity to execute a will. For example, in one recent case, the son who received the smaller share of his parent’s assets tried to invalidate the will and trust by challenging his mother’s testamentary capacity. His challenge failed. At trial, the probate court found that the mother had capacity to make a will and trust at the time she executed the disputed instruments. The court based its decision primarily on a video recording of the mother executing the documents.

2. Video Shows the Individual Signed Voluntarily

Just as video helps courts conclude that a decedent had capacity at execution, video also helps courts conclude that the decedent signed voluntarily. Dissatisfied heirs challenge the validity of wills by alleging that the decedent signed under coercion or duress. But a video can show that the decedent signed of their own free will.
3. **Video Clarifies the Individual’s Intent**

Just as video helps courts conclude that the decedent had capacity and signed voluntarily, video also helps courts discern the decedent’s intentions. For example, in a Massachusetts case, there was a conflict over whether a life tenant or the estate should bear the expense of capital repairs and improvements to property that was in substantial disrepair. The probate court found that while the will was ambiguous on this question, the intent of the decedent was clear and evident based on a video made at the time she signed her will.

### B. Benefits of Video Advance Directives

While individuals have been using video to supplement wills for decades, they have only just begun using video to supplement advance directives. Nevertheless, there is already growing evidence that it offers similar benefits. First, a video advance directive can show the patient had capacity when she signed the directive. Second, it can show that the patient signed voluntarily. Third, a video advance directive can clarify the patient’s intent, assuring more accurate interpretation of the traditional advance directive.

1. **Video Shows the Patient Had Capacity at Signature**

Perhaps the most recent vivid use of video involved billionaire Sumner Redstone, the majority shareholder in CBS/Viacom. In 2015, the lack of undue influence. See, e.g., *In re* Estate of Chapman, 966 So. 2d 1262, 1265 (Miss. Ct. App. 2007).


65. Id.

66. Video advance directives may also offer other benefits. For example, some individuals may be willing to record a video even if they are unwilling to prepare a document. See Lisa M. Quintiliani et al., *Feasibility and Patient Perceptions of Video Declarations Regarding End-of-Life Decisions by Hospitalized Patients*, 21 J. PALLIATIVE MED. 766, 771 (2018); see also Karen Bullock, *The Influence of Culture on End-of-Life Decision Making*, 7 J. SOC. WORK IN END-OF-LIFE & PALLIATIVE CARE 83 (2011) (discussing racial and ethnic differences in end-of-life care preferences).


ninety-two-year-old Redstone amended his advance directive, removing his live-in companion Manuela Herzer as his health care agent. Herzer sued, alleging that Redstone lacked capacity to make the changes. The court found that Redstone had capacity, based largely on a video of Redstone himself discussing the advance directive. The trial court observed that he appeared “alert” and “composed” and “did not appear to be confused about the questions, his wishes, or the reasons for his wishes.”

2. Video Shows the Patient Signed Voluntarily

Unfortunately, there have been several recent fraud and forgery cases concerning advance directives. Some of these cases challenged whether the patient signed the advance directive at all or completed it in the same way that it was presented to clinicians. Other cases questioned whether the patient signed the directive voluntarily.

Among others, the Supreme Court of India has expressed concern about advance directive fraud. Therefore, it is instructive to note how India assures the voluntariness of consent in analogous health care situations. For years, India grappled with concerns that human research subjects were not knowingly and voluntarily consenting to participate in medical research. To mitigate this risk, India now requires videotaping of the consent process. Evidence shows that this improves the quality of the consent.

69. Id. at *2-4.
70. Id. at *4-5.
71. Id. at *12.
72. Id. at *12, *32. The video that the court watched was a video deposition taken for purposes of the litigation rather than one completed at the time the advance directive was executed. Id. at *3. But the case illustrates the value of contemporaneously created videos. See also, e.g., Bartling v. Superior Court, 209 Cal. Rptr. 220 (Cal. Ct. App. 1984) (allowing disconnection of ventilator based on patient’s video deposition).
74. See, e.g., Bradley, supra note 73.
75. See, e.g., LaCapria, No. 805346-2018.
78. Id. Videos can also include geolocation digital markers (e.g., date, time, or GPS location) that enhance confidence in accuracy and reduce fraud.
3. **Video Clarifies the Patient’s Intent**

Perhaps the most significant and relevant body of research on video advance directives is The Realistic Interpretation of Advance Directives (TRIAD) study. TRIAD focuses on patient safety issues concerning interpretation of advance directives.\(^80\) The TRIAD study has identified widespread misinterpretation errors with advance directives.\(^81\) There are now twelve TRIAD reports spanning more than a decade.\(^82\) The most relevant is TRIAD VIII.\(^83\)

In TRIAD VIII, researchers surveyed over 1,300 physicians (subjects), including attending and resident physicians from emergency medicine, internal medicine, and family medicine, at thirteen teaching hospitals across the United States.\(^84\) Subjects were asked to consider nine patient cases, to choose the appropriate code status for the patients presented, and to make resuscitative decisions for the patients presented.\(^85\)

Subjects were sorted into two groups.\(^86\) Subjects in group one reviewed cases that included only a written advance directive to interpret.\(^87\) Subjects in group two reviewed the same materials plus a patient video testimonial/message that clarified the patient’s wishes.\(^88\) The survey results demonstrated that the addition of scripted patient video testimonials significantly improved physician interpretations of patient wishes for end-of-life care.\(^89\)

While TRIAD VIII focused on typical treatment decisions (like do-not-resuscitate orders), clarifying and confirming the patient’s intent is especially important with advance directives that request atypical interventions. For example, over the past two years, policymakers have been developing advance directives for voluntarily stopping eating and drink-
ing.\textsuperscript{90} Policymakers are even considering advance directives for medical aid in dying.\textsuperscript{91} Videos can help assure clinicians and regulators that patients with such directives really wanted these interventions.\textsuperscript{92}

C. Legal Status of Video Advance Directives

Despite evidence showing the value of video advance directives, state laws generally allow videos only to augment traditional advance directives, as if an appendix. Some states, including New Jersey, explicitly allow for a written “advance directive [to] be supplemented by a video or audio tape recording.”\textsuperscript{93} But that is surely permitted even when no statute specifically says so.\textsuperscript{94}

Only Maryland deems a video advance directive itself to be a legal advance directive. Maryland defines an advance directive as a “witnessed written or electronic document.”\textsuperscript{95} Importantly and uniquely, the statute further provides that “[a]ny competent individual may, at any time, make a written or electronic advance directive regarding the provision of health care to that individual, or the withholding or withdrawal of health care from that individual.”\textsuperscript{96} As states move toward recognizing electronic forms of advance directives, more may follow Maryland and recognize video advance directives.\textsuperscript{97}


\textsuperscript{92} See, e.g., N.J. STAT. ANN. § 26:2H-56 (West 1992).

\textsuperscript{93} Id.

\textsuperscript{94} See, e.g., MD. CODE ANN., HEALTH-GEN. § 5-602(a)(2) (West 2017) (“[I]n the absence of a validly executed or witnessed advance directive, any authentic expression made by an individual while competent of the individual’s wishes regarding health care for the individual shall be considered.” (emphasis added)); see also IDaho CODE § 39-4509(3) (2019) (“Any authentic expression of a person’s wishes with respect to health care should be honored.”).

\textsuperscript{95} Id. § 5-601(b)(1) (emphasis added).

\textsuperscript{96} Id. § 5-602(a)(1) (emphasis added). The statute continues: “Any competent individual may, at any time, make a written or electronic advance directive appointing an agent to make health care decisions for the individual under the circumstances stated in the advance directive.” Id. § 5-602(b)(2); see also Ireland Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (I.), http://www.irishstatutebook.ie/eli/2015/act/64/section/82/enacted/en/html#sec82 [https://perma.cc/W2D6-RCLG].

IV. SERVICES OFFERING VIDEO ADVANCE DIRECTIVES

Recognizing the value of video advance directives, several companies have already begun offering services to help individuals complete and store them. The seven most significant services are (1) MyDirectives, (2) Vimty, (3) MIDEO, (4) In My Own Words, (5) Honor My Decisions, (6) Caring Advocates, and (7) Life Messages Media. These companies are already grappling with (and solving) privacy, security, and other technical logistics involved in creating, storing, and retrieving video advance directives.

**MyDirectives.** The largest and most well-established video advance directive service is MyDirectives. Created by Dallas, Texas-based ADVault, Inc., MyDirectives has users in all fifty states and in over thirty countries. The service is free for individuals, because ADVault contracts with healthcare payers, providers, ministries of health, electronic health record companies, health information exchanges, and community partners to generate revenue from engagement, storage, integration and access programs, as well as efforts with providers, lawyers, and community partners in a Facilitated Advance Care Planning service. MyDirectives lets users easily upload their paper documents (like Five Wishes) or their digital files from other vendors (like MIDEO), if they have them, or users can create a digital advance care plan and audio and video recordings they call the “Most Unselfish SelfieTM.” Once uploaded or linked to its ADVault ExchangeTM, the global registry and repository allows interoperable, real-time sharing and access 24/7 anywhere in the world. This digital cloud-based platform alleviates the need for doctors or family members to track down paper documents during an emergency.

**Vimty.** Like MyDirectives, Vimty is an online platform that helps individuals make end-of-life decisions. Users go to an online portal that guides them through decisions about who their health care advocate is, what level of life-sustaining treatments they want, how they want to...
age pain, how they want to manage emotional well-being, and where they want to die (in a hospital, hospice, or at home). The system generates a document, and users can get it notarized over Skype. The Skype call is recorded, and a specially trained notary ensures that users understand what they are signing.

MIDEO. Ferdinando Mirarchi is the principal investigator of the TRIAD study. In 2015, he established the Institute on HealthCare Directives (the Institute) in Erie, Pennsylvania, to offer MIDEO (My Informed Decisions on Video). Compared to other video advance directive services like MyDirectives, MIDEO is more clinician driven. The videos are carefully scripted and usually last just forty-five to ninety seconds. The goal is to convey essential information to physicians making crucial decisions (such as whether to perform manual chest compressions or to insert a breathing tube) in time-pressed emergency medical situations to prevent medical errors of overtreatment and undertreatment. In order to address the need for secure storage and real-time access of MIDEOs within the electronic health record, the Institute has partnered with ADVault’s MyDirectives platform to provide those services.

In My Own Words. Melinda Ginne is a licensed psychologist in Oakland, California. She started In My Own Words to allow individuals to create a video record of their advance directives. Notably, in contrast to MyDirectives and MIDEO, the individual must store the video on their own. The user guide for In My Own Words advises storing the video file “on a USB flash memory drive which can easily be carried on [a] key chain” or “on Internet storage, a CD/DVD, or cell phone/music player.” The site wisely advises sending copies to one’s family, physician, attorney, or health care facility.

Honor My Decisions. In 2012, the Alpha-1 Foundation issued grants to research ethical, legal, and social aspects of advance care planning issues. These grants enabled two Florida bioethicists to develop a con-
sumer prototype now known as Honor My Decisions. The service allows individuals to create and store both traditional and video advance directives.

**Caring Advocates.** One of the more sophisticated set of advance care planning tools is offered by Caring Advocates. Their “Better Diligent Plan,” which focuses on dementia, offers two video options. First, the patient can have a trained advance care planning counselor conduct the recorded interview. Second, the patient can instead receive written guidelines on how to make the video on their own.

**Life Messages Media.** Unlike the other services described above, Life Messages Media does not specialize in advance directives. Based in Madison, Wisconsin, Life Messages Media specializes in recording a broader range of personal and family history, stories, and life experiences. Many of these have nothing to do with health care decision making. “Life Messages Media [goes] to [the individual’s] location, guides [them] through an interview, and records other footage that captures [their] unique story.”

**V. CONCLUSION**

Commentators often explain the point of traditional advance directives is to help surrogates and clinicians to figuratively “hear the voice” of the patient. Extending this metaphor, one might say that video advance directives permit surrogates and clinicians to literally hear the voice of the patient. Nancy Cruzan lived before a time when high quality video cameras were embedded in ubiquitous cellphones, tablets, and computers. Thirty years later, the voice of the citizen is still at risk of not being heard. It is time to supplement (or at least augment) traditional advance directives with video advance directives to better achieve value-concordant care. It is time to allow all Americans to live with confidence that they can have a voice in their care, even if they are in a health crisis and cannot communicate at that time.

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120. Id.


122. Id.

123. Id.

124. Id.


126. Id.

127. Anita Cava, Advance Directives: Taking Control of End-of-Life Decisions, 14 St. Thomas L. Rev. 5, 5 (2001) (“An advance directive achieves this by being the voice of a person who can no longer effectively speak . . . .” (emphasis added)).