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Understanding Awareness and Completion of Advanced Care Directives: An Exploratory Study

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the Faculty of the Undergraduate
College of Health and Behavioral Studies
James Madison University

by Katherine Anna Chiu and Katherine Grace Topf

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Accepted by the faculty of the Department of Health Sciences, James Madison University, in partial fulfillment of the requirements for the Honors College.

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PUBLIC PRESENTATION

This work is accepted for presentation, in part or in full, at VCHC and Honors Symposium on April 5.

Abstract

Background: Advance Care Directives (ACDs) are forms that are beneficial for expressing end-of-life wishes during Advance Care Planning (ACP); however, few studies have focused on awareness and completion among college-aged populations. Completion of ACDs are more common among populations forced to think about potential of death, such as the elderly and chronically ill.

Methodology: This research is comprised of two parts in order to explore the availability of resources on four-year public institutions' official websites (institutional level), and college-aged students' beliefs and values. The institutional level took inventory of information available on the official websites of four-year public institutions (n=1,642). The student level surveyed JMU students (n=360) with an online questionnaire comprised of demographic questions, beliefs and values scales, and general ACD questions.

Results: The majority of four-year public institutions do not provide public information to their students regarding ACDs and ACP. Students showed higher scores on the Death Depression Scale and College Beliefs and Values Scale when there was no knowledge of ACP.

Discussion: Institutions that do not provide information regarding ACDs and ACP should use other institutions as models for designing materials that will raise awareness and assist students in completing these documents. The Death Depression Scale and one subscale of the College Students Beliefs and Values Scale identified the likelihood of ACP knowledge. Lower average scores on the Death Depression Scale and organ donation are two of the most significant predictors of likelihood of ACP knowledge or completion.

Keywords: advanced care planning, advanced care directive, college students, four-year public institution, death, end-of-life

Background

The Principles of Patient' Rights and Responsibilities were approved by the National Health Council Board of Directors in January 1995 (National Health Council, 2016). These principles consider Advance Care Directives (ACDs) to be a part of patients' first right, which encompasses informed consent, timely access to care, and confidentiality protections (Appendix A). Completing an ACD is part of a much larger process called advance care planning (ACP), which involves self-reflection and self-identification of personal values and goals pertaining to health and illness. Components of ACPs include a living will, durable power of attorney for health care (DPAHC), and a do not resuscitate (DNR) form (Hinders, 2012; Sudore et al., 2013). Surprisingly, less than 30% of Americans have completed their own ACD (Hinders, 2012). The completion of ACP documents is a legal process that is not commonly fulfilled by individuals in the United States, especially among those that are young, able-bodied, and not facing the imminent danger of chronic disease or illness. By contrast, the ACP process is more commonly completed among the elderly (50%) and hospice patients (90%) (Sanders & Robinson, 2017). This pattern suggests there is a misconception that ACP is primarily devised for elderly and disabled populations, as well as those encumbered by severe or chronic disease or illness (Niebuhr, Eames, & Stephenson, 2014).

Completion of an ACD is important for all ages because it allows patients to identify individuals that they trust to execute their medical decisions and end-of-life wishes (Hinders, 2012; Sudore et al., 2013). ACDs promote patient autonomy as they give patients the opportunity to write their preferences in a legally-binding document that must be fulfilled in a situation where the patient is unable to express them personally (Hinders, 2012; Sudore et al., 2013). Completed ACP forms alleviate stress on both providers and patients because it removes the need to rely on family

members to determine medical decisions (Humphrey & Dell, 2015). Likewise, ACDs also establish which individuals have permission to make medical decisions on the patient's behalf, which can prevent arguments amongst loved ones (Humphrey & Dell, 2015). Programs have been created to start the discussion between family members about end-of-life care (Green & Levi, 2011; Levi et al., 2013; Splendore & Grant, 2017). These programs aim to ensure that family members understand one another's wishes and reduce stress in cases of medical emergency (Wiener et al., 2012; Zadeh, Pao, & Wiener, 2015). However, many families have not had an opportunity to learn about the importance, let alone existence, of ACDs.

Lack of completion of ACDs typically results from a lack of awareness on the patients' part due to various factors associated with health care professionals' training and work environments (Levi et al. 2013; Nash et al., 2016; Wiener, Zaheh, Wexler, & Pao, 2013; Woodlen & Bakken, 2016). Incorporating ACP completion into routine physician appointments is both emotionally challenging and time consuming for the provider (Levi et al., 2013). Feelings of conflict, tension, and uneasiness are all common barriers experienced by providers while discussing these topics, especially in conjunction with other considerations, such as culture and religion (Coleman, 2013; Peng, 2015; Woodlen & Bakken, 2016). These extenuating circumstances have created feelings of inhibition that prevent providers from engaging their patients in these conversations (Coleman, 2013; Ohad & Aya, 2016). Factors that have impacted physician attitudes include patient autonomy for making personal medical decisions; legal worries about litigation of completed ACDs; paternalism characteristics among physicians and medical professionals; and individual subjective beliefs regarding ACDs (Coleman, 2013). However, these attitudes and barriers do not only affect physicians; they also impact providers that have more

substantial patient interaction, such as nurses (Coleman, 2013; Connell & Mallory, 2007; Niebuhr, Eames, & Stephenson, 2014).

Only 18% of nursing students reported feeling confident and prepared to answer questions about ACP, and an even smaller 2% reported that they had completed their own ACDs (Connell & Mallory, 2007). Many recognized that they lacked awareness on the subject of ACP and believed that there was insufficient transfer of knowledge from class to practice (Connell & Mallory, 2007). These findings indicate a serious inadequacy at institutional levels, which contributes to a lack of awareness among future health professionals. Training sessions and workshops can be beneficial for not only explaining the content of ACPs to patients, but also reducing the fear of inappropriate behavior and conversations among providers (Nash et al., 2016). It has been found that most college students are in the precontemplation phase when making decision regarding ACP (Schnur & Radhakrishnan, 2019). The act of thinking about ACP as a college-aged student increases the awareness and understanding of these forms (Triipken & Elrod, 2018). With this knowledge available, it can better help health care providers have these difficult conversations and suggest potential programs.

Programs, such as *Making Your Wishes Known: Planning Your Medical Future*, have been designed to provide practicing and future physicians with strategies for handling ACP concerns and discussions (Green & Levi, 2011; Levi et al., 2013). Additionally, multiple national programs have been implemented in an effort to increase completion of ACP forms. One model for these programs is the *Five Wishes ACP Form*, a pre-post-survey designed to increase education and awareness of ACPs among patients (Splendore & Grant, 2017; Wiener et. al, 2008). *Five Wishes ACP Form* found that information presented by trained facilitators in visual, written and verbal modes created the most non-threatening environment and corresponded with an increase in the

likelihood of completion (Splendore & Grant, 2017; Wiener et. al 2008). The *Voicing My Choices* program consists of nine modules for assessment of adolescent readiness to discuss end-of-life care. The format of this program involved the transition from easier discussion topics to those that are more difficult or controversial, such as choosing one's health care proxy (Wiener et al., 2012; Zadeh, Pao, & Wiener, 2015). These programs aid the individual in contemplating values, making appropriate decisions regarding end-of-life wishes, and involving supportive networks in the process.

Despite these programs, a major gap still exists in ACP research. Existing literature has traditionally focused on elderly and aging populations, which creates a lack of emphasis on engaging younger, college-aged populations (Niebuhr, Eames, & Stephenson, 2014). Few studies have sought to better understand the lack of completion of ACDs among college students. A focus group of University students reported that a lack of information created a significant barrier for those that may want to engage in this health behavior (Kavalieratos, Ernecoff, Keim-Malpass, & Degenholtz, 2015). This problem stems from an institutional level, as most colleges only require information about students' medical histories and allergies (Kapp, 2000). A recent study using the *Five Wishes ACP Form* indicates that a college classroom would be an ideal location to provide students with information on the importance of ACP (Thoelke, 2018). It was also found that ACP benefits were the most common recurring theme throughout the student reflection portion of this study (Thoelke, 2018).

Failure to actively engage students in these discussions can cause inadequate preparation for unexpected health emergencies. Although this is not frequently discussed, health issues and major causes of death among college-aged populations extend much further than what is addressed in student medical forms. In a recent report, the top three causes of death for individuals ages 15-

24 were unintentional injury (13,895 deaths), suicide (7,366 deaths), and homicide (5,172 deaths) (Centers for Disease Control and Prevention, 2016). Recently, higher education professionals have taken a particular interest in alcohol and motor vehicle-related accidents and deaths. A pilot study showed accidental injury was the leading cause of mortality, accounting for 48% of deaths among college students (Turner, Leno, & Keller, 2013). CDC reports and various studies show that the three major causes of death common among college students are accidents, vehicular injuries, and alcohol or accidental poisoning (Asif, Harmon, & Klossner, 2013; Centers for Disease Control and Prevention, 2016; Turner et. al, 2013).

Given college students may experience unintentional or unexpected accidents that result in severe injury or death, it is important for them to have access to information and resources that assist in ACD completion. College-aged populations tend to rely on receiving health information from four main sources. Over a six-year period, parents remained the most used source of health information; which preceded the utilization of health educators, medical staff, and faculty or coursework (Vader, Walters, Roudsari, & Nguyen, 2011). Despite this relationship, the majority of college-aged populations have a higher trust in the information that comes from medical staff and health educators (Vader et al., 2011). This demonstrates that there is an underutilization of resources that college-aged population have high trust and confidence in. In order to address this observed difference in utilization and perceived trust, these researchers suggest that colleges should design more effective health information campaigns (Vader et al., 2011).

A majority of the United States population does not have an ACP due to the lack of awareness and education provided to both patients and providers (Levi et al. 2013; Nash et al., 2016; Wiener et al., 2013; Woodlen & Bakken, 2016). In order to resolve this problem, studies have been conducted to identify optimal methods for educating large public audiences about ACP

(Balint & Bilandzic, 2017; Morrow & Murray, 2007; Woodlen & Bakken, 2016). Researchers have also attempted to deconstruct perceived barriers that prevent individuals from engaging in ACP methods (Kavalieratos, Ernecoff, Keim-Malpass, & Degenholtz, 2015; Levy-Storms, 2005). Unfortunately, the lack of information provided to health care professionals hinders their ability, confidence, and preparedness to hold these potentially uncomfortable and controversial conversations (Coleman, 2013; Connell & Mallory, 2007; Nash et al., 2016). Although research has revealed key information regarding effective communication methods and barriers for health care providers, there is still a large gap in research dedicated to engaging young adults in ACP (Morrow & Murray, 2007; Woodlen & Bakken, 2016). In order to address these concerns, this study explored how much and what kind of ACD and ACP information is provided to students by four-year public institutions; as well as the awareness levels, completion rates, and potential predictors of ACD completion among college students.

Part I: Institutional Level Research Questions

1. How many four-year public institutions provide educational materials to their students regarding advance care directives and advance care planning on their official websites?
2. What type of materials are provided by institutions to address the completion of advance care directives among college students?
3. What major patterns exist among public institutions regarding the materials they provide to students on their official websites?
4. For institutions that do not provide information on their websites: how many four-year public institutions provide other resources regarding advance care directives?

Part II: Student Level Purpose Statement

The purpose of this study is to explore awareness levels, completion rates, and potential predictors of Advanced Care Directive completion among college students.

Methodology

Part I: Institutional Level

Sources of Information. The websites of four-year public institutions of higher education were used for this study. The list of institutions was obtained from the Carnegie Classification of Institutions of Higher Education's (CCIHE) publicly available, comprehensive database of all public and private higher education institutions. The initial list of 3,376 institutions was narrowed down using the codebook provided by the CCIHE. All private institutions were removed, leaving a remainder of 1,644 public institutions as the sample. This was done because provision of services are characteristically different between public and private institutions (United States Department of Education, 2016). Of the public institutions, 2 were found to be no longer open and were removed from the sample, leaving 1,642 institutions as the final sample.

Procedures. This part of the research did not require Institutional Review Board (IRB) approval because it did not involve human subjects. The CCIHE database was utilized to identify the names of the 1,642 public institutions in order to review and evaluate each institution's official website. On each institution's official website, the search utility was used to enter the following key words commonly associated with ACDs and ACP: "advance care directive," "advance care planning," "end of life care," "autonomy," and "gerontology." In addition, three search terms associated with the top three causes of death among college students were added. These include: "accident," "vehicular injury," and "binge drinking." If an institution's website did not have a

search utility, a thorough manual search of the website was conducted by looking for information in relevant online spaces. This includes information for incoming students, the health center, and the list of academic programs.

Measures. An Excel document was used to record the findings from each search, and a codebook was created to help characterize the general theme of each search. A “0” indicated no results; a “1” indicated results pertaining to public information students can use; a “2” indicated events pertaining to the term or phrase searched; a “3” indicated results pertaining to professors or programs offered; a “4” indicated results pertaining to emergencies, risk management, or reporting; and a “5” indicated results pertaining to the elderly. These themes are referred to as “No Results,” “Public Information,” “Events,” “Academia,” “Emergencies, Risk, and Reporting,” and “Elderly” in Table 1. When a search yielded multiple results, the researcher assigned that search to the number that best summarized the majority of the results.

Data Analysis. The data was analyzed using two basic Excel functions: COUNTIF and COUNTA. The COUNTIF function counts all cells that contain specific text. It was used to calculate the number of institutions that yielded a certain type of result for each search term. The COUNTA function counts all cells that are not empty. This function was used to calculate the number of terms that yielded results per institution, which provided a way to take inventory of the amount of information that institutions have available to their students. Institutions that yielded no results for all eight search terms were noted as having the least amount of public information available to their students. Those that had the greatest number of search terms that produced results were noted as having the greatest amount of public information available. Using the data, a deeper look was taken in order to characterize the public information available to students when they search “advance care directive” and “advance care planning” on institutions’ official websites.

Copies of these materials, along with the links that they were obtained from, were included in the appendix. These should serve as reference for other institutions to develop their own materials.

Part II: Student Level

Participants. As seen in Table 2, there were a total of 360 participants in the sample consisting of 88 freshmen (24.4%), 72 sophomores, (20.0%), 84 juniors (23.3%), 102 seniors (28.3%), and 14 other (3.9%). There were 289 females (80.3%), 65 males (18.1%), and 6 other (1.7%). The average age of participants was 20.09 years, and ranged from 19-32 ($M = 20.09$, $SD = 1.76$). The majority of participants identified as Caucasian (83.1%, $n = 299$). The most common religious preference was none (34.2%, $n = 123$), followed by Roman Catholic (18.3%, $n = 66$), Methodist (9.7%, $n = 35$), and equally by Baptist and Presbyterian (9.2%, $n = 33$). The response rate was 84.7%.

Procedures. Institutional Review Board (IRB) approval was obtained at JMU to conduct research. Data was collected from September 2018 to February 2019 by an anonymous survey. A bulk email was sent out to all JMU students containing a brief explanation of the study's purpose and a link to the Qualtrics survey. The researcher also used their personal social media accounts, specifically Facebook, Twitter, and Instagram, to post on their own accounts and JMU student organization pages requesting students to participate. Announcements were posted onto class Canvas pages requesting student participation. The researcher also used convenience sampling to recruit survey participants at the Student Success Center and the Quad. The survey was available on an iPad, provided by the researcher, for students to complete if they chose to. If students declined, they were thanked for their time. Upon survey completion, participants had the opportunity to be entered in a drawing to win a \$25 VISA gift card.

Measures. The survey used in this study contained 103 items with a mix of demographic questions, three pre-existing scales, and questions created by the researcher. The general demographic information collected from participants included: class standing, gender, race, and religion. Age, ethnicity, and religion were collapsed for the analysis. The Duke University Religion Index was used to measure religiosity by using a 3-item Likert scale and two multiple choice questions (Koenig & Büssing, 2010). For this scale, the lowest score a participant could receive was five and the highest was 27. Lower scores indicated lower levels of religiosity. The Death Anxiety Scale was used to identify general feelings of students regarding death by using a 17-item Likert scale (Templer, Lavoie, Chalgujian, & Thomas-Dobson, 1990). The range of possible scores for this scale was 17-85 with higher scores indicating higher levels of anxiety surrounding death. Four of the 32-subscales from the College Students Beliefs and Values Survey were used to identify a variety of beliefs and values held by college students (Astin, Astin, & Lindholm, 2003). The range of scores for the College Students Beliefs and Values Subscale were as follows: question 12 has a range of 17-68, question 13 has a range of 17-51, question 14 has a range of 4-12, and question 15 has a range of 28-140. Higher scores on the subscales indicate higher levels of beliefs and values in each subscale. The last three survey questions were used whether or not students have heard of ACPs, completed their own ACP, and registered as an organ donor. The scales and subscales used to create this survey have varying levels of internal consistency, question 12 having a Cronbach alpha of $\alpha = 0.332$, question 13 having a Cronbach alpha of $\alpha = 0.290$, question 14 having a Cronbach alpha of $\alpha = 0.563$, and question 15 with a Cronbach alpha of $\alpha = 0.834$. In its entirety, the survey took participants 10-15 minutes to complete (see Appendix A for survey).

Data Analysis. Data was analyzed using Statistical Package for the Social Science (SPSS) software system. The researcher evaluated demographic information, feelings towards death,

importance of certain statements, how often participants have participated in certain actions, self-evaluation of personality traits, and ACD completion questions. These variables were used to find relationships between knowledge of Advanced Care Directives and feelings on death and specific beliefs or values. One specific relationship that the researcher was interested in were the implications that personality characteristics had on knowledge of ACDs. Descriptive tests were used to determine the demographics of the sample population. An independent sample t-test was used to evaluate the relationship between knowledge of an ACD and items from the scales used. Chi-square tests were used to evaluate associations between ACD knowledge or completion and organ donation.

Results

Part I: Institutional Level

Search Inventory: The data reveals that the majority of four-year public institutions of higher education do not provide public information regarding ACDs and ACP (Table 1). There was plurality for no results when “advance care directive” (84.41%, n=1386), “advance care planning” (87.39%, n=1435), “end of life care” (76.25%, n=1252), “autonomy” (97.20%, n=1596), “accident” (72.35%, n=1188), “vehicular Injury”(93.06%, n=1528), and “binge drinking” (89.65%, n=1472) were searched. “Gerontology” is the only search term that received a high number of results that were almost evenly split between two different classifications: no results (53.39%, n=880) and academia (45.62%, n=749). The top search term with the greatest amount of public information available to students was “binge drinking” (8.40%, n=138), followed by “advance care directive” (7.49%, n=123) and “advance care planning” (3.35%, n=55).

Although the majority of institutions had no results for “advance care directive,” it still received positive results for academia (4.26%, n=70); emergencies, risk, and reporting (1.40%, n=23); events (1.28%, n=21); and elderly (1.16%, n=19). The term “advance care planning” also had a similar pattern. The majority of institutions produced no results, but it still received positive results for academia (4.69%, n=77); events (2.07%, n=34); emergencies, risk, and reporting (1.40%, n=23); and elderly (1.04%, n=17). Academia was the primary theme of positive results for the terms “end of life care” (17.90%, n=294) and “gerontology” (45.62%, n=749). Emergencies, risk, and reporting was the primary theme of positive results for the terms “accident” (24.91%, n=409) and “vehicular injury” (5.54%, n=91). The theme with the least number of results across all 8 search terms was elderly, with 0% return in the searches of “autonomy,” “gerontology,” “accident,” “vehicular injury,” and “binge drinking.”

Of the 1,642-institution sample, 569 (34.65%) had no positive results for any of the search terms; 980 (59.68%) had positive results for at least one, but no more than four of the search terms; and 93 (5.66%) had positive results for more than four of the search terms (Table 3). There were 3 (0.18%) institutions that had positive results for 7 of the 8 search terms; however, there were no institutions that had positive results for all 8 search terms. The institutions that had positive results for 7 of the 8 search terms are Boise State University, Eastern Illinois University, and Texas State University. Of the 1,642-institution sample, 1,393 (84.84%) had no public information for any of the 8 search terms; 247 (15.03%) had public information for at least one, but no more than four of the 8 search terms; and 2 (0.12%) had public information for more than four of the search terms (Table 4). There were 2 (0.12%) institutions that had public information for 5 of the 8 search terms; however, there were no institutions that had public information for 6 or more search terms. The

institutions that had results with public information for 5 of the 8 search terms were Texas State University and University of California-Berkeley.

ACD Materials Provided to Students Online: Institutions that had public information available to their students online often provided a list of patient rights and responsibilities. The University of Southern Mississippi, Penn State University-Altoona, University of Connecticut, North Carolina Agricultural and Technical State University, Winthrop University, Massachusetts College of Liberal Arts, and Salisbury University are just a few of the many institutions that provide this list to their students online. An example of The University of Southern Mississippi's patient rights and responsibilities can be found in Appendix C. The rights and responsibilities of their students appears to be an expanded list of that which was approved by the National Health Council. Many institutions format their lists in a bulleted style that includes institution-specific guidelines, such as the right "to refuse to receive care from a graduate trainee" (Appendix C).

Listing patient rights and responsibilities effectively communicates a wide variety of information; however, it does not provide in-depth information that specifically relates to ACDs. Institutions with more comprehensive information about ACDs and ACP included definitions of key terminology, external or internal resources, and explicit directions for how act. For instance, Northern Arizona University provides an overview of ACDs, an excerpt about why it is important to start planning now, resources with links to additional information, and detailed contact information for their Health and Learning Center (Appendix D). The official website of the Georgia Institute of Technology is very similar. In addition to basic information on ACDs and external references, their website also provides a detailed explanation of their Health Services policy and protocol (Appendix E). This provides students with a general idea of what to expect as well as what the Health Services staff can legally assist with.

Some of the most comprehensive resources found on public institutions' official websites; however, were of those that have a medical center or hospital associated with that particular institution. University of Missouri, Virginia Commonwealth University, Stony Brook University, University of Wisconsin, University of Washington, and The University of Alabama at Birmingham are among this list. The University of Missouri provides detailed descriptions of ACDs, living wills, durable power of attorney, and controversies of ACDs. The unique aspect of their website is that they also list situations and specific healthcare interventions that patients should consider when dictating their wishes (Appendix F). Virginia Commonwealth University and Stony Brook University are similar in that they address ACDs through a series of responses to frequently asked answers (Appendix G & H). Common questions between these two institutions' websites include: "What if I change my mind?" and "Where should I keep it after its signed?" Virginia Commonwealth University provides a comprehensive list of questions that a variety of audiences may have, such as those that are young, have children, are married, or have limited medical background knowledge (Appendix G).

Another helpful feature on Virginia Commonwealth University's website is a list that they provide including a number of national programs that exist to help with ACP. They provide external links to *Your Right to Decide*, *Advance Directive Tool Kit*, *Dying with Dignity: Medical Treatment*, *Caring Connections*, and *Five Wishes* among many others (Appendix G). The University of Alabama at Birmingham also links *The Conversation Project* (Appendix I). These national resources are specialized, comprehensive, and guaranteed to have the most accurate and up-to-date information regarding ACDs. With these resources available, institutions do not need to create new content for communicating with students about completing their ACDs and getting

involved in ACP. However, there are still a select few four-year public institutions that have employed their own resources to manage ACD awareness and completion.

Colorado State University stands out from others because of their Larimer Advance Care Planning Team (Appendix J). They provide free guidance for having these discussions with loved ones, expressing medical wishes in writing, and customizing life-sustaining treatments that the patient does and does not want (Appendix J). It is somewhat directed toward senior citizens, but they openly note that all services are available to individuals of at least 18 years of age. University of Minnesota, University of North Carolina-Charlotte, and Western Washington University also offer workshops for students to learn about ACP. The University of Minnesota's workshops are particularly interesting because they can be requested for a variety of different groups (Appendix K). It is an hour-long workshop that provides basic information on definitions, processes, and strategies for having difficult conversations. The workshop appears to be ongoing and can easily be requested through an online form.

The final four-year public institution that stands out among other is University of Maryland. Their University Health Center makes a direct statement to the parents of incoming students, suggesting that they consider discussing this topic with their students (Appendix L). The significance of this is that it is associating completing an ACD with starting college. During a student's time at an institution of higher education, they will inevitably turn 18 and need to start making decisions for themselves as an adult. This is especially true for healthcare decisions. When an individual is 18 or older, they no longer need permission from parents or guardians to receive medication or procedures. More importantly, that individual becomes the primary contact for relaying important medical information to the patient, With this new sense of autonomy and independence, students will need to take charge of their healthcare decisions. By associating the

completion of an ACD with other necessary action steps, the University of Maryland is at the very least providing an opportunity for parents and guardians to initiate this conversation with students.

Major Patterns: Based on existing literature, there was a high suspicion that most online information available to students would be geared toward elderly populations or students that are studying to enter a field that will primarily work with this population. Of the institutions that provided online information, many emphasized the necessity of ACDs and ACP for individuals that need to think about end-of-life care decisions. However, it was also extremely common for institutions to note the importance of planning ahead and starting conversations about end-of-life well before it becomes a true concern. This was done by noting that all individuals of at least 18 years of age are capable of and responsible for the completion of their own ACD. When “advance care directive” and “advance care planning” were searched, the number of institutions that had positive results with an overarching theme that pertained to the elderly were small (Table 1). This reveals that the number of institutions that provided no information is significantly higher than that of those that provided information geared toward the elderly. Another major pattern was the lack of information on patient autonomy (97.20%, n=1596) and the top three causes of death among students: accidents (72.35%, n=1188), vehicular injury (93.06%, n=1528), and binge drinking (89.65%, n=1472).

Part II: Student Level

There were 360 students who completed this survey. Demographic characteristics of the sample can be found in Table 2. Participants represented all years of school offered at JMU, 80.3% identified as female, the average age was 20.09 years, 83.1% identified as Caucasian, and the most

common religious practice was identified as none. 71.9% of participants identified themselves as organ donors, 26.9% have heard of ACP, and 5.0% have completed an ACP.

A chi-square test for association was conducted between organ donation and ACP completion. Participants who identify as organ donors were more likely to have a completed ACP ($\chi^2(1, N = 360) = 18.379, p < .05$). A chi-square test for association was conducted between organ donation and ACP knowledge. Participants who identify as organ donors were more likely to have knowledge of ACP ($\chi^2(1, N = 360) = 4.752, p < .05$).

An independent sample t-test was run to determine if there were differences in knowledge of Advanced Care Planning and average individual score for the Death Depression Subscale. According to Table 5, there was a lower score of depression surrounding the idea of death for those who have heard of Advanced Care Planning ($M = 44.82, SD = 8.283$) than those who have not heard of Advanced Care Planning ($M = 46.93, SD = 9.797$); ($t(358) = -1.880, p = 0.061$). Both of these were not statistically significant. An independent sample t-test was run to determine if there were differences in knowledge of Advanced Care Planning Knowledge and the average individual score on the College Beliefs and Values subscales. There was a higher average score for those who had not heard of Advanced Care Planning ($M = 56.25, SD = 4.884$) than those who have heard of Advanced Care Planning ($M = 53.29, SD = 4.587$); ($t(358) = -5.189, p = .664$ (Table 6). Both of these were not statistically significant.

Discussion

Part I: Institutional Level

The results demonstrate that there is a significant lack of public information available to students on public institutions' official websites. There was plurality for no results for 7 of the 8

search terms, including “advance care directive” (84.41%, n=1386) and “advance care planning” (87.39%, n=1435). Of the 1,642-institutions sample, 569 (34.65%) institutions had no positive results and 1,393 (84.84%) institutions had no public information, for any of the 8 search terms. This can have major implications for students who rely on their institutions for accurate information and guidance. Although existing literature indicates that medical staff and health educators are being underutilized for health information, these professionals have extremely high trust ratings among college-aged populations (Vader et al., 2011). This demonstrates that students believe they are receiving highly accurate and reliable information from their institutions. However, a lack of information on institutions’ official websites is indicative of the institution’s own lack of awareness and understanding of ACDs.

It is common for health centers to list their services online in order to make students aware of the tests, procedures, vaccinations, and other resources they can obtain there. The fact that ACDs are not mentioned on 1,386 institutions’ official websites suggests a much larger problem at hand. These institutions do not actively educate or raise awareness regarding the importance of ACDs, let alone advertise that they are legally able to assist students in completing these documents. At a minimum, many institutions with information available to students online included a list of Patient Rights and Responsibilities. Providing this list ensures that students are aware of what resources are available to them as well as what expectations there are of them (National Health Council, 2016). The average student at an institution of higher education will either already be of legal age to make personal health care decisions, or come of legal age during their enrollment. This is important because young students may not be aware of these rights and responsibilities.

The institutions that do not currently provide information to their students regarding ACDs and ACP should take note of the ways in which other institutions have chosen to present this

information. Although Virginia Commonwealth University has access to their own medical center, they linked external resources to national programs in order to provide the most accurate information to their students. Employing this technique may be particularly beneficial for the institutions that do not have access to specialized centers, programs, or personnel dedicated to ensuring the awareness and completion of these documents. External resources that have been noted in existing literature as particularly beneficial for increasing patient awareness and adolescent readiness include *Five Wishes* and *Voicing My Choices* (Splendore & Grant, 2017; Thaelke, 2018; Wiener et. al 2008; Wiener et al., 2012; Zadeh, Pao, & Wiener, 2015).

Public institutions can also look to Colorado State University, the University of Minnesota, and the University of Maryland for guidance in developing materials that will best serve college students. These institutions are redefining standard for advance care planning and can offer a certain degree of foresight to those that are interested in following suit. Although many colleges only require medical histories from students (Kapp, 2000), University of Maryland has incorporated a unique method that introduces ACDs to incoming students. ACD completion is not required; however, University of Maryland encourages parents and guardians of incoming students to initiate these conversations prior to the student's arrival on campus. Pre-existing studies suggested that a lack of information regarding ACP created barriers for engaging in ACD completion (Kavalieratos, Ernecoff, Keim-Malpass, & Degenholtz, 2015). By initiating these conversations at the onset of adulthood (age 18), University of Maryland has high potential to increase student awareness of, and engagement in, advance care planning.

A common theme among information available to students was the emphasis on planning ahead and engaging in the ACP process as early as possible. Regardless of a patient's age, these documents promote patient autonomy; direct end-of-life care wishes; alleviate stress for the

patient, family members, and health care providers; and identify trusted individuals that may execute medical decisions on the patient's behalf (Hinders, 2012; Humphrey & Dell, 2015; Sudore et al., 2013). At the age of 18, adulthood begins and individuals are fully responsible for their own medical decisions. Institutions that acknowledge this important change in students' lives are better preparing them for future situations where end-of life decisions must be made. In turn, this may enhance students' comfortability and familiarity with the subject, which would reduce the worry and inhibition that health care providers experience when engaging patients in these conversations (Coleman, 2013; Ohad & Aya, 2016; Peng, 2015; Woodlen & Bakken, 2016).

Overall, the results of this search inventory demonstrate a significant lack of information and resources available to students, which calls for a greater level of awareness and understanding among individuals working in student affairs. The official websites of Colorado State University, the University of Minnesota, Virginia Commonwealth University, the University of Maryland, and any other cited in the appendix, are excellent models for institutions that currently do not provide any information to their students regarding advance care planning.

Limitations: One of the primary limitations for this study was the lack of prior research regarding the amount and type of information available on four-year public institutions' official websites. Without any prior literature exploring this issue, it was difficult to determine the best methods for measuring these variables in order to make broad conclusions about how this translates to the lack of awareness and completion of ACDs among college students. Furthermore, there was only one individual conducting research and creating this inventory, which may have led to observer error. Future research should have multiple individuals checking others' findings.

Suggestions for Future Research: Future studies should focus on characterizing all of the search results in order to obtain a more in-depth assessment of all resources that are available at

four-year public institutions. Although it was not the purpose of this study, it would also be beneficial to conduct similar research among the official websites of four-year private institutions. This will help determine any differences that exist between these types of institutions and may lead to a deeper understanding of the information and services available to students. In addition, it would be valuable for future studies to perform a more detailed qualitative analysis that can evaluate the information available on a deeper level. Due to limitation of expertise among the researchers, this inventory is not able to provide information regarding the validity or accuracy of the information available. This should be done in future studies by a team of professionals with extensive knowledge or experience in handling ACDs and ACP. Finally, it should be determined how many students at institutions with more information provided have completed their ACDs compared to those at institutions where information is not provided. This research would reveal potential relationships that exist between provision of resource and ACD completion.

Part II: Student Level

While research begins to emerge focusing on the college-aged population, there is still not enough information to fully understand why this group chooses not to complete ACPs. The instruments used to compile this survey were aimed at identifying beliefs and values that would influence college students' level of completion or knowledge of these forms. The findings indicate that having knowledge of an ACP increases the likelihood of preparedness to have the conversation about end-of life decision and ACP. It was determined that only 29.6% of participants had heard of ACP and only 5% have actually completed an ACP. Lack of knowledge and completion is consistent with recent studies looking at the readiness of college students to complete these forms (Schnur & Radhakrishnan, 2019; Tripken & Elrod, 2018). Major reasons for why this population

do not complete ACPs can be lack of knowledge or awareness, not having conversations about end-of life with family, friends, or physicians, and lack of readily available resources (Kavalieratos, Ernecoff, Keim-Malpass, & Degenholtz, 2015; Schnur & Radhakrishnan, 2019; Tripken & Elrod, 2018). The Death Depression Scale and one subscale of the College Students Beliefs and Values Survey were selected to further analyze in conjunction with knowledge of ACP. The other subscales were omitted for analysis due to lack of variation in average scores for knowledge of ACP and the listed items.

The Death Depression Scale highlighted that knowledge of ACP decreased the overall score received when the scale was completed, indicating that concepts surrounding the negative connotations of death were increased when an ACP was not considered or completed. While there is a lack of research surrounding this topic, a majority of cross-generational ACP completion results in lack of personal knowledge or untrained health professionals which can lead to the higher levels of depression surrounding the topic of death (Connell & Mallory, 2007; Kavalieratos et al., 2015). The subscale selected from the College Beliefs and Values Scale highlighted various factors including artistic orientation and social activism. Those who have heard of Advanced Care Planning on average scored lower in these categories than those who have not. It is unclear due to lack of research as to why this is.

However, there was an association found when comparing ACP knowledge and Organ Donation. The findings of this analysis reflect an earlier study completed by Thornton, Curtis, and Allen (2006) showing an increase in likelihood of discussion regarding end of life care when a patient is a registered organ donor. Making the decision to be an organ donor is one part of the Advanced Care Planning process, so whether individuals are viewing this decision as a stand-alone end of life decision or as part of their ACP it is an important step to starting the conversation.

Identifying oneself as an organ donor and scoring lower on the Death Depression Scale are two major predictors of Advanced Care Directive knowledge.

Limitations: One main limitation for this study was lack of prior research regarding Advanced Care Planning and college students. Having more specific research would have provided more guided survey questions. Another limitation was length of the survey. A shorter survey could have increased the response rate. James Madison University has limited public information available regarding Advanced Care Planning for students, as seen in the Institutional level section, therefore different results could be obtained if this was conducted at an institution with more student access to information to Advanced Care Planning. Another major limitation of this survey was the overall sample size. With a larger sample size, other statistical analyzes could have been run to determine if trends were significant. Also, finding more students with completed ACPs and having equal groups would help to detect possible significant differences.

Suggestions for Future Research: In the future, a focus group could be used to discuss the topics that were covered in the survey. Conducting a focus group will allow elaboration on specific topics regarding survey contact to provide more guided and specific information for future surveys. Another approach that could be taken for this survey is to assess feelings regarding ACP completion and ethical beliefs and values. Drawing on ethics could require individuals to focus on how their decisions not only impact themselves, but others, which is an important factor in ACP. The last major suggestion for future research is having a larger sample size. Many tests showed trends towards significance and a larger sample size, especially more students who completed ACPs, would help to identify more specific beliefs and values.

Conclusion

Both parts of this study indicate that there is a significant lack of awareness and completion of ACDs among college-aged students. The results of this study can provide insight into understanding why college-aged populations do not complete ACDs based on the information provided to them and their personal beliefs and values. In general, knowledge of ACP decreases the likelihood for negative feelings surrounding death. Students who identified themselves as organ donors showed an increased knowledge of advance care planning. If higher education institutions require the completion of ACD, then those communities may be better equipped to address the most common causes of death among college-aged populations.

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Table 1

Public Institution Search Inventory (n=1642)

Results	No Results	Public Information	Events	Academia	Emergency, Risk, Reporting	Elderly
Advance Care Directive	1386 (84.41%)	123 (7.49%)	21 (1.28%)	70 (4.26%)	23 (1.40%)	19 (1.16%)
Advance Care Planning	1435 (87.39%)	56 (3.41%)	34 (2.07%)	77 (4.69%)	23 (1.40%)	17 (1.04%)
End of Life Care	1252 (76.25%)	30 (1.83%)	52 (3.17%)	294 (17.90%)	7 (0.43%)	7 (0.43%)
Autonomy	1596 (97.20%)	13 (0.79%)	2 (0.12%)	31 (1.89%)	0 (0%)	0 (0%)
Gerontology	880 (53.59%)	0 (0%)	13 (0.79%)	749 (45.62%)	0 (0%)	0 (0%)
Accident	1188 (72.35%)	11 (0.67%)	5 (0.30%)	29 (1.77%)	409 (24.91%)	0 (0%)
Vehicular Injury	1528 (93.06%)	6 (0.37%)	8 (0.49%)	9 (0.55%)	91 (5.54%)	0 (0%)
Binge Drinking	1472 (89.65%)	138 (8.40%)	16 (0.97%)	13 (0.79%)	3 (0.18%)	0 (0%)

Table 2

Demographic Characteristics (n=360)

Characteristic	N	%
Gender		
Male	65	18.1
Female	289	80.3
Other	6	1.7
Class Standing		
Freshman	88	24.4
Sophomore	72	20.0
Junior	84	23.3
Senior	102	28.3
Other	14	3.9
Age		
18	67	18.6
19	82	22.8
20	60	16.7
21	96	26.7
22	42	11.7
23+	13	3.8
Ethnicity		
African American	11	3.1
Asian	14	3.9
Caucasian	299	83.1
Hispanic	21	5.8
Other	10	2.8
Prefer Not to Answer	5	1.4
Religious Preference		
Baptist	33	9.2
Methodist	35	9.7
Presbyterian	33	9.2
Roman Catholic	66	18.3
Non-Denominational/Christian	19	5.3
Other	42	11.7
None	123	34.2
Prefer Not to Answer	9	2.5

Table 3

Number of Positive Search Results Per Institution (n=1642)

Results	N	%
0	569	34.65%
1	432	26.31%
2	280	17.05%
3	157	9.56%
4	112	6.82%
5	68	4.14%
6	21	1.28%
7	3	0.18%
8	0	0%

Table 4

Number of Results Containing Public Information Per Institution (n=1642)

Results	N	%
0	1393	84.84%
1	160	9.74%
2	60	3.65%
3	22	1.34%
4	5	0.30%
5	2	0.12%
6	0	0%
7	0	0%
8	0	0%

Table 5

Average Sums of Death Anxiety Subscale (DAS) and knowledge of Advanced Care Planning (n=360)

	Knowledge of ACP	n	M	SD
Average Sum of DAS	Yes	97	44.82	8.283
	No	263	46.93	9.797

Table 6

Average sums of College Beliefs and Values (CBVS) subscale and knowledge of Advanced Care Planning (n=360)

	Knowledge of ACP	n	M	SD
Average Sum of CBVS	Yes	97	53.26	4.587
	No	263	56.25	4.884

Appendix A

Please circle one answer choice per question or answer on the line provided when applicable.

1. Full cover letter included here.
 - a. I give consent
 - b. I do not give consent
2. Are you a JMU student?
 - a. Yes
 - b. No
3. Please select your current class standing
 - a. Freshman
 - b. Sophomore
 - c. Junior
 - d. Senior
 - e. Graduate Student
 - f. Other (please specify): _____
4. What is your age (in years)? _____
5. What is your gender? _____
6. Please select your ethnicity
 - a. African American
 - b. American Indian/Alaskan Native
 - c. Asian
 - d. Caucasian
 - e. Hawaiian/Pacific Islander
 - f. Hispanic
 - g. Other (please specify): _____
 - h. Prefer not to answer
7. Your current religious preference:
 - a. Baptist
 - b. Buddhist
 - c. Eastern Orthodox
 - d. Episcopalian
 - e. Hindu
 - f. Islamic
 - g. Jewish
 - h. LDS (Mormon)
 - i. Lutheran
 - j. Methodist
 - k. Presbyterian
 - l. Quaker
 - m. Roman Catholic
 - n. Seventh Day Adventist
 - o. Unitarian Universalist
 - p. United Church of Church of Christ

- q. Other (please specify): _____
 - r. None
 - s. Prefer not to answer
8. How often do you attend church or other religious meetings?
- a. Never
 - b. Once a year or less
 - c. A few times a year
 - d. A few times a month
 - e. Once a week
 - f. More than once/week
9. How often do you spend time in private religious activities, such as prayer, meditation, or Bible study?
- a. Rarely or never
 - b. A few times a month
 - c. Once a week
 - d. Two or more times/week
 - e. Daily
 - f. More than once a day
10. The following section contains 3 statements about religious belief or experience. Please mark the extent to which each statement is true or not true for you.
- 1 = Definitely not true
 - 2 = Tends not to be true
 - 3 = Unsure
 - 4 = Tends to be true
 - 5 = Definitely true

In my life, I experience the presence of the Divine (i.e. God)	1	2	3	4	5
My religious beliefs are what really lie behind my whole approach to life.	1	2	3	4	5
I try hard to carry my religion over into all other dealings in life.	1	2	3	4	5

11. Please read the following statements and then circle the number of response that best describes how you feel about the item as follows:
- 1 = Strongly Disagree
 - 2 = Disagree
 - 3 = Neutral
 - 4 = Agree
 - 5 = Strongly Agree

1. I get depressed when I think about death.	1	2	3	4	5
2. Hearing the word death makes me sad.	1	2	3	4	5
3. Passing by cemeteries makes me sad.	1	2	3	4	5
4. Death means terrible loneliness.	1	2	3	4	5
5. I become terribly sad when I think about friends or relatives who have died.	1	2	3	4	5
6. I am terribly upset by the shortness of life.	1	2	3	4	5
7. I cannot accept the finality of death.	1	2	3	4	5
8. Death deprives life of its meaning.	1	2	3	4	5
9. I worry about dying alone.	1	2	3	4	5
10. When I die, I will completely lose my friends and loved ones.	1	2	3	4	5
11. Death does not rob life of its meaning.	1	2	3	4	5
12. Death is not something to be depressed by.	1	2	3	4	5
13. When I think of death, I feel tired and lifeless.	1	2	3	4	5
14. Death is painful.	1	2	3	4	5
15. I dread to think of the death of friends and loved ones.	1	2	3	4	5
16. Death is the ultimate failure in life.	1	2	3	4	5
17. I feel sad when I dream of death.	1	2	3	4	5

12. Please indicate the importance to you personally of each of the following:

(Mark one for each)

E = Essential

V = Very Important

S = Somewhat Important

N = Not Important

Becoming accomplished in one of the performing arts (acting, dancing, etc.)	E	V	S	N
Being an authority in my field	E	V	S	N
Influencing the political structure	E	V	S	N

Influencing social values	E	V	S	N
Raising a family	E	V	S	N
Being very well off financially	E	V	S	N
Helping others who are in difficulty	E	V	S	N
Making a theoretical contribution to science	E	V	S	N
Writing original works (poems, novels, short stories, etc.)	E	V	S	N
Creating artistic works (painting, sculpture, decorating, etc.)	E	V	S	N
Becoming successful in a business of my own	E	V	S	N
Becoming involved in programs to clean up the environment	E	V	S	N
Developing a meaningful philosophy of life	E	V	S	N
Participating in a community action program	E	V	S	N
Helping to promote racial understanding	E	V	S	N
Becoming a community leader	E	V	S	N
Integrating spirituality into my life	E	V	S	N

13. Since entering college, please indicate how often you have: (Mark one for each)

F = Frequently

O = Occasionally

N = Not at All

Participated in community food or clothing drives	F	O	N
Helped at local houses of worship	F	O	N
Performed other volunteer work	F	O	N
Helped friends with personal problems	F	O	N
Donated money to charity	F	O	N
Felt angry with God	F	O	N
Felt loved by God	F	O	N
Struggles to understand evil, suffering, and death	F	O	N

Questioned you religious/spiritual beliefs	F	O	N
Spent time with people who share your religious views	F	O	N
Felt that your life is filled with stress and anxiety	F	O	N
Been able to find your meaning in times of hardship	F	O	N
Expressed gratitude to others	F	O	N
Felt at peace/centered	F	O	N
Explored religion online	F	O	N
Found my new meaning in the rituals and practices of my religion	F	O	N
Attended a class/workshop or retreat on matters related to religion/spirituality	F	O	N

14. Please indicate the extent to which you engage in the following activities:

(Mark one for each item)

3 = To A Great Extent

2 = To Some Extent

1 = Not at All

Searching for meaning/purpose in life	3	2	1
Tring to change things that are unfair in the world	3	2	1
Accepting others as they are	3	2	1
Having discussions about the meaning of life with my friends	3	2	1

15. Rate yourself on each of the following traits as compared with the average person your age. We want the most accurate estimate of how you see yourself. (Mark one for each item)

5 = Highest 10%

4 = Above Average

3 = Average

2 = Below Average

1 = Lowest 10%

Altruism	5	4	3	2	1
Compassion	5	4	3	2	1
Cooperativeness	5	4	3	2	1

Courage	5	4	3	2	1
Creativity	5	4	3	2	1
Dependability	5	4	3	2	1
Drive to achieve	5	4	3	2	1
Emotional health	5	4	3	2	1
Empathy	5	4	3	2	1
Forgiveness	5	4	3	2	1
Generosity	5	4	3	2	1
Gratefulness	5	4	3	2	1
Helpfulness	5	4	3	2	1
Humility	5	4	3	2	1
Kindness	5	4	3	2	1
Leadership ability	5	4	3	2	1
Loyalty	5	4	3	2	1
Open-mindedness	5	4	3	2	1
Patience	5	4	3	2	1
Physical health	5	4	3	2	1
Religiousness/religiosity	5	4	3	2	1
Respectfulness	5	4	3	2	1
Self-awareness	5	4	3	2	1
Self-confidence (intellectual)	5	4	3	2	1
Self-confidence (social)	5	4	3	2	1
Self-understanding	5	4	3	2	1
Spirituality	5	4	3	2	1
Understanding of others	5	4	3	2	1

16. Are you an organ donor?
- Yes
 - No
 - Prefer not to answer
 - I don't know
17. Have you ever heard of Advance Care Planning?
- Yes
 - No
 - Prefer not to answer
 - I don't know
18. Have you ever completed an Advance Care Plan?
- Yes
 - No
 - Prefer not to answer
 - I don't know

Appendix B

Retrieved from <http://www.nationalhealthcouncil.org/resources/nhc-publications/principles-patients-rights-and-responsibilities>



Principles of Patients' Rights and Responsibilities

Principles of Patients' Rights and Responsibilities was developed and approved by the National Health Council Board of Directors, January 1995

1. ALL PATIENTS HAVE THE RIGHT TO INFORMED CONSENT IN TREATMENT DECISIONS, TIMELY ACCESS TO SPECIALTY CARE, AND CONFIDENTIALITY PROTECTIONS.

Patients should be treated courteously with dignity and respect. Before consenting to specific care choices, they should receive complete and easily understood information about their condition and treatment options. Patients should be entitled to: coverage for qualified second opinions; timely referral and access to needed specialty care and other services; confidentiality of their medical records and communications with providers; and, respect for their legal advanced directives or living wills.

2. ALL PATIENTS HAVE THE RIGHT TO CONCISE AND EASILY UNDERSTOOD INFORMATION ABOUT THEIR COVERAGE.

This information should include the range of covered benefits, required authorizations, and service restrictions or limitations (such as on the use of certain health care providers, prescription drugs, and "experimental" treatments). Plans should also be encouraged to provide information assistance through patient ombudsmen knowledgeable about coverage provisions and processes.

3. ALL PATIENTS HAVE THE RIGHT TO KNOW HOW COVERAGE PAYMENT DECISIONS ARE MADE AND HOW THEY CAN BE FAIRLY AND OPENLY APPEALED.

Patients are entitled to information about how coverage decisions are made, i.e., how "medically necessary" treatment is determined, and how quality assurance is conducted. Patients and their family caregivers should have access to an open, simple, and timely process to appeal negative coverage decisions on tests and treatments they believe to be necessary.

4. ALL PATIENTS HAVE THE RIGHT TO COMPLETE AND EASILY UNDERSTOOD INFORMATION ABOUT THE COSTS OF THEIR COVERAGE AND CARE.

This information should include the premium costs for their benefits package, the amount of any patient out-of-pocket cost obligations (e.g., deductibles, copayments, and additional premiums), and any catastrophic cost limits. Upon request, patients should be informed of the costs of services they've been rendered and treatment options proposed.

5. ALL PATIENTS HAVE THE RIGHT TO A REASONABLE CHOICE OF PROVIDERS AND USEFUL INFORMATION ABOUT PROVIDER OPTIONS.

Patients are entitled to a reasonable choice of health care providers and the ability to change providers if dissatisfied with their care. Information should be available on provider credentials and facility accreditation reports, provider expertise relative to specific diseases and disorders, and the criteria used by provider networks to select and retain providers. The latter should include information about whether and how a patient can remain with a provider who leaves or is not part of a plan network.

6. ALL PATIENTS HAVE THE RIGHT TO KNOW WHAT PROVIDER INCENTIVES OR RESTRICTIONS MIGHT INFLUENCE PRACTICE PATTERNS.

Patients also have the right to know the basis for provider payments, any potential conflicts of interest that may exist, and any financial incentives and clinical rules (e.g., quality assurance procedures, treatment protocols or practice guidelines, and utilization review requirements) which could affect provider practice patterns.

ALL PATIENTS, TO THE EXTENT CAPABLE, HAVE THE RESPONSIBILITY TO:*

1. PURSUE HEALTHY LIFESTYLES.

Patients should pursue lifestyles known to promote positive health results, such as proper diet and nutrition, adequate rest, and regular exercise. Simultaneously, they should avoid behaviors known to be detrimental to one's health, such as smoking, excessive alcohol consumption, and drug abuse.

2. BECOME KNOWLEDGEABLE ABOUT THEIR HEALTH PLANS.

Patients should read and become familiar with the terms, coverage provisions, rules, and restrictions of their health plans. They should not be hesitant to inquire with appropriate sources when additional information or clarification is needed about these matters.

3. ACTIVELY PARTICIPATE IN DECISIONS ABOUT THEIR HEALTH CARE.

Patients should seek, when recommended for their age group, an annual medical examination and be present at all other scheduled health care appointments. They should provide accurate information to providers regarding their medical and personal histories, and current symptoms and conditions. They should ask questions of providers to determine the potential risks, benefits, and costs of treatment alternatives. Where appropriate, this should include information about the availability and accessibility of experimental treatments and clinical trials. Additionally, patients should also seek and read literature about their conditions and weigh all pertinent factors in making informed decisions about their care.

4. COOPERATE ON MUTUALLY ACCEPTED COURSES OF TREATMENT.

Patients should cooperate fully with providers in complying with mutually accepted treatment regimens and regularly reporting on treatment progress. If serious side effects, complications, or worsening of the condition occur, they should notify their providers promptly. They should also inform providers of other medications and treatments they are pursuing simultaneously.

**It is recognized that some patients may suffer significant physical and/or mental conditions which may limit their ability to fulfill these responsibilities.*

Appendix C

Retrieved from <https://www.usm.edu/student-health-services/patient-rights-and-responsibilities>



Patient Rights and Responsibilities

The University of Southern Mississippi Student Health Service Patient Rights and Responsibilities

As one of our patients, you have certain rights and responsibilities.

You have the right...

- To be treated with dignity, consideration, and respect
- To know the names and professional/malpractice status of people serving you
- To privacy to the best of our ability
- To confidentiality of your records
- To receive accurate information to the extent known about your health-related concerns
- To know the effectiveness, possible side effects, and problems of all forms of treatment
- To participate in choosing a form of treatment
- To receive education and counseling
- To select and/or change your health care provider
- To choose who your medical information is shared with
- To review your medical records with a clinician
- To receive information about services and any related costs
- To develop an advanced directive
- To refuse to participate in experimental research
- To refuse to receive care from a graduate trainee

You also have the responsibility...

- To be respectful of all health care providers, staff and other patients
- To inform your provider about any living will or advance directive
- To accept financial responsibility for charges not covered by insurance
- To seek medical attention promptly
- To be honest about your medical history
- To ask about anything you do not understand
- To follow health advice and medical instructions
- To provide a responsible adult to transport you home from this facility and remain with you for 24 hours if required by your provider
- To report any significant changes in symptoms or failure to improve
- To respect clinic policies
- To keep appointments or cancel in advance
- To seek nonemergency care during regular office hours
- To provide useful feedback about services and policies
- If you have suggestions, concerns, or questions to report them

Appendix D

Retrieved from <https://nau.edu/campus-health-services/advance-directives/>

Overview of Advance Directives

Advance directives are legal documents that allow you to state your personal healthcare decisions about end-of-life care in advance. This may not be a topic many of us think about or talk about, but it is definitely important for people of all ages to know about. While you cannot predict the future, you do have the power to make your healthcare choices heard and help your loved ones understand your values and preferences regarding your medical care.

An advance directive allows you to clearly communicate your personal healthcare wishes for times when you are unable to speak for yourself. As a legal document, it should be placed on file with your healthcare provider. Your advance directive provides information that will help your healthcare provider and loved ones know how to make decisions for you that match what matters most to you. This information can include:

- Person(s) you want to make your healthcare decisions for you
- Medical treatment you want or do not want
- How comfortable you want to be kept
- Instructions on life-sustaining treatments
- Organ donation wishes

Starting an Advance Directive

While it may be hard to know when the "right time" to write an advance directive is, there is never a wrong time to start planning. This can be a conversation with your loved ones and healthcare provider or a personal thought process.

To get started, you may begin by learning more about "end-of-life" choices. It is helpful to inform yourself about the issues and the options prior to a discussion with your healthcare provider. Resources on hospice, long-term care options, and documentation needs unique to your state are available to help you, as well as those you care about and those who care about you, with advance care planning.

"I have an advance directive, not because I have a serious illness, but because I have a family" –Ira Byock, MD

Resources

Arizona Secretary of State website: <https://azsos.gov/services/advance-directives>

Arizona Attorney General website: <https://www.azag.gov/seniors/life-care-planning>

Caring Info

website: <http://www.caringinfo.org/files/public/ad/Arizona.pdf>

Campus Health Services



Location

Building 25
Health and Learning Center
824 South San Francisco Street
Flagstaff, Arizona 86011

Mailing Address

824 South San Francisco Street
Flagstaff, Arizona 86011

[Contact Form »](#)

Email

campushealth@nau.edu

Phone

[928-523-2131](tel:928-523-2131)

Fax

[928-523-4411](tel:928-523-4411)

Social Media



Appendix E

Retrieved from <https://health.gatech.edu/advance>

Advance Directives: Your Right To Decide



What is the 'Georgia Advance Directive For Health Care'?

The 'Georgia Advance Directive For Health Care' is a legal document that you complete. It tells your doctor and your healthcare providers your written instructions about your future medical care in the event you become unable to speak for yourself.

As of July 1, 2007, the Georgia Advance Directive for Healthcare has replaced the Georgia laws on the Living Will and the Durable Power of Attorney for Healthcare. This document combines the characteristics of both the living will and the durable power of attorney for healthcare and still allows people to choose for themselves the medical care they want when they are no longer able to communicate with doctors or family. Those persons who already had living wills and/or durable powers of attorney for healthcare are allowed to keep the forms that they have and they are still legally binding until they are revoked. The Durable Power of Attorney for Healthcare was repealed or removed from the law and the Living Will law was completely rewritten and replaced.

The changes by the 2007 Georgia General Assembly were made to reduce confusion, inconsistency, out-of-date terminology and confusing and inconsistent requirements for execution as well as to follow trends set by other states to combine the concepts of the living will and healthcare agency into a single legal document.

Do I need Georgia Advance Directive for Healthcare?

No but an Advance directive give you a voice in decisions about your medical care when you are unable to do so. As long as you are able to express your own decisions, your advance directives will not be used.

Do I need a lawyer to complete an advance directive?

No. The form provided is legal in Georgia if the directions on the form are followed.

What is Stamps Health Services policy about advance directives?

Stamps Health Services recognizes that adults should consider end of life decisions and make responsible arrangements for this purpose. All competent adults (18 years or older) presenting to SHS with advance directives will be assisted by a staff member who will copy the advance directive and scan it into the EHR, and return the original form to the patient.

- The patient is responsible for informing his/her provider about any living will, medical power of attorney, or other directive that could affect his/her care.
- An appointment to discuss the advance directives with the Director, Primary Care will be scheduled.
- At that visit, the patient will be informed that in the event of a life-threatening medical emergency, the role of the SHS will be to render emergency medical care and to arrange transport of the patient, along with a copy of the advance directives and other materials in the medical record as indicated, to the appropriate medical facility.
- The patient will be given a copy of the SHS policy regarding Advance Directives and will be given a form to sign, which is witnessed and dated by the Director, Primary Care, indicating that the patient understands and has received a copy of the policy.
- A notation on the alert section of patient record will show that a copy of the advanced directives has been scanned in EHR.
- An Advance Directive for Health Care may be revoked at any time by writing a clear statement expressing the intent to revoke the advance directive or by orally expressing the intent to revoke the advance directive in the presence of a witness. The revocation is effective when a provider documents it in the EHR.
- Stamps Health Services staff MAY NOT sign as a witness to any of these documents.

Can I change my mind after I write an advance directive?

You may change or cancel your advance directive at any time. This means you can change the terms or change your agent for health care decisions. To change your advance directive, tear up the original advance directive and complete a new form, have it signed and witnessed.

How do I get my Georgia Advance Directive for Healthcare?

Click [HERE](#) for a copy of the Georgia Advanced Directive.

Need Assistance?

- Call us at (404) 894-1420
- [Schedule an appointment online](#)
- Use our [online support form](#)
- [After Hours Care](#)

Want to get our monthly newsletter? [Click here to sign up.](#)

[→](#) Visit the contact page

[Resources](#)

Appendix F

Retrieved from https://medicine.missouri.edu/centers-institutes-labs/health-ethics/faq/advance-directives?_ga=2.66358182.906146570.1551563731-176985452.1551563729

Center for Health Ethics

ADVANCE DIRECTIVES AND SURROGATE DECISION MAKING

[Home](#) / [Centers, Institutes & Labs](#) / [Center for Health Ethics](#) / [Ethics FAQ](#) / [Advance Directives and Surrogate Decision Making](#)

Introduction:

A person who is severely ill or injured may be unable to communicate about medical treatment he or she would wish to receive or decline. Advance directives are written statements prepared ahead of time that allow caregivers to know of a patient's wishes for treatment or that legally specify an alternate decision maker should the patient lose decision-making capacity.

Advance directives sound like a good idea, but they are controversial. Controversy includes such matters as whether advance directives create more confusion than clarity about a patient's wishes, whether they can always be taken as expressing the true desires of a patient, and whether healthcare staff should always follow them.

Types of Advance Directive

The phrase "advance directive" is used to refer to different kinds of document. There are two basic types: the living will and the durable power of attorney for healthcare.

In a living will a person specifies whether to receive or not receive interventions and treatments if they are needed at a future time but the person is incapacitated and unable to explicitly consent or refuse at that time. Other names for a living will are "medical living will" and "medical healthcare directive." Living wills are usually witnessed but are not always notarized.

A durable power of attorney for healthcare may also be called a "medical power of attorney" or "healthcare power of attorney." This document, which should be notarized, designates a proxy or surrogate to act as a decision maker for your care and treatment in the event you are incapacitated by illness or injury and unable to communicate your wishes. The patient is advised to thoroughly discuss intervention and treatment preferences with the surrogate decision-maker before their services are needed.

Legal Status of Advance Directives

Typically upon admission hospitals will ask the patient if there is a living will. If there is not, the hospital may offer the patient a living will form to complete.

If the patient has a living will, creating several copies and leaving them with family members will help ensure it can be found when needed. However, if different versions of the living will exist, this can create confusion.

If the patient is incapacitated and has a living will providers will often use the instructions to guide treatment and care. But healthcare providers do not always faithfully follow the instructions in a living will, particularly if there is a conflict with family wishes. States vary in how binding they consider living wills.

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Generally, if the patient is incapacitated and there is no living will, and no durable power of attorney establishing a designated single decision maker, the provider will follow the wishes of family members in order of degree of relatedness. This is typically spouse first, then, in order, adult children, parents, and adult siblings, but states may vary in defining the order of relations to be followed. It is commonly recommended that an attempt be made to resolve any family conflict about treatment for the patient through discussion and mediation as needed.

If the patient is under a guardian appointed by a court, the decisions of the guardian will be followed. Otherwise, if the patient has a durable power of attorney that appoints a specific person as the proxy to make decisions, then the hospital staff will usually follow his or her wishes. A notarized durable power of attorney is considered legally binding. The person designated as the proxy or surrogate decision maker should have a copy of the document to prove their status.

The Nature of a Living Will

Basic living will forms are available from hospitals, medical offices, attorneys, health advocacy organizations, and healthcare sites on the Internet. Living wills vary from the simple to the complex and from mostly narrative text to extensive use of lists.

Living wills typically specify particular treatments that should or should not be administered under specific circumstances, so the two main considerations in creating a living will are to anticipate the specific situations that may arise and to designate the particular treatments that should or should not occur in those situations. Key situations to consider are when the patient is not expected to recover at all and when the patient is not expected to recover a desired quality of life. Specify treatments to be given or withheld in those situations.

The following are situations one may consider:

- unaware of surroundings, unconscious, no movement
- unaware of surroundings but appearing “awake” and moving
- severe senile dementia – conscious but unable to recognize family, etc.
- mild senile dementia – sometimes confused
- unable to eat, drink, and care for basic needs (e.g., brush teeth)
- must be restrained to prevent injury
- degenerative disease (e.g., Lou Gehrig’s disease)
- Alzheimer’s disease
- brain damage
- one or more organs have failed
- significant paralysis
- intense pain
- highly agitated
- terminal disease
- incurable disease

The patient may wish to specify whether to administer any of the following possible interventions or other care.

This may be in general or tied to specific situations.

"Extraordinary" care:

- artificial respiration or ventilation
- artificial feeding or hydration
- blood transfusions
- cardiopulmonary resuscitation (CPR)
- chemotherapy
- electric shock therapy
- kidney dialysis
- organ transplant
- radiation therapy
- significant surgery

Palliative care: (attempting to relieve pain and suffering rather than to cure; commonly always provided):

- pain medication
- sedation
- family and friend visitation
- music
- television
- pictures
- pet therapy

Other preferences:

- prefer to die at home
- prefer to donate organs if possible
- desire hospice care if available

Other documents are sometimes created when people create living wills. A declaration for mental health treatment may be used to specify future mental health services. Some people create a "values history" to share with loved ones a statement of personal values and important events in life.

Durable Power of Attorney for Health Care

A durable power of attorney for healthcare designates someone to make healthcare treatment decisions for the patient if the patient is unable to do so. When specific circumstances arise, the proxy or surrogate will be asked to make decisions for the patient about particular types of treatment to provide or withhold. The surrogate could also choose to change the patient's physicians and healthcare facilities, will have access to the patient's confidential medical records, and can sue on the patient's behalf. A surrogate is not responsible for the patient's medical bills.

The question may arise about how a surrogate should arrive at the right decisions for the patient. Suggestions that have been proposed are to

1. use the patient's earlier comments or instructions, or if those are not available or decisive
2. use "substituted judgment," the treatment or care the patient would likely have chosen, or if that cannot be determined
3. use the standard of "best interests," the treatment or care that would be in the best interests of the patient.

Experts advise the patient to discuss his or her wishes thoroughly with the surrogate while the patient is able so the surrogate is likely to know what the patient wants or would have wanted. A living will form may be used by the patient to indicate their wishes to the surrogate, but the surrogate is not bound by anything the patient says or writes.

Controversies about Advance Directives

Healthcare professionals frequently recommend that patients obtain advance directives to avoid confusion and problems later. But critics have pointed out that advance directives are not without problems. Some healthcare professionals avoid creating a living will in favor of having long discussions about preferences with a spouse or surrogate decision maker.

Living wills can be very specific or very general. A basic problem with creating a very specific living will is that hardly anyone can anticipate, years ahead of time, what treatments and interventions they will want or not want in circumstances they have never faced and have little experience of. Beyond that, even if they can grasp all possible interventions and treatments and imagine all possible situations they might face in which they are incapacitated, and decide which interventions they will want in what circumstances, a feat in itself, years later technology will probably have advanced sufficiently to leave large gaps in their instructions. On the other hand, a very general living will that is vague may cause problems in interpreting the patient's wishes. With either type it is also possible the patient will change his or her mind.

The following are problems pointed out that may arise with living wills:

- The patient has a living will but it cannot be located when needed.
- The patient changed his or her mind about something in the living will but never got around to changing the living will itself. The living will conflicts with wishes the family and/or friends say they heard the patient previously express.
- The living will conflicts with what the patient's own family's desires.
- The patient changed the living will several times but did not destroy or "recall" copies of the old versions, leaving various family members and friends to produce different versions when the time occurs to consult the living will.
- The living will is too vague, unclear, or incomplete about what procedures or treatment options are allowed in specific circumstances.

- Medical technology has advanced since the living will was created and it is unclear whether the patient would wish to allow new treatments.
- Older treatments mentioned in the living will are no longer considered appropriate or are unavailable.
- The patient did not fully understand the types of situation and types of treatment mentioned in the living will and so did not know what they are allowing and disallowing. (There have been cases in which the person wound up indicating the exact opposite of what they wanted.)
- The surrogate advocates treatments which the healthcare staff views as futile in the patient's situation.
- In "incompetent revocation," a conscious patient under care but in a questionable mental state claims to reject the instructions of their living will, leaving the healthcare team uncertain about what to do.
- A surrogate decision maker named in a medical power of attorney disagrees with the instructions in a living will, or finds them confusing, incomplete, outdated, or in conflict with conversations they previously had with the patient.

Listed are some problems that might arise with surrogate decision-makers:

- A patient remains in an incapacitated state for an extended period of time, and the surrogate decision maker must be available to make decisions during that time period. This lasts months or even years, which can be a burden to the surrogate.
- The surrogate decision maker tries to choose the treatment or care the patient stated was desired, but the surrogate does not know what it is, is unable to recall it, or has never been told it. It may be that the patient stated several conflicting wishes at different times.
- The surrogate decision maker tries to use the standard of "substituted judgment," but the surrogate does not know the patient well enough to know what the patient would have wanted.
- The surrogate has different values than the patient has, and what the surrogate chooses is not what the patient or others think is in the patient's best interests. For example, the surrogate chooses a long life over maintaining human dignity, but the patient thought a dignified life was in their best interests.
- A dishonorable surrogate, betraying the patient's trust, chooses a treatment or care option for ulterior reasons. For example, suppose the proxy is in the patient's will and stands to benefit financially from the patient's quick death.

Similar problems could occur in the absence of a legal surrogate specified in a durable power of attorney for healthcare. A family member or friend might need to try to decide on behalf of the patient. The spouse is usually considered an ideal surrogate, but what if the couple has marital problems? Disagreements could occur between the spouse and adult children of the patient, particularly if the spouse is not the parent of the children. Adult children could disagree among themselves, especially in situations where one child lived far away for much of the patient's later years and has just now flown in to "take control." Decisions can be made on the basis of wishes for revenge, out of bitterness, or out of feelings of guilt. As in the case of an unworthy proxy, adult children may have a vested interest in an early death to gain an inheritance. But even morally honorable children can create conflict due to religious differences with a patient. The patient and other family members may hold different religious beliefs about specific types of treatments and this may influence how the family member decides for the patient when asked.

Appendix G

Retrieved from <https://massey.vcu.edu/patient-care/rights-responsibilities/virginia-advance-medical-directive/>



(https://massey.vcu.edu/patient-care/rights-responsibilities/virginia-advance-medical-directive/)

VCU Massey Cancer Center

[Home](#) / [Patient Care](#) / [Patient rights and responsibilities](#) / [Virginia advance medical directive](#)

Virginia advance medical directive

Ω

All adults in Virginia have a right to prepare a document called an "advance directive" to put their wishes regarding medical care in writing. An advance directive lets other people know the types of medical care you do and do not want in the event you are unable to express your wishes on your own. There are two kinds of advance directives:

Appointment of an agent: You may authorize another person, such as a spouse, child or friend, to be your "agent" or "proxy" to make decisions for you if you become incapable of making informed health care decisions for yourself. You can also specifically tell your agent what kinds of care you do and do not want. This authorization is, in legal terms, often called a "power of attorney for health care."

Living will: You may also state what kinds of life-prolonging treatment you want or do not want if you are diagnosed as having a terminal condition and are unable to express your own wishes. The legal term for this is a "living will."

[Virginia advance medical directive forms \(#Virginia advance medical directive forms\).](#)

[Questions and answers about advance medical directives](#)

[\(#Questions and answers about advance medical directives\).](#)

[Additional resources for advance directives](#)

[\(#Additional resources for understanding and creating an advance directive\).](#)

()_Virginia advance medical directive forms

Below are links to an advance directive form (with both "Appointment of an Agent" and "Living Will" sections) that you can print and fill out. You should make copies and provide a copy to your doctor, bring one when you come to the hospital and give copies to your family and friends.

[Virginia Advance Directive for Healthcare Form \(/media/massey-cancer-center/content-assets/documents/patients/forms/2012_VA_AMD_Simplified-Basic.PDF\).](#)

[YRTDSpanish](#) contains Spanish language information about advance directives

[Back to top>> \(#top\).](#)

()_Questions and answers about advance medical directives

Why create an advance medical directive?

An advance directive allows you to state your choices for health care or to name someone to make those choices for you if you become unable to make decisions about your medical treatment. It enables you to say "yes" to treatment you want or "no" to treatment you do not want.

What kind of advance directive do I need?

You may execute a power of attorney for health care, a living will or both. Of the two kinds of advance directives, a power of attorney for health care is broader. A living will is limited to situations in which you are diagnosed with a terminal condition and it only applies to life-prolonging treatment. The best way to protect your interests, however, is to execute both.

Can I just state my wishes orally?

You should always share your health care wishes with your loved ones and your doctors. However, you may only create an oral advance directive if you have a terminal condition and tell your wishes directly to your doctor. Also, putting your wishes in writing reduces confusion about your wishes since people often forget or misunderstand what was stated orally.

What if I'm unsure of what health care I might want?

You should still execute an advance directive to describe the important values and beliefs you have. You can also indicate your religious beliefs. Often, these types of statements will help others make appropriate health care choices for you when you cannot make them yourself.

I don't know medical terms. What do I need to say?

You can and should put your wishes in your own words. Just describe as best you can what medical care you do and do not want.

I'm young and/or in good health, do I need an advance directive?

Yes. No one knows what the future might bring. For example, you might need someone to make medical decisions for you in the event that you suffer a sudden injury or illness (such as a car accident). It is better to choose this person in advance and tell him or her about your health care wishes. If you do not choose someone in advance, the law will assign a decision maker who must guess about your wishes.

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Who should I pick as my agent for health care power of attorney?

You may appoint any adult (18 years or older). This person needs to be accessible, but he or she does not need to live in Virginia. When you choose your agent, make sure that you have chosen someone who will be able to make potentially difficult decisions about your care, is willing to serve as your agent and is aware of your wishes. You should also choose an alternate in case your first choice is unavailable (for example, your first choice may not be found or may not be willing to be your agent).

I have several children; can I appoint all of them?

You really should pick just one person as your agent. Picking more than one person can result in a conflict, delay decision-making or result in an inability to make any decision at all. You can include your other children by letting them know your choices. You may also require your one agent to talk with your other children prior to making any decisions.

If I appoint an agent will I lose my ability to make my own decisions?

No. Your agent only gets to make health care decisions for you if your doctor and another doctor or licensed clinical psychologist examine you and determine you cannot make decisions for yourself. Furthermore, as soon as you can speak for yourself again, decision-making authority returns to you.

What if I change my mind?

You may cancel or modify your advance directive at anytime, but it is important that you tell others that you have cancelled or changed your advance directive.

What does it mean to have a terminal condition?

It means that your doctor has determined that you are likely to die soon or that you are in a persistent vegetative state, which is when you have no awareness of your surroundings and your doctors have determined you will not recover.

What does life-prolonging treatment mean?

It means using machines, medicines and other artificial means to help you breathe, eat, get fluids in your body, have a heartbeat and otherwise stay alive when your body cannot do these things on its own. Life-prolonging treatment will not help you recover. It does not include drugs to keep you comfortable.

I do not want to limit my care if I have a terminal condition. Will an advance directive help me?

Yes. Your advance directive will enable your physicians and family to know that this is your wish.

I'm worried about pain, but I don't want to be hooked up to machines if I have a terminal condition. Should I have an advance directive?

Yes. No matter what you choose about life-prolonging treatment, you will be treated for pain and kept comfortable.

Will I get less respect and medical attention if I do not want to have life-prolonging treatment?

No. Your physicians and nurses may not discriminate against you based on your health care choices. You will get whatever care is appropriate, but you will not get any treatment that you have stated you do not want.

Can my spouse be one of my two witnesses? What about other blood relatives?

Yes, your husband/wife can be your witness. Other blood relatives can also be witnesses as long as they are adults.

Can my agent be a witness?

Yes, but to avoid the chance of conflict, it is better to have someone who is not your agent (or your alternate agent) be a witness.

Does an advance directive in Virginia need to be notarized?

No.

Are copies of advance directives valid?

Yes.

I have a financial power of attorney. Does it cover health care decisions?

Probably not. It is better to have a separate health care power of attorney document. If you are in doubt, consult a lawyer or ask at a hospital.

Can my family or physicians override my decisions if I am unable to speak for myself?

No. This is one of the major reasons to create an advance directive.

Will my Virginia advance directive be valid in other states?

It should be. Just as Virginia honors Advance directives properly executed in other states, most states have similar rules to honor out-of-state advance directives. Nevertheless, if you spend a considerable amount of time in another state, you may want to have an advance directive executed for that state as well. You may also want to register your advance directive with the [U.S. Living Will Registry \(http://www.uslivingwillregistry.com/\)](http://www.uslivingwillregistry.com/).

Where should I keep my advance directive? Who gets copies?

Just as important as creating an advance directive is making sure that other people know that you have it and know where it is located. Specifically, you should:

- Give a copy or the original to your agent or proxy
- Give a copy to your physician(s)
- Give a copy to family and friends
- Bring it to the hospital with you

Additionally, you should keep a copy of your advance directive in a safe place where it can be found easily. Do not keep your only copy in a lock box or safe.

Does it cost anything to create an advance directive?

No. The [Virginia Advance Directive Form](#)  is free.

Do I need a lawyer to draft an advance directive? Must I use these forms?

No. The free form at the link above is all you need, but a lawyer may help you if you have additional questions or complex health care needs. The free form is also only a model. You can use it or numerous other forms or no form at all. Just be sure that whatever you use includes: (1) your health care wishes, (2) your signature and (3) the signatures of two adult witnesses.

What is a "Do Not Resuscitate" (DNR) order?

A DNR is a doctor's order saying that you will not get CPR, drugs or electric shock to restart your heart or breathing if your heart stops or you stop breathing. A "Durable Do Not Resuscitate" (DDNR) order is a special DNR order that your doctor can provide you so that EMS, fire and rescue and any health care provider will know your wishes about resuscitation.

Is information available in Spanish?

Yes. Download the free [YRTDSpanish](#) .

Is information available in other languages?

Your local hospital should have translation services to help with other languages.

Where can I go for additional information?

Advance directive forms and additional information are available at any hospital. In addition, numerous Web sites have advance directives information.

(.) Additional resources for understanding and creating an advance directive

[Your Right to Decide \(http://www.vsb.org/docs/sections/health/Decide2009.PDF\)](http://www.vsb.org/docs/sections/health/Decide2009.PDF)

[Advance Directive Tool Kit](#)

[Health Care Decision Making: What You Need to Know](#)

[\(http://www.vsb.org/site/publications/health-care-decision-making-what-you-need-to-know/\)](http://www.vsb.org/site/publications/health-care-decision-making-what-you-need-to-know/)

[Information on advance directives \(http://estate.findlaw.com/estate-planning/living-wills.html\)](http://estate.findlaw.com/estate-planning/living-wills.html)

(from Findlaw.com)

[Dying With Dignity: Medical Treatment \(http://public.findlaw.com/\)](http://public.findlaw.com/) (from Findlaw.com)

[U.S. Living Will Registry \(http://www.uslivingwillregistry.com/\)](http://www.uslivingwillregistry.com/)

[Put It In Writing \(http://www.putitinwriting.org/putitinwriting_app/index.jsp\)](http://www.putitinwriting.org/putitinwriting_app/index.jsp)

[Caring Connections \(http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1\)](http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1)

[Five Wishes \(http://www.agingwithdignity.org/index.php\)](http://www.agingwithdignity.org/index.php)

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Appendix H

Retrieved from <https://www.stonybrookmedicine.edu/patientcare/livingwill>



[Contact Us](#) | [Find a Doctor](#) | [Pay Doctor Bill](#)

- Find A Doctor
- Patient Portal
- Directions & Parking
- Locations
- Preparing For Your Care
- Medical Records
- Connections
- Get Connected
- Spiritual Care
- Patient Advocacy
- Paying for Your Care
- Pre-Surgical Admissions
- Billing & Insurance
- Hospital Health Plans
- Know Your Rights ▾**
 - Patient Rights & Responsibilities
 - Patients Bill of Rights Spanish
 - Parent's Bill of Rights
 - Parents Bill of Rights Spanish
 - Health Care Proxy/Living Will**
 - Do Not Resuscitate Orders (DNR)
- Patient Privacy
- Health Connect@
- Health Education Resources
- Telehealth
- Tobacco-Free Policy
- Calendar of Events

Health Care Proxy/Living Will

A new law, called the New York healthcare proxy law, allows you to appoint someone you trust - for example, a family member or close friend - to decide about treatment if you lose the ability to decide for yourself. You can appoint someone by signing a form called a **Healthcare Proxy**.

You can give the person you select, your "healthcare agent", as little or as much authority as you want. You can allow your **healthcare** agent to decide about all healthcare or only about certain treatments. You may also give your agent instructions that he or she has to follow. Your agent can then make sure that healthcare professionals follow your wishes and can decide how your wishes apply as your medical condition changes. Hospitals, doctors and other healthcare providers must follow your agent's decisions as if they were your own.

Below are the answers to some questions you may have:

- Why should I choose a healthcare agent?
- How can I appoint a healthcare agent?
- When would my healthcare agent begin to make treatment decisions for me?
- What decisions can my healthcare agent make?
- How can I give my agent written instructions?
- How will my healthcare agent make decisions?
- Who will pay attention to my agent?
- What if my healthcare agent is not available when decisions must be made?
- What if I change my mind?
- Can my healthcare agent be legally liable for decisions made on my behalf?
- Is a healthcare proxy the same as a living will?
- Where should I keep the proxy form after it is signed?

Why should I choose a healthcare agent?

If you become too sick to make healthcare decisions, someone else must decide for you. Healthcare professionals often look to family members for guidance. But family members are not allowed to decide to stop treatment, even when they believe that is what you would choose or what is best for you under the circumstances. Appointing an agent lets you control your medical treatment by:

- allowing your agent to stop treatment when he or she decides that is what you would want or what is best for you under the circumstances;
- choosing one family member to decide about treatment because you think that person would make the best decisions or because you want to avoid conflict or confusion about who should decide; and
- choosing someone outside your family to decide about treatment because no one in your family is available or because you prefer that someone other than a family member decide about your healthcare.

How can I appoint a healthcare agent?

All competent adults can appoint a healthcare agent by signing a form called a Healthcare Proxy. You don't need a lawyer, just two adult witnesses. A **form** is available for printing on this page.

When would my healthcare agent begin to make treatment decisions for me?

Your healthcare agent would begin to make treatment decisions after doctors decide that you are not able to make healthcare decisions. As long as you are able to make treatment decisions for yourself, you will have the right to do so.

What decisions can my healthcare agent make?

Unless you limit your healthcare agent's authority, your agent will be able to make any treatment decisions that you could have made if you were able to decide for yourself. Your agent can agree that you should receive treatment, choose among different treatments, and decide that treatments should not be provided, in accord with your wishes and interests. If your healthcare agent is not aware of your wishes about artificial nutrition and hydration (nourishment and water provided by feeding tubes), he or she will not be able to make decisions about these measures. Artificial nutrition and hydration are used in many circumstances, and are often used to continue life of patients who are in a permanent coma.

How can I give my agent written instructions?

Unless you limit your healthcare agent's authority, your agent will be able to make any treatment decisions that you could have made if you were able to decide for yourself. Your agent can agree that you should receive treatment, choose among different treatments, and decide that treatments should not be provided, in accord with your wishes and interests. If your healthcare agent is not aware of your wishes about artificial nutrition and hydration (nourishment and water provided by feeding tubes), he or she will not be able to make decisions about these measures. Artificial nutrition and hydration are used in many circumstances, and are often used to continue life of patients who are in a permanent coma.

How will my healthcare agent make decisions?

You can write instructions on the proxy form. Your agent must follow your oral and written instructions, as well as your moral and religious beliefs. If your agent does not know your wishes or beliefs, your agent is legally required to act in your best interests.

Who will pay attention to my agent?

All hospitals, doctors and other healthcare facility are legally required to obey the decisions by your agent. If a hospital objects to some treatment options (such as removing certain treatment) they must tell you or your agent **IN ADVANCE**.

What if my healthcare agent is not available when decisions must be made?

You can appoint an alternate agent to decide for you if your healthcare agent is not available or able to act when decisions must be made. Otherwise, healthcare providers will make treatment decisions you gave while you were still able to do so. Any instructions that you write on your Healthcare Proxy form will guide healthcare providers under these circumstances.

What if I change my mind?

It is easy to cancel the proxy, to change the person you have chosen as your healthcare agent, or to change any treatment instructions you have written on your Healthcare Proxy form. Just fill out a new form. In addition, you can require that the Healthcare Proxy expire on a specified date or if certain events occur. Otherwise, the Healthcare Proxy will be valid indefinitely. If you choose your spouse as your healthcare agent and you get divorced or legally separated, the proxy is automatically cancelled.

Can my healthcare agent be legally liable for decisions made on my behalf?

No. Your healthcare agent will not be liable for treatment decisions made in good faith on your behalf. Also he or she cannot be held liable for costs of your care, just because he or she is your agent.

Is a healthcare proxy the same as a living will?

No. A living will is a document that provides specific instructions about healthcare treatment. It is generally used to declare wishes to refuse life-sustaining treatment under certain circumstances.

In contrast, the healthcare proxy allows you to choose someone you trust to make treatment decisions on your behalf. Unlike a living will, a healthcare proxy does not require that you know in advance all the decisions that may arise. Instead, your healthcare agent can interpret your wishes as medical circumstances change and can make decisions you could not have known would have to be made. The healthcare proxy is just as useful for decisions to receive treatment as it is for decisions to stop treatment. If you complete a Healthcare Proxy form, but also have a living will, the living will provides instructions for your healthcare agent, and will guide his or her decisions.

Where should I keep the proxy form after it is signed?

Give a copy to your agent, your doctor and any other family members or close friends you want. You can also keep a copy in your wallet or purse or with other important papers.

Appointing a healthcare agent is a serious decision. Make sure you talk about it with your family, close friends and your doctor.

Do it in advance, not just when you are planning to enter the hospital.

Appendix I

Retrieved from <http://uabpastoralcare.org/patients/resources/>

NEWS

Prayers to Go

UAB Community Rallies to Host Wedding in RNICU

Celebration of Life Service

Resources

This page provides resources for patients and families, as well as for the general public.

If you would like to see resources here on special topics of interest, please let our Director of Pastoral Care, Malcolm Marler, know by [emailing him here](#).

1. “The Conversation Project“

It’s not easy to talk about how you want the end of your life to be. But it’s one of the most important conversations you can have with your loved ones.

This Starter Kit will help you get your thoughts together and then have the conversation. This isn’t about filling out Advance Directives or other medical forms. It’s about talking to your loved ones about what you or they want for end-of-life care. [Open this Starter Kit here \(PDF form\)](#).

2. Advance Directives (Living Wills)

It can be difficult for doctors and loved ones to know what kind of treatment you want if you are unable to tell them. The best way to make sure your wishes are respected is to discuss them with your health care provider and your loved ones while you’re healthy and then fill out an Advance Directive form. We hope you will consider filling one out.

[Open and print this Advance Directive for your own use \(PDF form\)](#).

3. UAB Hospital Patient and Visitor Guide »

UAB Medicine is here to assist you in all aspects of your care and to provide you with relevant information regarding your upcoming experience at one of our clinic or hospital locations. We understand how stressful hospitalization or treatment can be, and we want to ensure that we provide a safe and comfortable healing environment for all involved.

4. UAB Medicine Patient Resources

- [Plan your Visit to UAB Medicine](#)
- [Before Your Stay at UAB](#)
- [During Your Stay at UAB](#)
- [After Your Stay at UAB](#)
- [Visiting a Patient](#)
- [Special Services](#)
- [Your Clinic Visit](#)

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Appendix K

Retrieved from <https://extension.umn.edu/health-education/health-care-directive-workshop>



University of Minnesota Extension
<https://extension.umn.edu>

Health care directive workshop



Do you have a group of people who need basic information about planning for future health care decisions? Then the health care directive workshop is for you!

University of Minnesota Extension educators can deliver this workshop to your group. You may be:

- An employer
- Human resources director
- Clinic administrator
- Community organization leader
- Church director
- Other community leader

We can help your clients start to take steps towards creating a health care directive.

About the workshop

This one-hour workshop will help your clients learn the basics about planning for future health care decisions by creating a health care directive. Through this workshop and the related materials they will receive as part of this training, participants will learn:

- Decision making rights in times of incapacity.
- Key terms and language involved in advance care planning.
- The difference between a "living will" and a "health care directive."
- Information other individuals need to know when someone can't communicate for themselves.
- Minnesota health care directive policies and practices.
- How to complete a suggested "Health Care Directive" form.
- Common myths and facts about health care directives.
- Strategies for starting conversations about end-of-life issues.


After participating in the workshop, your participants are expected to take one or more of the following actions:

- Talk with family and health care providers about incapacity and advance care planning.
- Choose and name appropriate health care agent(s).
- Identify and leave instructions and preferences for health care decisions.
- Complete a suggested Minnesota health care directive form.
- Review and update existing plans, decisions, and written documents.
- Talk with aging parents and other family members to understand their wishes and preferences.

This workshop can be customized for your group and can be delivered in-person or online. For more information, [contact us](https://extension.umn.edu/food-health-and-nutrition/contacts-food-health-and-nutrition#health-care-879111) <<https://extension.umn.edu/food-health-and-nutrition/contacts-food-health-and-nutrition#health-care-879111>> .

Appendix L

Retrieved from <https://health.umd.edu/parents>



UNIVERSITY
HEALTH CENTER

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Parents

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Welcome to the University of Maryland community! Parents and families have an important role as students learn to take great care of themselves. We encourage parents to coach their students toward making wise health choices and through getting health care, when needed.

All University of Maryland students may use the Health Center. We participate in a number of national insurance plans ([link](#)) and have a reduced-rate fee schedule for certain services for students with insurances that do not contract with the UHC.

Here are some things you'll want to pay attention to before your new Terp arrives on campus...


1. Read the student entrance letter
2. Review immunizations and ensure that your student is up to date
3. Ensure that your student fills out and submits their [Immunization Record](#)
4. Annually complete the [Mandatory Insurance/Hard Waiver](#)
5. Talk with your student about alcohol consumption, sexual assault, and healthy choices. It is important for your student to hear explicitly about your expectations. Here is [some information to help](#) from our own School of Public Health!
6. Consider discussing an [Advance Directive](#) with your student.
7. Read our information about [Privacy and Confidentiality](#) (below)

Information for Parents

- [+ Behavioral Health](#)

- [+ CARE to Stop Violence](#)

- [+ Privacy and Confidentiality](#)



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