

# Clinical Social Work End-Of-Life Survey: Constructive Work with Patients and Family Members on Advance Directives and Medical Orders for Life-Sustaining Treatment

Kevin A. Ceckowski, MSW, LICSW, FNKE, Marie Salimbeni, PhD, MSW, LCSW, and Dustin Little, MD, Walter Reed National Military Medical Center, Bethesda, MD; Elizabeth I. Jones, MSW, LCSW, FNKE, DaVita Sterling, Sterling, VA; Teri Browne, PhD, MSW, and Samuel R. Bethel, MSW, LCSW, University of South Carolina, Columbia, SC; Christina Yuan, MD, Walter Reed National Military Medical Center, Bethesda, MD

*This article identifies how clinical social workers in medical-surgical, mental health, and nephrology settings at Walter Reed National Military Medical Center (WRNMMC) and the End-Stage Renal Disease (ESRD) Network 5 Mid-Atlantic Renal Coalition assist nephrologists and other physicians in overcoming barriers to end-of-life (EOL) care planning, particularly in patients with end-stage renal disease (ESRD) or acute kidney injury (AKI). To assess differences in practice patterns, an anonymous survey was administered to determine whether social workers were comfortable having EOL care discussions with their patients, and to also assess if these social workers were able to assist the physicians with EOL care planning. Findings showed that social workers identified multiple barriers to discussing EOL care planning. Participants also identified the most important conversations to have when discussing EOL care planning with their patients.*

## INTRODUCTION

There is a great need for advance-care planning (ACP), and palliative and hospice care in our health system. As the United States population ages, there is a growing number of people who could benefit from these services. Currently there are 90 million people in America with a serious illness and this number is predicted to double by 2040 (Morrison, Augustin, Souvanna, & Meier; The Center to Advance Palliative Care, 2011). Educating patients and their families about advance directives and the benefits of palliative and hospice care is strongly advised.

This is urgently needed in kidney disease care. Although hospice use appears to be growing for end-stage renal disease (ESRD) patients, it is usually used for only a short time (USRDS, 2013), and only 24% of eligible ESRD patients are referred to hospice (Gravaren, 2015). We previously surveyed nephrologists who were associated with a single training program ( $n = 93$ ; 61% response rate) and asked them what they saw as the barriers to referring patients to hospice (Table 1). Six percent cited a lack of available hospice resources in their region; 27% said referral and end-of-life (EOL) discussions were too time consuming; and 69% felt patients had misconceptions about end-of-life (EOL) care. Encouragingly, 92% of these nephrologists felt comfortable having EOL care discussions with their patients (Ceckowski, Little, Merighi, Browne, & Yuan, 2017).

Patients who were approached by a healthcare professional and had a discussion on EOL care planning spent much less time in the hospital, particularly in the ICU (Curtis, 2004; Holden et al., 2015). Furthermore, Medicare now provides payment for such conversations (Gawande, 2016). Previous research suggests that social workers who have their own advance directive are more likely to discuss completing an advance directive with their patients (Perry, Swartz, Smith-Wheelock, Westbrook, & Buck, 1996). In 2012, only 7% of patients who

were seriously ill had an EOL care conversation with their doctor, compared to 60% who had that same discussion with their social worker (The Conversation Project & The Institute for Healthcare Improvement, 2015; Grubbs et al., 2014).

**Table 1.** Nephrology Survey 2015:  
Barriers to EOL Discussions in ESRD Patients  
(Ceckowski, Little, Merighi, Browne, & Yuan, 2017)

### Predominant Barriers

- Time-consuming nature of discussions (27%)
- Difficulty in determining prognosis for < 6-month survival (35%)
- Patient (63%) and family (71%) unwillingness
- Patient (69%) and family (73%) misconceptions
- Lack of palliative care (12%) and hospice (6%) resources

### Nephrologist Survey Summary

- Anonymous, online, cross sectional survey of 93 nephrologists associated with Walter Reed National Military Medical Center (WRNMMC) program since 1987 (including 75 graduated fellows). All contacted by email or fax
- 61% response rate, 95% of whom were in active practice
- 65% in practice > 10 years
- 92% were comfortable discussing EOL care, with no significant difference between those > 10 years in practice and those 10 years or less.
- 31% felt they under-referred
- 57% would refer more patients if dialysis/ultrafiltration could be done in hospice.

**Corresponding author:** Kevin A. Ceckowski, MSW, LICSW, FNKE, Walter Reed National Military Medical Center, 8901 Wisconsin Avenue, Bethesda, MD 20889; [kevin.a.ceckowski.civ@mail.mil](mailto:kevin.a.ceckowski.civ@mail.mil)

Discussing EOL care with patients can be very difficult for clinical social workers, especially if they lack training or have not experienced a major life changing event themselves (Gutheil & Heyman, 2011; Perry et al., 1996). However, it is also known that patients strongly desire to have EOL care discussions with their care providers (Curtis, 2004; Davison, 2010). In order to have EOL care discussions, it is recommended that scheduled time be set aside for the social worker to sit down with the patient and the family, and that the resources required to complete advance directives (ADs) are available at the hospital, the dialysis center, or the mental health clinic. Unfortunately, some regions lack these resources due to funding priorities (Barnato et al., 2007).

In 2011, *America's Care of Serious Illness: A State-by-State Report Card on Palliative Care in Our Nation's Hospitals* noted that there has been a 138% increase in palliative programs in hospital settings since 2000, and that 92% of Americans would consider taking part in a palliative care program for themselves or their families if they had a serious illness (Morrison et al., 2011). Hospice is a major part of the continuum of care in palliative care programs. Based on a 2011 needs survey of patients and family members (Table 2), Morrison et al. (2011) identified areas in hospice care that could be improved. Many patients still experience pain and shortness of breath in the last few days of their life. Many patients fear pain, and pain management is one factor of ACP that needs improvement. Also, in keeping with the goal of "continuum of care," hospice should offer grief and loss counseling for the patient's family (CMS, 2017), yet only about 33% reported receiving this benefit. Furthermore, 33% stated that they were discharged from the hospital with no follow-up care, which appears to be a complete breakdown of ACP. Holley and Davidson (2015) sum this up by stating that ACP:

...can enhance communication among patients and care providers ensuring that EOL care wishes are known, reduce unwanted and aggressive treatments at the EOL, improve patient and family/loved one satisfaction with care, and reduce stress, anxiety and depression in surviving relatives.  
(p. 345)

### STUDY AIM

The aim of this study was to describe how clinical social workers in medical-surgical, mental health, and nephrology settings assist nephrologists and other physicians in overcoming barriers to EOL care planning, particularly in patients with ESRD or acute kidney injury (AKI).

### METHOD

We surveyed 221 clinical social workers at the Department of Social Work at Walter Reed National Military Medical Center (WRNMMC) and the ESRD Network 5 Mid-Atlantic Renal Coalition regarding EOL care. We distributed by email a 49-item anonymous online survey using SurveyMonkey® (<http://www.surveymonkey.com>) from October 20 to November 22, 2016 (survey available for review upon request).

No personal identification information was collected, no IP Addresses were retained, and respondents were allowed to complete as little or as much of the survey as desired. The survey could only be completed once. Additionally, no email addresses were disclosed to the authors; all were sent through an office administrator at WRNMMC.

**Table 2.** Results from Hospice Needs Survey

Patients Reported	People Living with Serious Illness Experience
25%	Inadequate treatment of pain
25%	Inadequate treatment for shortness of breath
33%	Inadequate emotional support
33%	No education about how to treat pain and other symptoms following discharge from the hospital
33%	Not provided with arrangements for follow-up care after being discharged from the hospital

(Morrison et al., 2011)

Social workers were asked about clinical caseloads, number of patients who died in a given year, and where these patients died (e.g., hospice, home, hospital, nursing home). They were asked how many of these deaths were surprising or unexpected. Respondents were asked if they were trained in EOL care planning, and to also assess their own comfort with advance directives and medical orders for life-sustaining treatment (MOLST) discussions with patients and family members. Questions were also asked to assess whether having an advance directive for one's self increased respondents' comfort in completing advance directives for their patients. Respondents were asked if they experienced a significant event in their own lives that prompted their utilization of a personal advance directive (e.g., family death), or if they experienced completing advance directives with their patients' families. Lastly, respondents were also asked about the level of importance they placed on specific patient conversations addressing barriers to EOL care.

**Table 3.** WRNMMC and ESRD Network 5 Social Work Survey: Description of Respondents and Caseload

Social Work Respondents (n = 84)			
	CMSSW n = 11	CMHSW n = 6	CNSW n = 67
Years of Practice (Mean)	25	19	19
SW with their own AD/MOLST (%)	36%	50%	35%
SW personally experienced a significant EOL event (%)	55%	67%	48%
SW EOL training received (Median hrs)	11–20	11–20	6–10
Patients in caseload (Median)	1–20	21–45	> 100
SW assisted a Family Member in AD/MOLST (%)	64%	83%	46%
Patients with AD/MOLST in their chart (Median %)*	1–25%	1–25%	26–50%
Deaths that were surprising or unexpected (Median % in last year)*	None	1–10%	1–10%
Died in hospice (Median %)*	11–25%	1–10%	1–10%
Died at home (Median %)*	1–10%	1–10%	1–10%
Died in the hospital (Median %)*	26–50%	1–10%	26–50%
Died in nursing home (Median %)*	None	None	1–10%

**\*Excluding respondents who indicated “unsure.”**

AD = advance directive; CMSSW = clinical medical surgical social workers; CMHSW = clinical mental health social workers; CNSW = clinical nephrology social workers; ESRD = end-stage renal disease; MOLST = medical orders for life-sustaining treatment; WRNMMC = Walter Reed National Military Medical Center.

Data are presented descriptively as percentages, medians, and means. Comparisons were performed using the Fisher Exact test, with significance threshold set at  $p < 0.05$ . The WRNMMC Institutional Review Board (IRB) approved this study [Reference #875078, Project #16-00562].

### RESULTS

Eighty-four clinical social workers completed the survey (38% response), summarized in **Table 3**. Eighty percent identified as clinical nephrology social workers (CNSW), 13% as clinical medical surgical social workers (CMSSW), and 7% as clinical mental health social workers (CMHSW).

The mean number of years in practice for CMSSWs was 25, 19 for CMHSWs, and 19 for CNSWs. The median caseload for CMSSWs was 1–20, for CMHSW 21–45, and > 100 patients for CNSWs. The mean number of hours EOL care training was 11–20 hours for CMSSWs and CMHSWs and 6–10 for CNSWs. There was no statistical relationship between training hours

and number of years in the field as a clinical social worker.

Social workers did not think it was too time consuming to discuss AD/MOLST with their patients. Interestingly enough, respondents indicated it was too time consuming for them to complete their own ADs/MOLSTs. Approximately 36% of CMSSWs and CNSWs filled out an AD/MOLST for themselves, and 50% of CMHSWs reported having completed them. In fact, 88% of social workers discussed AD with their patients, but only 28% of social workers reported that they discussed this topic as a team with their physicians. Fifty-three percent of respondents thought that patients were willing to engage in EOL discussions, and 39% reported that family members were willing to engage in this topic. Twenty-eight percent of social workers reported feeling unsure if family members were willing to engage in AD/MOLST conversations and 33% stated that family members were *unwilling* to discuss this topic.

Overall 39% of respondents had completed their own AD/MOLST. Those who reported they had personally experienced a significant life changing event with regard to EOL care (51% overall) were *no more likely* to have completed their own AD/MOLST vs. those who had not (39% vs. 31%;  $p = 0.49$ ). Social workers with their own AD/MOLST were significantly more likely to have assisted a family member with an AD/MOLST than social workers without a completed AD/MOLST (80% vs. 49%;  $p = 0.015$ ). However, social workers with their own AD/MOLST were no more likely to discuss EOL issues with patients than those who did not have their own AD/MOLST (90% vs. 87%;  $p = 1.0$ ). Of those with an AD/MOLST, 33% reported that > 50% of their patients had an AD/MOLST vs. 30% for social workers without ( $p = 0.80$ ).

Ninety-five percent of social workers surveyed either strongly agreed or agreed that it was their responsibility to discuss EOL care with their patients, and 98% strongly agreed/agreed that physicians have a responsibility to help patients at EOL to prepare for death. However, when asked if their physicians discussed EOL care with patients and family members, only 42% of respondents said these conversations were occurring.

Overall, respondents reported a total of 1,152 deaths in one year (an average of 15 patients per social worker annually). This suggests respondents were quite experienced in encountering EOL issues. A majority of social workers indicated that among all the patients who died in a year, the deaths were not considered “surprising” or unanticipated. In our survey, it appears that patients were more likely to die in the hospital rather than at home, and most were not enrolled in hospice prior to death (Table 3).

As seen in **Supplement 1**, social workers in our survey reported the most important lesson(s) they learned about addressing EOL care situations in their practice. One social worker thought it very helpful to bring up the discussion with their patients to find out if there were any changes to their decision about having a “do not resuscitate” (DNR) order in their medical record. One social worker also felt that the process should be started by the physician, and that once a treatment process has begun, it is often difficult to change it without being awkward or intrusive. Lim et al. (2016) found there was a barrier to ACP if the physician was not available to initiate the process. It may be that a social worker should work more closely with the physician during the initial visit with the patient. In our survey, we found that physicians, indeed, do not appear comfortable discussing hospice insurance benefits with their patients, a task that has always been handled by the social worker in many institutions.

Clinical social workers “strongly agreed” / “agreed” (77%) that palliative care resources were readily available in their area, as was local hospice care (89%). They “strongly agreed” / “agreed” that EOL care was indicated for their patients (79%), and that EOL-care discussions were not too time-consuming with their patient population (62%). They also observed that while reluctance to discuss EOL issues among patients (24%) and family members (32%) was low, they were likely to have misconceptions about EOL care.

### Social Workers’ Discussions with Patients and Families

Discussing AD or MOLST with the patient before serious complications arise is preferred (Perry et al., 1996). Many social workers in a clinic or in a hospital setting engage in healthcare proxy discussions when: a) it is mandatory or company policy; b) initiated by healthcare providers only after the patient’s health begins to decline; or c) the patient initiates the process (Perry et al., 1996). In our survey, social worker respondents ranked 15 conversations (Table 4) they could have with their patients as being “very important” to “very unimportant.” Sitting down with the patient and asking them to discuss this difficult topic was seen as very important.

Empowering the patient and his/her family is a goal for social workers (Van Dorn, Scheyett, Swanson, & Swartz, 2010). Asking the patient what they understand about their diagnosis after the physician discussed it with them was also seen as an important in assessing the patient’s health literacy. Alleviating confusion and doubt has been shown to improve overall health outcomes (Peace & Phillips, 2015).

When asked if their patients had an AD, 33% of CMSSWs surveyed did not know, but 67% thought that 1–50% of their patients had completed one. Fifty percent of CMHSWs also thought that 1–50% of their patients had an AD filled out. CNSWs reported a higher percentage of their patients as having an AD, a median of 26–50%. CNSWs often use AD completion as a quality measure in the patient’s yearly Quality Assessment Performance Improvement (QAPI) plan, which may account for the larger percentage. Often, the discussion of EOL care occurs but the patient may wish to fill out their AD at a later date. In our survey, 94% of CNSWs had a conversation about AD/MOLST with their patients, whereas 70% CMSSWs and 50% CMHSWs reported having had this discussion. The relatively low percentage of CMHSWs who had completed an AD/MOLST with their patients was somewhat surprising. However, the sample of CMHSWs in this study was low. In the Commonwealth of Virginia, key stakeholders have committed to making ADs as one of the “legal tools into routine mental health care” throughout the state (Kemp, Zelle, & Richard, 2015). Through the legislative process, Virginia has taken the lead on this issue nationwide over other states. Interested readers are encouraged to access the Virginia Hospital and Healthcare Association ([www.VHHA.com](http://www.VHHA.com)) website for their open-access Supplemental Mental Health Advance Directive.

Lim et al. (2016) found a significant positive correlation between social workers having their own personal AD and their inclination to have a conversation with their patients about AD. However, in our study, social workers with and without ADs did not differ in terms of their likelihood to discuss EOL with patients. In our study, 39% of social workers had a fully executed AD/MOLST, and those who did were significantly more likely to have assisted their own family member in completing one. However, social workers without their own AD/MOLST were no less likely to discuss EOL issues with their patients and had similar completion rates among their patients.

In our study, social workers felt that patient and family members both had misconceptions about EOL care. Nephrologists surveyed in our previous study (**Table 1**) stated that patients (63%) and families (71%) had an unwillingness to discuss EOL issues, and that patients (69%) and families (73%) also had misconceptions about EOL discussions. In one study comparing African Americans to non-African Americans with regard to not trusting the healthcare system, the greater the lack of trust, the greater the decline in effective communication and healthcare compliance (Watkins et al., 2012). If African American patients were in any way suspicious of the healthcare system or had a lack of trust in it, this led to an overall sense of powerlessness when discussing EOL care and their AD. Above all, patients and their families want honesty and caring words in the conversation. This may be the first time a patient has sat down with a provider to discuss AD issues. The physician and the social worker should do all they can to make this a meaningful and empathic experience for every patient.

In The Conversation Project's booklet entitled *Your Conversation Starter Kit by the Institute for Healthcare Improvement* (The Conversation Project and The Institute for Healthcare

Improvement, 2015), the discussion first allows the patient to collect their thoughts so that they can then ultimately reach out to their friends and family with a clear goal. It was noted in Conversation Project data that 90% believed it was important to talk about EOL care planning, but that only 27% actually did so. Eighty percent said they thought it was vital to talk to their doctor about their wishes for medical treatment at the EOL, but only 7% actually had that conversation.

Our respondents ranked the importance of certain conversations that they could have with their patients in discussing EOL care planning (**Table 4**).

We also observed some ambivalence on the part of the social workers with regard to seven of the survey questions (**Table 5**). The respondents "neither agreed nor disagreed" with these statements with some frequency—and thus the responses fell within the "neutral range." These findings were unexpected, especially in view of the questions that the social workers indicated as very important to have with their patients (**Table 5**).

**Table 4.** WRNMMC and ESRD Network 5 Social Work Survey: Top-Ranking Conversation Questions

Social Workers were asked to rate the level of importance for each of the following patient conversations that address potential barriers to EOL care:

Asking if...	Very Important/ Somewhat Important Discussions (%)
Patients wish to discuss what is most important to them in the last phase of their life?	94%
Patients wish to put their end-of-life care wishes in writing?	90%
Patients have discussed end-of-life care with their family members?	91%
Patients have a plan for where they want and do not want to receive end-of-life care (e.g., home, hospice, nursing home, hospital, etc.)?	91%
Patients want to discuss life milestones (e.g., birthdays, anniversaries, celebrations) that they would like to try to be present for before they die?	91%
Patients have a plan for the kind of treatments they want or do not want during end-of-life care (e.g., pain control, nutrition supplements, intravenous fluids, etc.)?	90%
Patients wish to discuss changing their mind about end-of-life care in the event their circumstances change?	89%
Patients know about their diagnosis(es)?	88%
Patients know about their prognosis?	85%
Patients have disagreements with family members about their decisions for end-of-life care?	86%
Patients wish to make decisions about end-of-life care while meeting with you?	85%
Patients have problems regarding family finances/property, responsibilities, or personal/professional relationships?	76%
Patients are ready to discuss shifting the focus from curative care to comfort care?	76%
Patients want to rehearse the conversation they would like to have with their doctor about end-of-life care?	72%

To support the physician, the clinical social worker should be able to guide the patient through these difficult conversations surrounding EOL care. Yet we see that in one question, “I, together with the physicians with whom I work, discuss Advance Directives or MOLST with our patients as a team,” respondents seem ambivalent. A substantial percentage of the social workers rated this statement as “neither agree nor disagree.” It may be that the social worker is able to have this conversation fully with the patient, but not “as a team” with the physician. Moreover,

for the survey questions, “Most of the physicians with whom I work discuss end-of-life care with their patients” and “Most of the physicians with whom I work discuss end-of-life care with the patient’s family,” we also see a substantial percentage of the social workers state that they “neither agree nor disagree” with the statement.

<b>Table 5.</b> WRNMMC and ESRD Network 5 Social Work Survey: Ambivalence on the Part of the Social Worker	<b>Mean Likert response (1.67–2.33 indicates neutral area)</b>	<b>% responding “Neither Agree nor Disagree” to the statement</b>
Patients are unwilling to engage in end-of-life discussions.	1.7	23%
Family member(s) are unwilling to engage in end-of-life discussions.	1.9	24%
Most of the physicians with whom I work discuss end-of-life care with their patients.	2	17%
Most of the physicians with whom I work discuss end-of-life care with the patient’s family.	2	20%
I, together with the physicians with whom I work, discuss Advance Directives or MOLST with our patients as a team.	1.8	21%
I discuss insurance benefits for palliative care with my patients.	2	18%
I discuss insurance benefits for hospice care with my patients.	2.1	12%
It is my understanding that it is difficult to accurately determine if a patient’s prognosis for survival is less than 6 months.	2	26%

## IMPLICATIONS FOR SOCIAL WORK

Social workers responding to our survey indicated that the physicians with whom they work do not feel comfortable discussing insurance benefits for hospice care (68%) or for palliative care (63%) with patients. A prior study showed that family/internal medicine physicians were nearly 9 times more likely to make EOL referrals than other doctors, and that physicians comfortable discussing EOL care were nearly 7 times more likely to refer (Kogan, Brumber, Wilber, & Euguidenos, 2012).

Lim et al. (2016) showed that not only are social workers more willing to assist patients in filling out an AD/MOLST if they have filled out their own, but those patients whose peers discussed filling out an advance directive were also more likely to complete an AD/MOLST. This is an important topic, one that may have not been discussed in much detail in the past in the literature. In an interdisciplinary and multisystemic approach to patient care, it may be important to consider whether the patient's peers have completed ADs/MOLSTs and how this might affect the patient's actions. Social workers should work with their team to increase the number of patients with an AD/MOLST and who enroll in hospice. Social workers also need more conversations with their physicians about this topic. Further research on this topic is needed, especially on the effects on social work resilience to frequent patient deaths.

## CONCLUSION

ACP provides many of the answers the healthcare worker and the patient are seeking to help resolve dilemmas with EOL preparation. ACP enables the patient to put in writing their wishes in the form of a living will and to designate a surrogate in the form of a healthcare power of attorney. ACP can clarify goals of care, including cardiopulmonary resuscitation; intubation/ventilatory support; feeding tube placement; and pain management. If completed in advance, all of these conversations can transpire while the patient is lucid and has capacity, and they are being conducted at a deliberate and calm pace. One goal that is repeatedly cited is permitting maximization of the patient's quality of life (Lim et al., 2016).

Recently, the Centers for Medicare and Medicaid Services (CMS) has approved a payment process for physicians and other healthcare providers who discuss ACP with patients and families. This is a breakthrough moment, and the hope is that healthcare providers will begin these conversations with their patients earlier in the care planning process. More patients are being referred to hospice, but they continue to be referred too late in the overall disease process, with most patients dying within two weeks of entering the hospice program and overall less than 45% dying while enrolled in hospice (Peres, 2016). Further research is needed to better understand why physicians do not discuss EOL care planning with all their patients with a poor prognosis. Most patients wish to die in their own home, and yet nationwide there are more patients dying in the hospital setting (Davison, 2010; Peres, 2016; Teno et al., 2013).

In the future, when asked the question of who has an AD, the number of patients can and should be higher than our survey suggests. ADs/MOLSTs are powerful documents that allow for patients' input for future care. They are ethical and empowering tools for the patient, family, physician, healthcare team, and the institution(s) providing care. Considerable patient, family, and systemic barriers exist, and many social workers noted that there were considerable misconceptions among patients and family members about EOL care planning. Additional efforts are needed to overcome familial and structural barriers to facilitate timely referral to EOL care services. We believe social workers in any setting can serve as pivotal interdisciplinary healthcare team members to increase the use of ADs/MOLSTs. Social workers who use ADs/MOLSTs can empower patients to make the best decisions about their healthcare and can also help the healthcare team best carry out each patient's wishes.

## RESOURCES

Social workers in our survey made it a point to ask for resources to further discuss EOL care planning with their patients. Below is a list of a few resources used in writing this article:

- *Your Conversation Starter Kit: When It Comes to End-of-Life Care, Talking Matters*  
[https://theconversationproject.org/wp-content/uploads/2015/09/TCP\\_StarterKit\\_Final.pdf](https://theconversationproject.org/wp-content/uploads/2015/09/TCP_StarterKit_Final.pdf)
- The GoWish game  
<http://www.gowish.org/>
- Conversations for Life  
<http://www.conversationsforlife.co.uk/>
- Mental Health Supplement to Advance Directive form  
<https://www.inova.org/patient-and-visitor-information/making-healthcare--decisions/mental-health-supplement>
- America's Care of Serious Illness  
<https://www.capc.org/report-card>
- Medicare Hospice Benefits  
<https://www.medicare.gov/pubs/pdf/02154-medicare-hospice-benefits.pdf>

## ACKNOWLEDGEMENT

We would like to thank Joseph R. Merighi, PhD, MSW, LISW, Associate Professor and Director of Graduate Studies, University of Minnesota School of Social Work, for assisting in our first draft. In addition, we thank all outside reviewers for their helpful advice and comments.

## AUTHOR NOTE

*The views expressed in this article are those of the author and do not reflect the official policy of the Department of Army/Navy/Air Force, Department of Defense, or U.S. Government.*

## REFERENCES

- Barnato, A. E., Herndon, M. B., Anthony, D. L., Gallagher, P. M., Skinner, J. S., Bynum, J. P. W., & Fisher, E. S. (2007). Are regional variations in end-of-life care intensity explained by patient preferences? A study of the US Medicare population. *Medical Care, 45*, 386–393.
- Care Planning Act of 2015, S. 1549, 114<sup>th</sup> Congress. (2015). Retrieved from <https://www.congress.gov/bill/114th-congress/senate-bill/1549>
- Ceckowski, K. A., Little, D. J., Merighi, J. R., Browne, T., & Yuan, C. M. (2017). An end-of-life practice survey among clinical nephrologists associated with a single nephrology fellowship training program. *Clinical Kidney Journal, 10*(4), 437–442.
- Centers for Medicare and Medicaid Services (CMS). (2017). Medicare and hospice benefits. Baltimore, MD: U.S. Department of Health and Human Services, U.S. Centers for Medicare and Medicaid Services. Retrieved from <https://www.medicare.gov/Pubs/pdf/11361-Medicare-Hospice-Getting-Started.pdf>
- The Conversation Project and The Institute for Healthcare Improvement. (2015). *Your conversation starter kit: When it comes to end-of-life care, talking matters*. Boston: Institute for Healthcare Improvement, The Conversation Project. Retrieved from: [https://theconversationproject.org/wp-content/uploads/2015/09/TCP\\_StarterKit\\_Final.pdf](https://theconversationproject.org/wp-content/uploads/2015/09/TCP_StarterKit_Final.pdf)
- Curtis, R. J. (2004). Communicating about end-of-life care with patients and families in the intensive care unit. *Critical Care Clinics, 20*, 363–380.
- Davison, S. N. (2010). End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clinical Journal of the American Society of Nephrology, 5*(2), 195–204.
- Gawande, A. (2016). Quantity and quality of life: Duties of care in life-limiting illness. *Journal of the American Medical Association, 315*(3), 267–269.
- Graveran, C. T. (2015 April). Hospice, dialysis and health care reform. *Nephrology News & Issues, 29*(4), 46–47.
- Grubbs, V., Moss, A. H., Cohen, L. M., Fischer, M. J., Germain, M. J., Jassal, S. V., ... Mehrotra, R. (2014). A palliative approach to dialysis care: A patient-centered transition to the end of life. *Clinical Journal of the American Society of Nephrology, 9*, 2203–2209.
- Gutheil, I. A., & Heyman, J. C. (2011). A social work perspective: Attitudes toward end-of-life planning. *Social Work in Health Care, 50*, 763–774.
- Heyman, J. C., & Gutheil, I. A. (2006). Social work involvement in end of life planning. *Journal of Gerontological Social Work, 47*(3–4), 47–61.
- Holden, T. R., Smith, M. A., Bartels, C. M., Campbell, T. C., Yu, M., & Kind, A. J. H. (2015). Hospice enrollment, local hospice utilization patterns, and rehospitalization in Medicare patients. *Journal of Palliative Medicine, 18*(7), 601–612.
- Holley, J. L., & Davison, S. N. (2015). Advance-care planning for patients with advanced CKD: A need to move forward. *Clinical Journal of the American Society of Nephrology, 10*, 344–346.
- The Kaiser Family Foundation. (2016, September 26). *10 FAQs: Medicare's role in end-of-life care*. Retrieved from <http://kff.org/medicare/fact-sheet/10-faqs-medicare-role-in-end-of-life-care/>
- Kemp, K., Zelle, H., & Richard, J. B. (2015). Embedding advance directives in routine care for persons with serious mental illness: Implementation challenges. *Psychiatric Services, 66*(1), 10–14.
- Kogan, A. C., Brumley, R., Wilber, K., & Enguidanos, S. (2012). Physician factors that influence patient referrals to end-of-life care. *American Journal of Managed Care, 18*(11), 416–422.
- Lim, C. E. D., Ng, R. W. C., Cheng, N. C. L., Cigolini, M., Kwok, C., & Brennan, F. (2016 July 26). Advance-care planning for haemodialysis patients [Review by Cochrane Kidney and Transplant Group]. *Cochrane Library, Cochrane Database of Systematic Reviews*. Retrieved from [https://www.cochrane.org/CD010737/RENAL\\_advance-care-planning-haemodialysis-patients](https://www.cochrane.org/CD010737/RENAL_advance-care-planning-haemodialysis-patients)
- Morrison, R. S., Augustin, R., Souvanna, P., & Meier, D. E. The Center to Advance Palliative Care, National Palliative Care Research Center. (2011, October). America's Care of Serious Illness: A state-by-state report card on access to palliative care in our nation's hospitals. *Journal of Palliative Medicine, 14*(10), 1094–1096. Available at: <https://reportcard.ccapc.org> doi: 10.1089/jpm.2011.9634
- Peace, L., & Phillips, M. (2015). Improving health literacy in kidney patients: Nephrology social workers as leaders. *Journal of Nephrology Social Work, 39*(2), 32–37.
- Peres, J. (2016). A time and place: The role of social workers in improving end-of-life care. *Journal of Social Work in End-of-Life & Palliative Care, 2*(3), 185–194.
- Perry, E. C., Swartz, R., Smith-Wheelock, L., Westbrook, J., & Buck, C. (1996). Why is it difficult for staff to discuss advance directives with chronic dialysis patients? *Clinical Journal of the American Society of Nephrology, 7*, 2160–2168.
- Rinehart, A. (2013). Beyond the futility argument: The fair process approach and time-limited trials for managing dialysis conflict. *Clinical Journal of the American Society of Nephrology, 8*, 2000–2006.



Teno, J. M., Gozalo, P. L., Bynum, J. P. W., Leland, N. E., Miller, S. C., Morden, N. E., ... Mor, V. (2013). Change in end-of-life care for Medicare beneficiaries, site of death, place of care, and healthcare transitions in 2000, 2005, and 2009. *Journal of the American Medical Association*, *309*(5), 470–477.

U.S. Renal Data System (USRDS). (2013). 2013 USRDS Annual data report: Atlas of chronic kidney disease and end-stage renal disease in the United States. Bethesda, MD: National Institutes of Health, National Institute of Diabetes, Digestive, and Kidney Diseases. Retrieved from <https://www.usrds.org/atlas13.aspx>

Van Dorn, R. A., Scheyett, A., Swanson, J. W., & Swartz, M. S. (2010). Psychiatric advance directives and social workers: An integrative review. *Social Work*, *55*(2), 157–167.

Watkins, Y. J., Bonner, G. J., Wang, E., Wilkie, D. J., Ferrans, C. E., & Dancy, B. (2012). Relationship among trust in physicians, demographics, and end-of-life treatment decisions made by African American dementia caregivers. *Journal of Hospital Palliative Nurses*, *14*(3), 238–243.

#### **Supplement 1.** Social Workers' EOL Lessons

##### **Please tell us the most important lesson(s) you have learned about addressing end-of-life care situations in your clinical practice.**

“Be Proactive. Have visual resources handy.”

“Patients usually come from the hospital with a DNR (do not resuscitate) but have no idea what that is. Patients need to be educated better by hospital staff.”

“Patients generally are hesitant to discuss, or they have documents addressing their choices. Others will not discuss.”

“MDs in nephrology do not address end-of-life care in dialysis units, most of these discussions occur in hospitals by attending physicians.”

“I bring up the discussion often, but I find that when it comes up; patients don't wish to discuss it, as if discussing it will bring on death.”

“To question patients about any changes they wish to make, such as revising a DNR, and their feeling about advanced (sic) directives.”

“I try to be very unbiased. I see AD [advanced directives] as a present to [a] patient and to their family. I do discuss that there are free options in our state to get [a] healthcare decision maker [sic] and living will. [I] Also discuss personality of families matters and [remember] that all children are equal.”

“Doctors need to be honest with patients and families, and they need to speak in terminology that is simple and comprehensive. It is important to ensure that the entire clinical/core team is on the same page with one another, as well as the patient and his/her family.”

“I think the most important lesson I learned is that people often wait on their medical provider to signal that it's time to end treatment. Families find it difficult to stop a love[d] one's treatment once its begun, no matter how cumbersome the process becomes.”

“I found it is important to have an honest, open conversation about end-of-life care. It is helpful to give patients written and verbal information about end-of-life care and including ways to discuss the matter with family and friends.”

“Understanding the cultural difference[s] when talking to patients about end-of-life care and respecting the patient's choice not to discuss.”

“Patient's wishes need to be documented with legally supported documentation. However, many patient's (sic), even in end-of-life care (dialysis), are uncomfortable thinking/speaking about these wishes. Patients also don't understand the importance of legal documentation for end-of-life. Patients think, ‘My kids know what I want,’ or, ‘It doesn't matter,’ or, ‘Someone else will take care of it.’”

“Medical team and social work must be on the same page.”

“Worked with hospice for 11 years. Everyone is going to die at some point in time, and we need to accept this. We have some control over how we want the last part of our life to look like (except in unexpected deaths). I feel strongly that these discussions are very helpful in how we grieve. Not having the discussion leaves a lot of questions that can't be answered ‘after the fact.’ I met a man once who said it all... ‘[I] never wanted to meet you (hospice), but now that I need you, I'm damned glad you're here.’”

“Brings peace to people.”

“Be sensitive to patient's and family's position/feelings when addressing this issue.”

“Each conversation is custom-crafted with and for each person, even if the basic ingredients of an end-of-life conversation are the same, and, done well, each end-result will be a customized package designed to meet each person's needs and wishes.”

“End-of-life questions are not addressed that much.”

“Never assume that patients know that it's an option not to continue dialysis.”

“Listen to the patient and family member[s] and let them tell how and when it is important to them.”

“To take the opportunity or the ‘teachable moment’ when another patient dies or experiences a near-death event.”

“I do not have enough resources or do not know where to get resources to help with discussions. An example would be some literature they can take home to their families.”

“Patient and family need to make decisions together.”

“Physicians seem to ignore that this is a guaranteed part of the life cycle process, and it is as much their responsibility to acknowledge this as it is the rest of the team's.”

“The courage of people when facing end-of-life issues.”

“Follow [the] patient[’s] lead and respect their wishes.”

“It's best to meet with the patient and any of their loved ones the patient's decisions will impact.”

“Mothers always want heroic measures. Patients often do not really care how their end-of-life circumstance affects their family.”

“It is never too early to start planning.”

“That life review is very important and the idea that if circumstances or prognosis (sic) change, their decision can change. I've also learned that fear and mistrust of the medical system can be formidable barriers to planning.”

“Trust your own judgement.”

“While working in ICU, I learned that patients do not know what full code means, and they need to be asked direct, clear questions about allowing the dying process vs. being brought back to life, especially in cases of anticipated terminal illness tx (sic). Also, to discuss patients' spiritual beliefs, as this is important to process as they are dying, normalizing traditional vs. non-traditional spirituality.”

“Education and forms.”