Engaging Homeless Persons in End of Life Preparations

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BACKGROUND: There are no prospective studies that have investigated the effects of an intervention to improve end of life (EOL) care in an underserved population.

OBJECTIVE: To determine whether homeless persons will complete an advance directive (AD).

DESIGN: Randomized trial comparing two modes of providing an opportunity for homeless persons to complete an AD. Half of the subjects were randomized to a self-guided group (SG) who were given an AD and written instructions; the other half were given the same material but, in addition, were offered the opportunity to receive guidance to complete the AD (CG).

PARTICIPANTS: Fifty-nine homeless persons recruited from a drop-in center.

MEASURES: Rate of AD completion and baseline and 3-month follow-up EOL-related knowledge, attitudes, and behaviors.

RESULTS: The overall AD completion rate was 44%, with a statistically significant higher completion rate of 59% in the CG group compared to 30% in the self-guided only group. Frequency of worry about death decreased among those who filled out an AD from 50% to 12.5%, and also among those who did not (25% to 12.5%) ($p < .05$). Among those who filled out an AD, there were increases in plans to write down EOL wishes (56% to 100%; $p < .05$) and plans to talk about these wishes with someone (63% to 94%; $p < .05$).

CONCLUSION: This study demonstrates that people living in dire economic and social situations will complete an AD when offered the opportunity. While offering guidance resulted in higher rates of completion; even a simple self-guided AD process can achieve completion of ADs in this population.

KEY WORDS: homelessness; poverty; end of life; advance directives.

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BACKGROUND

Improving end of life (EOL) care is an important goal of the US health system¹. One main finding of the NIH State of the Science conference on EOL care was that the majority of EOL research has been conducted on narrowly defined populations². Consensus recommendations included more study of under-represented populations, such as the underserved or underinsured. The limited EOL research examining individuals from lower socioeconomic strata is mainly descriptive but indicates that disparities exist in the delivery and experience of EOL care.

A core process in good EOL care is advance care planning (ACP) and writing advance directives (ADs)¹, but these are known to occur less often within disadvantaged populations. There are, for example, associations between lower levels of education, socioeconomic (SES) and insurance status, minority status and lower completion rates of ADs^{3–9}.

Homeless persons face the most disadvantaged financial and social circumstances. Poverty is the greatest risk factor for homelessness¹⁰—half of all homeless adults receive less than \$300 a month in income¹¹. This population is significant, with a point prevalence of several hundred thousand^{12,13} and a lifetime prevalence of 7.4%¹⁴. Homeless persons suffer from poor health disproportionately^{15,16}, have many barriers to health care^{17,18} and die at 3 to 10 times the rate of domiciled populations^{19–21}. In addition, there are high rates of mental illness and substance abuse among homeless persons^{22–24}, which are associated with poorer health status and outcomes^{25–27}. These morbidities may be hypothesized to similarly adversely affect EOL care and outcomes; perhaps by presenting additional barriers to care or affecting specific aspects of care, such as pain control²⁸.

Recent empirical work has demonstrated that homeless persons are concerned about EOL care^{28–32}, and have unique challenges, barriers, and wishes when seeking or obtaining EOL care^{28–31}. One normative theme that emerges from this nascent literature is the prescription for making one's EOL wishes known, particularly through written means, such as ADs^{28–31}.

However, in addition to the empirical evidence that homeless persons value and desire written ADs, there are concep-

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tual justifications to explore the use of ADs among the homeless. In a population characterized by poor quality personal^{33,34} and health care relationships^{17,18,35,36}, it is likely that many homeless persons lack surrogate decision-makers. In addition, they may be less likely to have persons emerge who might overrule an AD. Research demonstrates that written documentation may be all that exists among homeless persons to direct care providers should they become seriously ill and/or unable to express their wishes about medical care²⁸⁻³¹. In this context, then, ADs, tailored to the unique concerns of homeless persons, can be hypothesized to be completed at a higher rate than in the general population.

OBJECTIVE

There is a need for research on interventions that may improve EOL care in impoverished subgroups². A comprehensive literature search found no prospective trials tailored to improving EOL care in poor or underserved populations. This paper describes a prospective, randomized pilot trial to improve the EOL decision-making process for homeless persons by facilitating ACP. The intervention is derived from EOL concerns elicited from previous investigations of homeless persons²⁹⁻³¹. The following were the primary study questions: 1) Given the opportunity, will homeless persons complete an AD, and is the completion rate higher when one-on-one guidance is offered as compared to self-guided material only and 2) Did completion of an AD improve knowledge and change attitudes and beliefs regarding EOL care among homeless persons?

PARTICIPANTS

Participants were recruited in September 2006 from Listening House, a drop-in center for homeless individuals located in St. Paul, Minnesota. Participants represent a convenience sample. On the recruitment day, a general announcement was made and the project described orally to potential participants by the investigators as a "study to see whether homeless persons would fill out a Living Will if given the chance and whether filling one out would change your attitudes and beliefs about EOL planning." Participants were then invited to participate and screened for eligibility. Participants were required to speak English, be at least 18 years old, and have been homeless during the previous six months, using the operational definition of homelessness adapted from the Stewart B. McKinney Homeless Assistance Act (P.L. 100-77 enacted in July 1987). For this study, homeless adults are defined as persons age 18 or older who spent the previous night in one of the following situation: 1) in a public or private shelter or 2) "on the streets" (in a public or private place not designed for, or ordinarily used as, regular sleeping accommodations for humans. These include, for example, public or abandoned buildings or places out-of-doors like parks)³⁷. All potential participants met study criteria and were then enrolled after informed consent was obtained. The study was approved by the IRB of the University of Minnesota.

DESIGN

After consent was obtained, all participants completed a baseline survey including demographics and questions about EOL and ACP knowledge, attitude, and behaviors (KAB). After completion of the survey, subjects received compensation and were then randomized into one of two intervention arms: self-guided AD materials (self-guided, SG) or self-guided AD materials plus the opportunity to receive one-on-one guidance from a counselor (counselor guided, CG). Participants were informed of their assigned arm and also instructed that there would be no additional compensation for completing an AD. It was very important for the integrity of the main study outcome to make it clear that completion of an AD was voluntary and not associated with compensation.

All participants received an AD entitled HELP (Honoring End of Life Preferences) and written educational materials about ADs and ACP. Participants randomized to the SG group were invited to fill out the HELP form on their own and, if requested, were given limited assistance including witnessing signatures to insure legality of the document. Participants randomized to the CG group were provided with the same self-guided AD as the SG participants and told that they could either complete it on their own or, should they choose, meet with an investigator for one-on-one counseling to complete the AD on another, scheduled day.

All participants were offered assistance in storing the completed ADs at Listening House. They were also encouraged to keep the original document—several requested multiple copies to distribute to health care providers, loved ones, and other relevant parties.

The HELP AD was specifically designed for marginalized populations and is constructed from three components: 1) elements necessary so that it would be a legal document in Minnesota; 2) the core elements of the dignity conserving care model (DCC) proposed by Chochinov^{38,39}; and 3) adaptations for the homeless population based on previous studies²⁹⁻³¹. Dignity has been identified as one of the most basic requirements in caring for the dying patient^{2,38,39}. The HELP AD includes the higher level, dignity-related needs identified in the DCC model and also incorporates EOL concerns identified by homeless persons, some of which are unique to this population, such as a fear of improper body disposal or dying anonymously²⁹⁻³¹.

Three months after enrollment, post-intervention assessments were conducted with both SG and CG subjects. Participants were compensated for returning for this 3-month follow-up survey.

MEASUREMENT

The primary outcome of interest was the completion of the HELP AD. A document was considered complete if a copy was given physically to the investigators at any time during the duration of the study or self-reported as completed at follow-up, and could only be counted once. If a participant did not return for the 3-month follow-up visit or did not turn in a copy of the HELP document, it was assumed that the participant did not complete an AD.

Secondary outcomes include EOL and ACP KAB variables measured through a questionnaire administered at baseline

and at 3-month follow-up. As a comprehensive literature search did not produce an appropriate instrument that had been validated in this population, a questionnaire was developed incorporating EOL concerns shown to be relevant among homeless persons²⁹⁻³¹.

ANALYSES

Descriptive summary frequencies characterizing the baseline sample are presented. Proportions of participants completing an AD stratified by baseline characteristics and intervention assignment (SG vs. CG) are estimated by observed percents and tested for differences using Fisher's exact tests and Cochran-Armitage trend tests. Longitudinal trends in EOL KAB are based on the individuals who had complete data, i.e. those who returned for the 3-month follow-up. Potential differences in baseline characteristics between 3-month responders and non-responders are examined. The longitudinal models tested for the following: A) overall difference in EOL KAB outcomes between those who filled out an AD versus those who did not; B) overall longitudinal changes in EOL KAB outcomes; and C) differential longitudinal change in EOL KAB outcomes for those who filled out an AD compared to those who did not. Generalized estimating equations regressions (PROC GENMOD in SAS with a REPEATED statement) which account for correlated measurements within individuals were used to test the effects.

RESULTS

Fifty-nine individuals were enrolled in the study. The mean age was 45, and 89% had at least a high school education (Table 1). 57% lived in a shelter, 22% in outdoor areas, and 40% had not seen their family in over a year. Forty-one percent of all participants (n=24) returned for the three-month follow-up (9 of 29 from the CG and 15 of 30 from the SG group). There were no significant baseline demographic differences between those who returned for follow-up and those who did not.

Completion of Advance Directive

The overall HELP AD completion rate was 44% (26/59), with a higher rate of 59% (17/29) in the CG group compared to 30% (9/30) in the SG group (p-value=.02). While not statistically significant, higher education and female gender were associated with a higher completion rate. Half of blacks completed the HELP form compared to one-third of whites. Half of persons with a recent serious illness completed an AD, compared to 42% of those who did not report one.

Change in EOL Knowledge, Attitudes, and Behaviors

Longitudinal regression analyses performed on those who returned for follow-up (n=24) demonstrated no change in knowledge tested about EOL care (Table 2). Those participants who did not fill out an AD had a greater belief that there were "people who could help make decisions for me if I were seriously ill" (p-value=.05) than those who completed one. Similarly,

there was an increase in belief that "someone will know and follow my wishes" among those who did not fill out an AD while those who completed an AD showed a decrease in this belief (p-value=.07).

Frequency of worry about death decreased among those who filled out an AD from 50% to 12.5%, but also among those who did not (25% to 12.5%) (p-value=.05). Among those who filled out an AD, there were statistically significant increases in plans to write down EOL wishes (56% to 100%) and plans to talk about these wishes with someone (63% to 94%) as well as overall higher baseline tendencies for these plans and behaviors. Finally, those that filled out an AD had overall higher reporting of plans for a funeral and carrying of contact information in case of emergency.

DISCUSSION

Encouraging individuals to document preferences for EOL care through ADs has been central to efforts to improve EOL care. The importance of this process is recognized in the Patient Self Determination Act, which mandates that health care institutions ask patients about ADs and offer an opportunity to complete one. ADs, however, cannot resolve all conflicts about EOL care and have been subject to conceptual and empirical criticism in recent years². Some experts, for example, believe that written ADs, as traditionally constructed and executed, are inadequate for several reasons, including difficulty completing such documents^{40,41}; their inability to address changing circumstances⁴⁰⁻⁴²; poor rates of completion^{40,43,44}; being unavailable when needed^{40,45}; or being overruled by family or health care providers⁴⁰. Evidence also suggests that they may not affect care received^{46,47}.

However, in disenfranchised populations, such as the homeless, there are good empirical and theoretical justifications for pursuing ADs. Homeless people have less trust and greater worry about how they will be cared for by health professionals. They also are frequently alienated from family and have less confidence in surrogate decision-makers.²⁸⁻³¹ Homeless persons have demonstrated their belief in and desire for ADs to help direct medical decision-making and preserve autonomy²⁸⁻³¹, and there are reasons to believe ADs may prove effective among persons who are alienated. The process of exploring and documenting preferences for EOL care may provide a means of preserving autonomy, enhancing dignity, and giving voice to the unique concerns of disenfranchised and impoverished groups such as homeless persons.

This study demonstrates that homeless individuals can and will carefully consider and document their EOL preferences. The AD completion rate, even in the self-guided (SG) group, was higher than generally described in other populations, typically in the range of 20%^{48,49}. This study also demonstrates that a simple, reproducible one-on-one counseling guidance (CG) can have profound effects on the completion of ADs in this population, doubling the rate of completion from 30% to 59%.

Just as significant is the effect of the interventions on the attitudes towards EOL care and expression of autonomy. Completing an AD appeared to affect how homeless participants viewed their ability to control their death and dying process. For example, there was a decrease in pessimism about the worth of ADs among those who

Table 1. Descriptive Characteristics of Study Population and Corresponding Percent Who Filled out the Advanced Directive by Each Category

		Total sample % (n=59)	Percent who filled out the HELP form % (n=26)
Intervention group	SG	51% (30)	30% (9)
	CG	49% (29)	59% (17)
Gender	Male	75% (44)	43% (19)
	Female	25% (15)	47% (7)
Age	≤30	17% (10)	40% (4)
	31–40	17% (10)	50% (5)
	41–50	42% (25)	44% (11)
	≥50	24% (14)	43% (6)
Race	White	34% (20)	35% (7)
	Black	51% (30)	53% (16)
	Native American	7% (4)	50% (2)
	Hispanic	3% (2)	0% (0)
	Asian	2% (1)	0% (0)
	Mixed	3% (2)	50% (1)
Education	<HS	11% (6)	17% (1)
	HS	48% (25)	40% (10)
	>HS	40% (21)	48% (10)
Veteran	Yes	24% (13)	46% (6)
	No	76% (42)	43% (18)
Living location ^a	In street/park/car	22% (13)	38% (5)
	In shelter	57% (34)	50% (17)
	In hotel	10% (6)	33% (2)
	With family/friends	20% (12)	42% (5)
	Rent a place	15% (9)	22% (2)
Reported chronic disease/Disability	Yes	53% (31)	42% (13)
	No	47% (28)	46% (13)
Recent serious illness/Hospitalization	Yes	24% (14)	50% (7)
	No	76% (45)	42% (19)
When seen family	Within last year	60% (34)	47% (16)
	Over a year	40% (23)	43% (10)

^a Locations are not mutually exclusive, thus adding up to more than 100%

Table 2. Change from Baseline to 3-Month Follow-up for EOL Knowledge, Attitudes/Feelings, and Behaviors/Intentions for Those Who Filled out HELP form and Those Who Did Not (n=24 returned for 3-month follow-up)

	Did NOT fill out HELP (n=9) mean or percent		Did fill out HELP (n=15) mean or percent		Statistically significant tests [†]
	Baseline	F/U	Baseline	F/U	
KNOWLEDGE					
Knowledge regarding EOL care (# correct out of 4 questions)	3.5	3.5	3.5	3.1	
ATTITUDES/FEELINGS*					
Death is one of my major concerns or worries	1.75	1.75	1.82	1.88	
Injury or pain is one of my major concerns or worries	2.50	2.13	2.13	2.37	
I believe there are people who could help make decisions for me if I were seriously ill and could not say what kind of medical care I would want	2.89	2.13	2.19	2.13	A, C
It doesn't matter if I make a living will or tell someone about my wishes, because doctors and nurses will do whatever they want in any case	1.13	1.38	1.31	1.06	C
I am confident that someone will know and follow my wishes about my medical treatment if I go to the hospital with a serious illness	2.38	2.75	2.25	2.06	C
I am confident that the right person will be notified if I am sick or dying	2.50	2.50	2.69	2.56	
I am treated with respect when I go to the doctor's or the hospital	2.50	2.25	2.31	2.38	
Do you worry about death	25%	13%	50%	13%	B‡
BEHAVIORS/INTENTIONS					
I plan to talk to someone I know about what I would want to happen when I am seriously ill or dying (yes/no)	50%	63%	63%	94%	A, B
I plan to (or have already) write down my wishes about end of life care	25%	25%	56%	100%	A‡, B‡, C‡
I have made funeral arrangements or plans for my body's final resting place	13%	0%	44%	19%	A, B
I carry contact info of people if I become sick or die (yes/no)	25%	38%	69%	54%	A

* 3-point Likert scale, 1=Don't agree, 2=Somewhat agree, 3=Strongly Agree

[†] A. indicates an overall trend between filling out HELP form or not regardless of time; B. indicates an overall longitudinal trend regardless of filling out HELP form or not; C. indicates a differential longitudinal trend between those who filled out HELP and those who did not. Trends determined at the 0.10 level. [‡] indicates statistical significance at 0.05 level

completed one, and an increase in those who did not; i.e., filling out an AD was associated with the belief that ADs could enhance one's autonomy and fulfillment of wishes in health care setting.

The intervention also had a significant effect on the amount of worry about EOL care and dying among homeless subjects. Reflecting the prevalence of worry described in a Minnesota statewide survey of homeless persons⁵⁰, this study found that nearly half of the participants worried about whether they would receive appropriate EOL care if they were sick or dying. Among those who filled out an AD, the prevalence of worry decreased from 50% to 12.5%, which may reflect confidence that making EOL wishes known would contribute to the provision of appropriate care. There was also a trend towards decreasing worry among those who did not complete an AD, which may reflect discussions with family or others without written documentation. Another plausible explanation accounting for the decrease in worry among both groups is the speculation that merely raising this issue and encouraging discussion in a safe context may alleviate some of the fears around dying and EOL care.

Advance care planning forces consideration of the social circumstances one might face in event of serious illness. For example, those who filled out an AD were less likely to believe they would have surrogate decision makers, and the completion of an AD was associated with decreasing confidence that someone would know and carry out their wishes. In the context of alienation faced by many homeless persons, ACP and ADs reflect estrangement from family or potential surrogates and are most attractive to those with the least confidence in their relationships.

Beyond affecting attitudes and beliefs, completing an AD appears to have fostered empowering and autonomy preserving EOL planning behaviors among participants. Among those who filled out an AD, for example, there were significant increases in plans to write down wishes about care and plans to discuss their desires with others; these behaviors are recognized to be an integral part of good EOL care and planning¹.

Limitations of this study include its small sample size, which limits generalizability, and findings may not be generalizable to homeless persons who did not obtain services from Listening House; however, our sample reflected the demographics in a Minnesota survey of homelessness⁵⁰, and is also similar in composition to that found nationally¹³. It is also possible that the success of the intervention might not be replicable in settings where program staff would conduct the intervention, rather than our trained and motivated research staff.

Given that our attrition rate at the three months was higher than 50%, it is possible that subjects who stayed in the study differed from those lost-to-follow-up; however, there were no baseline differences between these two groups. Surprisingly, a greater proportion of subjects from the SG group were retained at 3 months than the CG group. We had expected that the greater attention received by the CG group would have resulted in greater retention rates. Several explanations are possible, but one might be that SG participants may have returned expecting or

desiring assistance in completing an AD. Alternatively, it is possible that the CG group had met their objectives by completing an AD. Future studies might reduce the high attrition rate by 1) having sufficient resources for tracking and follow-up, as seen in previous large longitudinal studies of homeless persons^{51,52}; and 2) revising the study design after consulting homeless persons and shelter staff regarding barriers and facilitators to follow-up.

Since the subjects were not blinded to intervention allocation, it is possible this knowledge may have affected how they responded to the study. However, blinding was not possible in this study—the subjects had to be told about the content of the arm to which they were randomized. In addition, the baseline survey was completed prior to randomization and was thus not affected by their assignment.

Finally, additional research is needed to determine whether AD completion leads to a change in care received; but, as noted earlier, it can be theorized that these written directives would have greater impact in an estranged population like the homeless. However, issues of dissemination and availability of these documents needs to be studied further as other studies in general populations have demonstrated that ADs are often not readily accessible^{40,45}; this may be exacerbated by homelessness and the episodic, fragmented health care associated with unstable housing.

Despite these limitations, this study demonstrates that people living in dire economic and social contexts are extremely interested in and worried about EOL care, and can be engaged to complete and continue autonomy and dignity preserving behaviors with a simple intervention. These data call for further investigation—in larger populations with longer follow-up times. Also, with longer follow-up periods, other outcomes should be studied, such as whether homeless persons' expressed wishes are followed when they become ill or die.

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Conflict of Interest: Dr. Bartels serves as a consultant for Advanced Circulatory Systems on an NIH-funded project, the ResQ trial. None of the other authors have any real or potential conflicts of interests to disclose or report.

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APPENDIX A

HONORING END OF LIFE PREFERENCES (HELP)

Health Care Directive

Identification

Name: _____ Date of Birth: _____

Religion: _____ email _____

Things which would help emergency and health care staff to identify me (e.g. scars, birthmarks, photo, other identification):

I _____, understand that this document allows me to do ONE OR BOTH of the following:

Part I: Name another person (called the health care agent) to make health care decisions for me if I am unable to decide or to speak for myself. [My health care agent must make health care decisions for me based on the instructions I provide, if any, the wishes I have made known to him or her, or must act in my best interest if I have not made my health care wishes known.] AND/OR

Part II. Give health care and post death instructions to guide others in making decisions for me. [These instructions may be used by health care providers, others assisting with my health care and my family, in the event I cannot make decisions for myself.]

Part I. Appointment of Health Care Agent:The person I want to make health care decisions for me is:

Relationship to me: _____

Telephone: _____

Address:

Optional appointment of another health care agent:

Name: _____

Relationship: _____

Phone: _____

Address: _____

I want my health care agent to do the following if I am unable to decide or to speak for myself:

If I am unable to decide or speak for myself, my agent has the power to (check):

- a. Consent to, refuse, or withdraw any health care treatment, service, or procedure _____
- b. Stop or not start medical intervention which is keeping or might keep me alive _____
- c. Choose my health care providers _____
- d. Choose where I live when I need health care and what personal security measures are needed to keep me safe _____
- e. Obtain copies of my medical records and allow others to see them _____
- f. Decide whether or not to donate organs, tissues, and eyes, when I die. _____
- g. Decide what will happen with my body when I die _____

List any additional powers or limits for my health care agent:

If a health care professional is appointed, describe the reasons for selecting that person:

People who should NOT be contacted in case of serious injury or death:

II: Health Care and After Death care instructions

If I have appointed an agent, I want him/her to follow the instructions which reflect my preference below.

People/agencies who should be notified in case of serious illness, injury or death (in addition to decision-maker(s) listed above):

These are instructions for my health care when I am unable to decide or speak for myself. These instructions must be followed (so long as they address my needs).

THESE ARE MY BELIEFS AND VALUES ABOUT MY HEALTH CARE

(I know I can change these choices or leave any of them blank)

I want you to know these things about me to help you make decision about my health care: _____

My goals for my health care: _____

My fears about my health care: _____

My spiritual or religious beliefs and traditions: _____

My beliefs about when life would be no longer worth living: _____

My thoughts about how my medical condition might affect my family: _____

THIS IS WHAT I WANT AND DO NOT WANT FOR MY HEALTH CARE
(I know I can change these choices or leave any of them blank)

Many medical treatments may be used to try to improve my medical condition or to prolong my life. Examples include artificial breathing by a machine connected to a tube in the lungs, artificial feeding or fluids through tubes, attempts to start a stopped heart, surgeries, dialysis, antibiotics, and blood transfusions. Most medical treatments can be tried for a while and then stopped if they do not help.

(Note: You can discuss general feelings, specific treatments, or leave any of them blank)

If I had a reasonable chance of recovery, and were temporarily unable to decide or speak for myself, I would want:

If I were dying and unable to decide or speak for myself, I would want: _____

If I were permanently unconscious and unable to decide or speak for myself, I would want: _____

If I were completely dependent on others for my care and unable to decide or speak for myself, I would want:

In all circumstances, my doctors will try to keep me comfortable and reduce my pain.

This is how I feel about pain relief if it would affect my alertness or if it could shorten my life: _____

There are other things that I want or do not want for my health care, if possible.

Who I would like to be my doctor: _____

Where I would like to live to receive health care: _____

Where I would like to die and other wishes I have about dying: _____

My wishes about donating parts of my body when I die: _____

My wishes about what happens to my body when I die (cremation, burial): _____

Any other things: _____

PART III: MAKING THE DOCUMENT LEGAL

This document must be signed by me. It also must either be verified by a notary public (Option 1) *or* witnessed by two witnesses (Option 2) to be made legal. It must be dated when it is verified or witnessed.

I am thinking clearly, I agree with everything that is written in this document, and I have made this document willingly.

My signature: _____

Date signed: _____

Date of birth: _____

Address: _____

If I cannot sign my name, I can ask someone to sign this document for me.

Signature of the person who I asked to sign this document for me:

Printed name of the person who I asked to sign this document for me:

OPTION 1: NOTARY PUBLIC

In my presence on _____ (date), _____
_____ (name) acknowledged his/her signature on this document or acknowledge that he/she authorized the person signing this document so sign on his/her behalf. I am not named as a health care agent or alternate health care agent in this document.

Signature of Notary

Notary Stamp

OPTION 2: WITNESSED SIGNATURE

Printed name: _____

Signature: _____

Witnesses' Signatures (2) :

Things to consider before completing HELP Form (pages 1-3)

It may be helpful to keep this form with HELP form when filed/stored

Illness-related Concerns:

Current illnesses/health challenges that concern me:

Symptoms of greatest concern:

A. Physical distress:

Psychological distress:

b1. Things I worry about related to death:

b2. Concerns I have about being recognized in case of emergency or death:

b3. Relationships that cause me concern or worry:

b4. Possible actions that would relieve any of the above concerns:

Level of Independence concerns:

Worries or concerns I have about my ability to think, communicate, or act:

Continuity of Self:

Roles or relationships which are important to me:

Person(s) I want to make medical decisions in case I am unable to make them (primary decision makers)

Note: list contact information on page 1 of this HELP form:

Maintenance of Pride:

I am most proud of these things:

I would want to be remembered as a person who:

People who care for me could do the following to respect my dignity:

Autonomy/ control:

Describe of options for expressing/recording EOL wishes:

I would like this information about care at the end of my life information stored as:
(check format(s)):

- a. Web-based format _____
- b. Paper-based format _____
 - a. If paper, where stored?

- c. I prefer no record of this discussion

Finding Spiritual Comfort

After death, what should happen to my body (Record contact information on page 2 of HELP form):

- a. Burial (where) _____
- b. Cremation and ashes put where _____

- c. A memorial service (where/ by whom) _____

- d. Other _____

My concerns related to religion of spirituality are:

- a. Who should be notified for assistance with these needs (name, address, phone or other contact information):

- b. Who could be helpful in making arrangements/ notifying others (name, address, phone or other contact information):

If medical treatment failed to restore consciousness, and I would remain seriously ill or disabled, I would want (check on line):

- a. all medical measures taken for survival _____
- b. limited medical measures for comfort (e.g. medications, treatment of other symptoms that make you uncomfortable) _____
- c. no treatment _____
- d. I would want these directives followed even if I were pregnant? Yes ____ No ____
- e. I would want nutrition/hydration (food and fluids) to be considered a medical treatment which could be discontinued as part of an end of life care plan?
Yes ____ No ____

Wishes regarding organ donation:

When I die:

- I want to be an organ donor _____
- I do NOT want to be an organ donor _____

Wishes regarding care of my body when I die:

- a. burial or cremation site (place, contact, address, phone)

b. a memorial service at (place, contact, address, phone)

c. other wishes in the event I die: (describe)

Other values that should influence my care in the event of serious injury or death:

Additional concerns:

Are there any questions not asked or concerns that we haven't considered that are important for end of life care planning for you?