

AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults

Timothy W. Farrell, MD, AGSF, Eric Widera, MD, Lisa Rosenberg, MD, Craig D. Rubin, MD, AGSF, Aanand D. Naik, MD, Ursula Braun, MD, MPH, Alexia Torke, MD, MS, Ina Li, MD, Caroline Vitale, MD, AGSF and Joseph Shega, MD for the Ethics, Clinical Practice and Models of Care, and Public Policy Committees of the American Geriatrics Society

Abstract

In this position statement, we define unbefriended older adults to include patients who: (1) lack decisional capacity to provide informed consent to the medical treatment at hand; (2) have not executed an advance directive that addresses the medical treatment at hand and lack capacity to do so; and (3) lack a legally authorized surrogate, family or friends to assist in the medical decision-making process. Given the vulnerable nature of this population, clinicians, health care teams, ethics committees and other stakeholders working with unbefriended older adults must be diligent when formulating treatment decisions on their behalf. The process of arriving at a treatment decision for an unbefriended older adult should be conducted according to standards of procedural fairness and also include capacity assessment, a search for potentially unidentified surrogate decision makers (including non-traditional surrogates) and a team-based effort to ascertain the unbefriended older adult's preferences by synthesizing all available evidence. A concerted national effort is needed to help reduce the significant state-to-state variability in legal approaches to unbefriended patients. Proactive efforts are also needed to identify older adults, including "adult orphans," at risk for becoming unbefriended and to develop alternative approaches to medical decision making for unbefriended older adults. This document updates the 1996 AGS position statement on unbefriended older adults.

Key words

Unbefriended, capacity assessment, surrogate decision maker, substituted judgment, best interest, ethics committee, position statement

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When caring for older adults who lack capacity to make medical treatment decisions, clinicians often rely upon advance directives or surrogate decision makers for guidance. However, at times clinicians face the particularly challenging situation of making medical treatment decisions for unbefriended older adults. Unbefriended older adults are unable to participate in directed decision making, lack an advance directive pertaining to the medical decision under consideration and the ability to execute an advance directive, and also lack a legally assigned surrogate decision maker or others (such as family or friends) to assist in the medical decision-making process.¹ Given the barriers to the care of unbefriended older adults, special attention must be paid so that treatment decisions regarding these highly vulnerable patients are made in a practical and ethical manner.

This paper represents a statement of the official policy positions of the American Geriatrics Society (AGS) and is an update of the 1996 AGS position statement on this topic.² The rationale for each recommendation is provided in the full position paper (see the Appendix, available at www.GeriatricsCareOnline.org).

METHODS

The AGS Ethics Committee, which is charged with addressing issues that improve public and professional understanding of ethical and moral issues intrinsic to caring for older adults, developed these policy and clinical recommendations in collaboration with the AGS Clinical Practice and Models of Care Committee and the AGS Public Policy Committee. These committees conducted a structured literature review and examined other relevant reports and studies pertinent to this statement. The draft recommendations were reviewed and approved by the following AGS Committees: Clinical Practice and Models of Care, Ethnogeriatrics, and Public Policy. The position paper and recommendations were reviewed and approved by the AGS Executive Committee on behalf of the AGS Board of Directors.

AGS Policy and Clinical Practice Recommendations

The AGS believes that a concerted national effort is needed to help reduce the significant state-to-state variability in legal approaches to unbefriended patients. Variations in laws across states create confusion for health care providers, particularly those who practice near state borders. As a consequence, harms including treatment delays or prolongation of potentially burdensome treatments

may result. Proactive efforts are also needed to identify older adults without potential surrogates (often referred to as “adult orphans”) who are at risk for becoming unbefriended and to encourage this group to engage in advance care planning and/or identify a health care surrogate. These individuals retain capacity to make their own medical decisions, but lack a surrogate decision maker or have yet to complete advance health care directives including living wills or durable power of attorney documents.³

Policy Recommendations

1. National stakeholders should work together to create model legal standards regarding unbefriended older adults that could be considered for adoption by the states.
2. Clinicians, health care organizations, and other stakeholders should work proactively to prevent older adults without potential surrogates from becoming unbefriended.
3. Clinicians, health care organizations, communities, and other stakeholders should develop innovative, efficient and accessible approaches to promote adequate protections and procedural fairness in decision making for unbefriended older adults.

Clinical Practice Recommendations

4. Medical decision making for unbefriended older adults should include adequate safeguards against *ad hoc* approaches and ensure procedural fairness.
5. Clinicians should consider non-traditional surrogate decision makers for unbefriended older adults.
6. Clinicians should assess medical decision-making capacity in a systematic fashion.

7. Clinicians and healthcare institutions should develop and standardize/systematize methods to make decisions for unbefriended older adults in urgent, life-threatening situations.
8. For patients with long-term incapacity, clinicians and healthcare institutions should ensure longitudinal access to a decision-making surrogate who is familiar with the patient's medical condition and specific circumstances.
9. When applying the best interest standard to unbefriended older adults, institutional committees (such as an ethics committee) should synthesize all available evidence, including cultural and ethnic factors, during deliberations about treatment decisions.

Summary:

Unbefriended older adults are among the most vulnerable members of society and, as such, those responsible for making medical treatment decisions on their behalf owe them a special duty of diligence and care. Healthcare policy makers, clinicians, health care institutions and communities alike must work to ensure that medical decision making for this population proceeds in an ethical and equitable fashion. Proactive preventive steps should be taken to reduce older adults' risk of becoming unbefriended. When older adults do become unbefriended, their best interest would be served by applying a consensus legal standard across all states to their medical decision making. Clinicians who care for unbefriended older adults should follow a systematic process to determine capacity and identify surrogate decision makers.⁴ In order to ensure procedural fairness, health care teams, and not individual clinicians, should synthesize all available evidence when making medical treatment decisions for unbefriended older adults.⁴

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Requests for Single Reprints: Mary Jordan Samuel, Senior Manager, Special Projects and Governance, American Geriatrics Society, 40 Fulton Street, 18th Floor, New York, NY 10038.

Current author addresses and author contributions are available at: [www.
http://onlinelibrary.wiley.com/journal/10.1111/%28ISSN%291532-5415](http://www.onlinelibrary.wiley.com/journal/10.1111/%28ISSN%291532-5415).

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Current Author Addresses:

Timothy W. Farrell, MD, AGSF, University of Utah School of Medicine, VA Salt Lake City Geriatric Research, Education and Clinical Center, 30 N 1900 E, AB 193 SOM, Salt Lake City, UT 84132-0001

Eric Widera, MD, University of California San Francisco, San Francisco VA Medical Center, NHCU, SFVAMC Bldg 208, San Francisco, CA 94121

Lisa Rosenberg, MD, Roseman University of Health Sciences, 2963 Kedleston St., Las Vegas, NV 89135-2232

Craig D. Rubin, MD, AGSF, University of Texas Southwestern Medical Center, 5323 Harry Hines Blvd, Dallas, TX 75390-8889

Aanand D. Naik, MD, Michael E. DeBakey VA Medical Center and Baylor College of Medicine, 2002 Holcombe (152), Houston, TX 77030

Ursula Braun, MD, MPH, Baylor College of Medicine, 1 Baylor Plz, MS230, Houston, TX 77030-3411

Alexia Torke, MD, MS, Indiana University, 1101 West 10th St., Indianapolis, IN 46202

Ina Li, MD, Christiana Care Health System, N. 1400 Washington St., Suite 327, Wilmington, DE 19801-1024

Caroline Vitale, MD, AGSF, University of Michigan, VA Ann Arbor Healthcare System, 2215 Fuller Rd, GRECC 11G, Ann Arbor, MI 48105-2303

Joseph Shega, MD, VITAS Healthcare, 9616 Lake Hugh Dr, Gotha, FL 34734-4600

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The AGS Ethics Committee members who contributed to this position statement include: Christina Bell, MD, PhD; Ursula Braun, MD, MPH; Anthony Caprio, MD; Jeffrey Escher, MD; Manuel Eskildsen, MD, MPH; Timothy W. Farrell, MD, AGSF; Aanand D. Naik, MD; Ramona Rhodes, MD; Lisa Rosenberg, MD; Joseph Shega, MD; Alexia Torke, MD, MS; Elizabeth Vig, MD, MPH; Caroline Vitale, MD, AGSF; and Eric Widera, MD.

The Clinical Practice and Models of Care Committee, Ethnogeriatrics Committee and Public Policy Committee reviewed the statement. The AGS Executive Committee reviewed the statement and provided final approval on July 21, 2016.

APPENDIX: EXPANDED BACKGROUND AND RATIONALE

Over the last decade there has been growing recognition of the need for improved approaches to medical decision making for unbefriended older adults, likely due to the confluence of several factors that affect medical decision-making capacity and the availability of surrogate decision makers. The US population is aging, and consequently, there has been increased attention to geriatric syndromes that impact capacity, such as dementia or delirium. Older adults may often lose the capacity to make their own decisions during an acute exacerbation of a serious medical illness that requires an invasive or intensive therapeutic intervention. According to one study, among older adults near the end of life, 42.5% required a medical decision at the end of life, of which 70.3% lacked decision-making capacity when care decisions were required.¹ Within the intensive care unit setting, 16% of those individuals admitted² and one in four who died lacked decision-making capacity and a surrogate during their entire ICU stay.³ Approximately 3 to 4% of patients residing in the long-term care setting are thought to be unbefriended.⁴ Many older adults might have had surrogates earlier in their lives, but as they reach the extremes of age, those surrogates may be unavailable to act as medical decision makers. The aging Baby Boomer generation is particularly at risk as more than 10 million live alone and 20% are childless.⁵ Additional research is needed to better quantify the number of unbefriended older adults across other care settings, including outpatient practice. Additional research is also needed to better understand how cultural and ethnic factors affect preferences for care and to help identify options for non-traditional surrogate decision makers.

POLICY RECOMMENDATIONS

Creating Model Legal Standards

The AGS supports greater uniformity with respect to states' legal standards involving unbefriended older adults. Existing laws and pending legislation governing surrogate decision making lack uniformity and are often unclear.⁶ Seven states lack surrogate consent laws. Among those states with surrogate consent laws, some states adopt a hierarchical approach involving a ranked list of family members, while other states require consensus among a group of surrogate decision makers.⁷ There are differences among jurisdictions as to the extent of the surrogate's authority, the authority of nonfamily members, the permissibility of the patient's physician to act as a surrogate in certain circumstances, the degree of illness or disability that a patient must have in order for the surrogate to make decisions regarding life-sustaining treatment and how to proceed when limits are placed on specific surrogates. In addition, some jurisdictions require "clear and convincing evidence" of the patient's previously expressed wishes, a standard that might be interpreted to require such compelling evidence that it is of little practical use. Decision-making standards that depend on knowledge of the patient's wishes, whether clearly known or merely presumed, will be insufficient for patients who lack both an advance directive and a surrogate decision maker, or who never had decisional capacity, such as those with severe developmental disability.

In jurisdictions where laws and regulations are cumbersome, impractical, or do not advance the widespread preferences for natural and comfortable dying, health professionals should work to educate legislators as to the need for change in these laws. Laws should be based on the needs and interests of the patient as he or she might have defined them, and not as the physician, the institution, or the state would define them.

Preventing Older Adults without Potential Surrogates from Becoming Unbefriended

Advocacy for unbefriended older adults must extend beyond the design of protocols for medical decision making on their behalf. Clinicians, health care organizations and other stakeholders must also proactively attempt to prevent older adults from becoming unbefriended. Older adults without potential surrogates (often referred to as "adult orphans") are individuals who retain capacity for medical decisions, but lack a surrogate decision maker or have yet to complete advance health care directives, including living wills or durable power of attorney documents.⁸ Robust patient-centered and interdisciplinary team-based efforts in the community setting, through the involvement of health care professionals including but not limited to primary care physicians and social workers, are needed to

assist these individuals in documenting their care preferences. Community-based clinicians may lack sufficient resources to provide the time-intensive and resource-intensive advance care planning services required for older adults without potential surrogates, especially if the older adult has impaired decision-making capacity for the matters of concern. As of January 2016, specific, Center for Medicare & Medicaid Services (CMS)-approved reimbursement codes for advance care planning⁹ should promote goals of care and advance care planning discussions, hopefully allowing for older adults without potential surrogates to have increased documentation of their care preferences in the medical record or in the form of a living will. For these individuals, this documentation is paramount - especially if they have no surrogate decision maker to appoint as a durable power of attorney for healthcare decisions - and may facilitate future decision making, according to the substituted judgment standard.

Whenever possible, clinicians should strongly encourage older adults who have an available and appropriate surrogate decision maker to appoint him or her as the durable power of attorney for health care decisions (and for other domains as appropriate, such as financial decisions). Assigning an appropriate surrogate decision maker in this way usually prevents the arduous process of appointing a guardian through a court of law. Documentation of patient preferences will also help to improve the likelihood that end of life preferences are known and followed by a future surrogate. Clinicians should consider utilizing patient-friendly materials to facilitate the advance care planning process.^{10,11,12}

Promoting Protections and Procedural Fairness in Decision Making for the Unbefriended

Identifying public guardians can be time consuming, expensive and slow. Moreover, some states prohibit public guardians from authorizing DNR orders or other end of life decisions, potentially creating additional barriers to the provision of high-quality care for older adults with advanced illness.⁶ As a result, the AGS encourages clinicians, health care organizations, communities and other stakeholders to develop innovative models for medical decision making for unbefriended older adults, such as several already developed.¹³ For example, the Veterans Administration allows physicians to make certain decisions, but applies increasingly strict procedural standards as the treatment decision becomes more complex. Decisions to withhold or withdraw life sustaining treatments can also be made after review by an interdisciplinary committee,¹⁴ which might include a physician, nurse, social worker and community member. Certain states, such as Arkansas, allow attending physicians to make decisions on behalf of

unbefriended adult patients in consultation with an institution's ethics officials.¹⁵ Indiana law allows for volunteers to serve as guardians.¹⁶ One successful program developed by the Indianapolis safety-net hospital matches trained volunteers to unbefriended adults.¹⁷ All volunteers are supervised by an attorney with expertise in guardianship and elder care. Guardians receive extensive training and are generally paired with one patient at a time. In a published report describing the first 50 patients enrolled in this program, 15 patients died during the observation period. All had a DNR order in place at the time of death and all but one had a comfort-focused plan of care documented in the medical record. In 3 cases, the patient regained capacity and the guardianship was terminated. The program has since transitioned to a local non-profit organization and serves several area hospitals.¹⁸

CLINICAL RECOMMENDATIONS

Medical Decision making for the Unbefriended

Regardless of the person or entity involved, the process used for decision making for unbefriended older adults should not proceed on an *ad hoc* basis. Rather, health care institutions' policies should be created which specify how decisions should be made. At minimum, such policies should be consistent with state law and ensure adequate protections for the unbefriended. This includes ensuring that there is oversight by a legitimate body, transparency in decision making, reason-giving based on relevant principles and procedures for appealing and revising individual decisions.¹⁹

When caring for unbefriended older adults, clinicians often rely on their own best judgment on how to proceed, with little to no oversight. For example, in a landmark study, 14% of life support decisions for unbefriended ICU patients were made without hospital or judicial oversight.³ Potential advantages of the clinician as decision maker include a genuine understanding of an individual's prognosis, a theoretically enhanced ability to consider what is in the patient's best interest, a sense of professional obligation and the ability to make timely decisions. Laws in several states, however, prohibit clinicians from serving as medical surrogate decision makers, even when requested by the patient.²⁰

Disadvantages of the clinician as decision maker include inadequate protections for unbefriended patients against physician bias or conflicts of interest within the medical decision-making process.²¹

Furthermore, clinicians making unilateral decisions do not typically explain the benefits, burdens, and alternatives to a decision maker who is independent from the clinical team.

For some incapacitated persons, displaced health care decisions are made by a guardian, also called a guardian of person or conservator of person – a surrogate decision maker appointed by a judge. However, guardianship might not always be appropriate or available. Guardianship creates a duty for one individual to make decisions for another individual, and may be restricted to medical decision making or may be more global in scope. With the imposition of global forms of guardianship, the individual's constitutional rights are removed; in recent years, more limited forms of guardianship have been favored by the courts. The guardian may be completely unknown to the patient, or a "stranger guardian."²² While indicated in some circumstances, guardianship is generally a last resort to be avoided through less restrictive alternatives whenever possible.²³ For those individuals who are permanently incapacitated and who also lack an advance directive, guardianship is a reasonable option. For an individual who is acutely ill with the possibility of recovering capacity, guardianship is less appropriate (see position 7).

In contrast to health care proxies and durable powers of attorney, guardianship protections include court oversight by definition. Disadvantages of the guardianship system include the time and expense required to establish guardianship. These barriers can potentially delay the provision of appropriate care, including symptom relief at the end of life. If assigned a guardian while temporarily incapacitated, the individual under guardianship must prove that he or she has regained capacity in order for guardianship to be removed. This proof must be provided in a court of law at a time when the individual does not control her own resources (e.g. no authority to spend money on an attorney or on medical consultation to re-evaluate capacity). For these reasons, guardianship is generally ill-suited for complex and often urgent treatment decisions (see position 7).

Decision-making pathways for unbefriended older adults must have adequate safeguards. For example, treatment decisions derived from team consensus (including, but not limited to, 2 or more attending physicians and also available surrogate(s)), are preferred over treatment decisions derived from an individual. When time allows, an external entity such as an ethics committee could be authorized to review treatment options and to consent to the proposed treatment decision on behalf of the unbefriended patient.

Non-traditional Surrogates

There should be an attempt made by health care teams to locate an advance directive and to identify family members and friends who have been meaningfully involved in the patient's life such that they are familiar with the patient's values and preferences. If the clinical circumstances permit, clinicians should consider enlisting the assistance of a social worker, case manager or state agency to assist in identifying a person or persons who know the individual well.

It should not be assumed that the absence of traditional surrogates (next-of-kin) means the patient lacks a suitable surrogate decision maker. A nontraditional surrogate,²⁴ such as a close friend, partner, a live-in companion who is not married to the patient, a neighbor, a close member of the clergy, or others who know the patient well, may be the appropriate surrogate. Health professionals should make a conscientious effort to identify such individuals. The most appropriate surrogate for the incapacitated patient is one who has loving and intimate knowledge of the patient's wishes or value system. In some cases, surviving family members have only remote knowledge of the patient's values, or are estranged, whereas close friends or others with more proximate interactions with the incapacitated patient might better represent the patient's recent and relevant value system. If such a patient has developed other intimate relationships, there may well be an identifiable and appropriate surrogate. Clinicians should familiarize themselves with hospital and other institutional policy and state law regarding the involvement of nonfamily surrogates.²⁵

Assessing Medical Decision-Making Capacity

Autonomy in decision making is a fundamental ethical principle that should be adhered to whenever possible. Clinicians should advocate for older adults' participation in decision making to the extent possible, even after they have been determined to lack capacity to make medical decisions.²⁶ Decisional capacity is specific to each patient and to a particular medical decision. For example, although it is increasingly recognized that patients with mild cognitive impairment are at risk for impaired decisional capacity,²⁷ these patients still often retain decisional capacity for most or all choices, including the ability to designate a surrogate decision maker. Furthermore, those with more severe cognitive impairment who cannot comprehend complex decisions may still possess the capacity to make simple decisions or to convey their opinions regarding the burdens and benefits of ongoing treatments. In instances of

cognitive impairment, delirium, or psychiatric conditions, every attempt should be made to alleviate any exacerbating factors and improve capacity for participation in decision making.

Capacity should be formally assessed using accepted guidelines if not already done within a reasonable period of time. Such assessment need not be reserved for specialists such as psychiatrists, as primary care physicians and geriatricians should also be capable of performing capacity assessments. Since capacity can change over time, it should also be assessed periodically even when there is not a medical decision at hand. When an explicit capacity evaluation is required, clinicians should be encouraged to use a structured approach to capacity assessment since evidence suggests that unstructured capacity assessments are often performed poorly.²⁸

Clinicians should attempt to address communication barriers prior to making medical treatment decisions for all older adults, including unbefriended patients. Communication barriers may include sensory deficits (e.g. vision or hearing loss), limited health literacy, differences in language or differences in culture. Appropriate recognition of communication barriers may identify patients previously thought to lack capacity who in fact retain capacity to make some or all of their medical decisions.

Making Decisions for the Unbefriended in Urgent, Life-threatening Situations

For urgent, life-threatening situations, such as emergent surgery, clinicians and health care institutions should develop methods to make decisions for incapacitated older adults who lack surrogates. These methods might include allowing the attending physician and a consulting physician to make time-sensitive choices within established protocols subject to retrospective review.

Surrogate decision-making laws and policies should not hinder the patient's ability to die naturally and comfortably. Non-beneficial life-sustaining treatments should not be performed on terminally ill patients solely because they lack a surrogate decision maker. Among the few patients who survive resuscitation, patients with advanced illness experience poor outcomes,²⁹⁻³⁴ including the inability to live independently and/or a quality of life which may not represent what is valuable to them in living.

Long-term Incapacity

There are many incapacitated patients, such as those residing in long term care institutions, for whom health care decisions will be recurrent over their remaining lifetime. The admission process to a long term care institution should trigger ascertainment of surrogacy by a formalized process. Patients with long-term incapacity and no surrogate available are best served by having a longitudinal surrogate who is familiar with their medical conditions and specific circumstances. The broader community should develop a formal process to ensure that an appropriate guardian is appointed or that other decision-making procedures are followed.

Use of Institutional Committees

The best interest standard³⁵ is typically applied only as a last resort when there is no advance directive available and a surrogate decision maker cannot be identified. According to this approach, when informants do not exist or are not able or willing to provide information about a patient's wishes, decision makers must rely on this best interest standard in which decisions are made from the perspective of a reasonable person after weighing a treatment's benefits and burdens.

Institutional committees, such as ethics committees, should require the synthesis of all available evidence about unbefriended older adults' treatment preferences, including cultural and ethnic factors, when applying the best interest standard. This evidence can include information from those who are not legally assigned surrogates but who nonetheless have participated in the unbefriended patient's care, such as a primary care physician. For example, one hospital emphasizes marshalling all available resources,³⁶ including learning about the patient's social and medical history through discussion with friends, religious affiliations, current and previous care providers and the patient's own statements or wishes to gain a sense of the patient's life story and priorities. Next, this institution formulates an objective assessment of the patient's current response to his or her illness and treatment course, including whether it will be in the best interest of the patient to continue this course. Lastly, all options from the health care team (caregivers, consultants, primary care providers, social workers, etc.) are considered. This process allows a group of people directly connected to the patient to build a consensus on what the patient would have likely chosen.

CONCLUSION

This position statement updates the 1996 AGS position statement on unbefriended older adults.³⁷ Key additions include a call to help decrease state-to-state variability in legal standards regarding the unbefriended, as well as a strong recommendation to develop innovative models to overcome significant legal, financial, and other barriers to timely and appropriate medical decision making for this population. Clinicians should ensure procedural fairness regarding medical decision making by adopting a systematic, team-based approach that synthesizes all available evidence regarding unbefriended older adults' treatment preferences. The AGS also supports proactive efforts to prevent older adults from becoming unbefriended. By adopting these measures, clinicians and policymakers will be well positioned to improve the care of unbefriended older adults.

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