

# Life-Sustaining Treatment Decisions for Unbefriended Nursing Home Residents: Application of a Clinical Ethics Algorithm

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## Abstract

**Background:** Due to fear of running afoul of regulations, clinicians are reluctant to make decisions to withhold or withdraw life-sustaining treatment (LST) when patients cannot express treatment preferences and also lack available surrogate decision-makers. For these *unbefriended* patients, the resulting failure to make LST decisions can lead to medically inappropriate treatments of great burden and little benefit. To assist clinicians with making LST decisions, New York City’s public hospitals and nursing homes developed an Algorithm for the Unbefriended in 2016, which is intended to serve as a quality improvement aid, delineating a procedural method that provides a framework for clinical ethics consultations and is compliant with applicable laws and regulations, including New York’s Family Health Care Decisions Act (FHCDA).

**Methods:** From June 2016 through December 2017, the Algorithm was applied by the clinical ethics consultant (CEC) at Coler Rehabilitation and Nursing Care Center (a NYC Health + Hospitals nursing home) for 25 nursing home residents in order to help make end-of-life (EOL) care decisions which involved LST. In each of these 25 cases, LST decisions were endorsed by a multidisciplinary ethics panels assembled for the case discussions. From these initial 25 cases, aggregate outcome results were

**Table 1. New York City Health + Hospitals Clinical Ethics Consultation Guidelines: Algorithm for the Unbefriended**

**AN ALGORITHM FOR DECISIONS REGARDING WITHHOLDING OR WITHDRAWING LIFE SUSTAINING TREATMENT FOR ADULT PATIENTS WITHOUT DECISIONAL CAPACITY AND WITH NO SURROGATE**

Attending physicians may use the process described below to develop a plan of care when making a decision whether to withhold or withdraw life sustaining treatment from unbefriended patients without decisional capacity. If an attending physician seeks an ethics consultation for such a plan of care for an unbefriended patient, the clinical ethics consultation process should include the following elements:

1. Convene a multidisciplinary group, including primary care providers, major consultants, nursing and social work staff and the Palliative Care team to explore the medical/ethical issues related to options for care;<sup>1</sup>
2. Explore and decide if the patient had any advance directives; advance words, ideas, documents; or communicated values before considering the “best interest” standard;
3. Identify potential therapeutic interventions. Then identify those interventions that are unlikely to provide benefit, highlighting those that might increase suffering for no medical or health gain;
4. Consider national guidelines, NIH consensus statements and end-of-life standards developed by medical and specialty societies;
5. Specify the comfort and palliative interventions that are appropriate given the patient’s condition. Consider all options for comfort and palliative care; itemize those elements of the condition of the patient that would qualify the patient for palliative care;
6. Articulate the recommendation of the multidisciplinary group;
7. Prepare a Clinical Ethics Consultation Report documenting the meeting, including the issues discussed, and the recommendation that the multidisciplinary

- group reached in a form that reflects: 1. Ethically Relevant Medical Facts, 2. Ethically Relevant Social Facts, 3. Ethical Analysis of Treatment Options and 4. Ethics Recommendation;
8. Circulate the Clinical Ethics Consultation Report to the multidisciplinary; and
  9. In the event that the multidisciplinary group recommends withholding or withdrawing life-sustaining treatment, the attending physician with the independent concurrence of a second physician,<sup>2</sup> must determine whether the criteria below are satisfied to a reasonable degree of medical certainty before entering an order implementing the recommendation:
    - (i) life-sustaining treatment offers the patient no medical benefit because the patient will die imminently,<sup>3</sup> even if the treatment is provided; and
    - (ii) the provision of life-sustaining treatment would violate accepted medical standards.

This paragraph shall not apply to any treatment necessary to alleviate pain or discomfort.

- 1 NYC Health + Hospitals/Legal Affairs and/or Risk Management of the subject facility are available for consultation if necessary.
- 2 In a residential health care facility, the medical director of the facility, or a physician designated by the medical director, must be the second physician that provides the independent concurrence.
- 3 The standard for the unbefriended patient is designed to be more rigorous than that for a patient with a surrogate. For a patient with a surrogate the patient will be projected to die within 6 months. Thus, “imminent” must be somewhat of a shorter time but need not be immediate, which is not the term used.

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compiled and analyzed by the Coler CEC, who presided over each of these case discussions.

**Results:** In all 25 cases, the ethics panel, based upon the algorithm, endorsed withholding cardiopulmonary resuscitation (CPR), along with intubation and mechanical ventilator support. In 14 out of the 25 cases (56 percent), the panel endorsed no tube feeding orders. 6 out of the 25 residents (24 percent) were placed on a fully palliative care plan, and 10/19 (53 percent) of the remaining residents were placed on limited medical interventions/ mainly palliative care plan. In 17 out of the 25 cases (68 percent), the panel endorsed either no acute care transfers or limited acute care transfers. As of 12/31/17, 12 out of the 25 residents (48 percent) died with all but one death occurring at Coler. Based upon the results of a satisfaction survey later performed, there was widespread agreement among the users that the algorithm was very effective in helping to address the residents' EOL advanced care planning needs.

**Conclusions:** Based upon the outcome results achieved at Coler and a satisfaction survey, the algorithm has proven to be a very useful measure to help address the EOL care needs of this highly vulnerable population in an ethical and compassionate manner, with built-in safeguards that greatly minimize the likelihood that arbitrary decisions are made. It has de-emphasized solo decision-making by the attending physician and empowered the interdisciplinary care team with the lead of the ethics consultant to fully address the goals of care for the vulnerable unbefriended adult. The algorithm has provided guidance in addressing burdensome life-sustaining treatment with limited clinical benefit to individuals at the EOL. At Coler, EOL care planning has transitioned from prescriptions of aggressive treatment to palliative measures aimed at increasing comfort. The authors attribute the success of the algorithm to a transparent interdisciplinary panel approach, allowing each care team member to participate in decision-making for the patient's best interest while adhering to evidence-based best practices.

### Introduction

The decision to withhold or withdraw life-sustaining treatment (LST) can be difficult when patients cannot express treatment preferences and also lack available surrogate decision-makers. For these *unbefriended* patients, clinicians are understandably reluctant to withhold or withdraw LST for fear of running afoul of policies, regulations, or laws. The resulting failure to make LST decisions can lead to medically inappropriate treatments of great burden and little benefit.

To assist clinicians with making LST decisions, New York City's public hospitals and nursing homes have developed an *Algorithm for the Unbefriended*. The algorithm

(Table 1, see page 80) is intended to serve as a quality improvement aid as it delineates a procedural method that provides a framework for clinical ethics consultations and is compliant with applicable laws and regulations, including New York's Family Health Care Decisions Act (FHCDA).<sup>1</sup>

According to the algorithm and the FHCDA, life-sustaining treatment<sup>2</sup> (LST) can be withheld or withdrawn if it (1) offers no medical benefit because the patient would die imminently (even if the treatment is provided) and (2) would violate accepted medical standards.<sup>3</sup> The duration of "imminently" is undefined in the FHCDA. Ethics consultants and legal advisors at NYC Health + Hospitals (the organization comprising New York City's public hospitals and nursing homes) have concluded that "imminently" is longer than "immediately" but should be no longer than a few weeks or months (Table 1, footnote 3).

LST decisions are dependent on the treatment in question and on the medical condition and prognosis of the hospital patient or nursing home resident. For example, cardiopulmonary resuscitation (CPR) in the nursing home setting is almost invariably associated with imminent death. Decisions to not perform CPR therefore would meet the requirements of the algorithm. In contrast, antibiotic treatment of pneumonia can materially prolong life. The withholding of antibiotics would therefore require the patient to have an underlying condition that is predictive of imminent death.

It is also important to determine that the treatment in question is LST. For example, tube feeding in advanced dementia has not been demonstrated to prolong life, let alone decrease morbidity or provide symptomatic benefit.<sup>4</sup> Therefore, it can be argued that the withholding of tube feeding for patients with advanced dementia, in accordance with the evidenced-based medical literature, should not be considered an LST decision, and, thus, it would not violate the requirements of the algorithm.

### Usage of Algorithms in Medicine

Checklists in medicine, the forerunner to algorithms, were borrowed from the aviation industry, in which their initial usage was to prevent accidents or errors by establishing a systematic tool that describes a series of actions for a particular process. These methods include action and verification steps to ensure that each action was performed with the intended goal of improving the quality of production. The most widely used checklist in medicine is the World Health Organization Surgical Safety Checklist, which is organized in a logical sequence of events that involves participation by the surgeon, anesthetist, and surgical nursing team for successful completion.<sup>5</sup> Clinical ethics consultations, however, do not easily fit into the world of "checklists," which direct and constrain linear

procedures; they require a more complex decision support tool. The Algorithm for the Unbefriended presented here is reflective of the deep complexity of the decisions about EOL patient care which are often the reason for calling a clinical ethics consultation. The purpose of this algorithm is to serve as a quality of care improvement aid to allow patients to die with dignity and to be spared at the EOL medically inappropriate treatments of great burden and little benefit in keeping with the current standards for end-of-life care.

### **General Requirements to be Met Prior to Application of the Algorithm for the Unbefriended**

Before we describe the actual experience of Coler Rehabilitation and Nursing Care Center (a NYC Health + Hospitals nursing home) in using the algorithm, it is important to take note of two general requirements that must be met, the first of which is that a diligent, good faith search was made to establish that the patient has no viable surrogates. The second is that a determination was properly made to establish that the patient lacks the capacity to make informed medical decisions.

### **Diligent Search to Establish That the Patient Has No Viable Surrogates**

A good faith effort must be undertaken to determine that there are no potential surrogates and/or advanced directives (oral and/or written). As nursing home residents at Coler are routinely referred for admission by short-term acute care hospitals (STACHs), the initial determination that the individual is unbefriended is made by the STACH, which utilizes all reasonably available modalities for searching for patient information. Upon admission to Coler, a further diligent search is conducted by key personnel including social workers, patient account representatives and members of the care team to corroborate the determination made at the STACH. This process is exhaustive as new information is always sought by the social workers and care team members, and is discussed at care team meetings and documented in the medical record. Lastly, prior to the actual application of the algorithm by the ethics multidisciplinary panel, a discussion is held about potential surrogates as a determination must be made, based upon the available evidence, that the resident is unbefriended.

### **Determination of Decisional Capacity**

As the Algorithm for the Unbefriended applies specifically to those without decisional capacity,<sup>6</sup> this key element must also be determined prior to its application. Under the direction of the chief of psychiatry at Coler, the methodology for determination of decisional capac-

ity since 2009 has been based upon the model described by Appelbaum,<sup>7</sup> which utilizes the following four key factors: (1) the consistency of the decision; (2) an understanding of the given information in terms of risks vs. benefits of accepting/rejecting the choice; (3) the ability to manipulate the information presented in a rational manner; and (4) the ability to appreciate the impact of the decision on his or her health and life. In addition to his consultant psychiatrists, the chief of psychiatry educated the attending physicians on how to apply this model, which has been utilized continuously since the Algorithm for the Unbefriended was initially applied at Coler in June 2016.

In July 2017, NYC Health + Hospitals released the *Clinical Ethics Consultation [CEC] Guidelines Concerning Management of Patients with Possibly Compromised Decisional Capacity* (Table 2). This algorithm was developed by the NYC Health + Hospitals Ethics Council for the express purpose of assisting the attending physicians and clinical ethics consultation services in assessing patients' decisional capacity. The methodology described in this algorithm is largely based upon the Appelbaum model, which was already in effect at Coler.

### **Application of the Algorithm for the Unbefriended Nursing Home Residents**

From June 2016 through December 2017, the algorithm has been applied at Coler for 25 nursing home residents in order to help make LST decisions. In each of these 25 cases, LST decisions were endorsed by multidisciplinary ethics panels assembled for the case discussions. In some cases, there were multiple consults on the same resident. A chart of the aggregate outcome results (Table 3) was compiled by the Coler Clinical Ethics Consultant who presided over each of these case discussions.

### **DNR and DNI**

In 25 out of 25 cases in which a clinical ethics consultation was requested to aid in making an LST decision, the multidisciplinary ethics panel (described in table 1, step 1), with the approval of the attending physician and the concurrence of a second attending physician designated by the nursing facility medical director, endorsed withholding cardiopulmonary resuscitation (CPR), along with intubation and mechanical ventilator support, with resulting orders to "do not resuscitate" (DNR) and "do not intubate" (DNI). The withholding of CPR and intubation were necessary to help shape palliative EOL care plans. In the very unlikely event that the patient somehow managed to survive CPR, then an ICU level of care in an acute care hospital would have been necessary. Without orders for DNR and DNI, the door would have been left open to a broad array of aggressive medical treatments with an exceedingly poor likelihood of success.

## Evidence-Based Rationale for DNR

Nursing home residents undergoing CPR have survival rates to discharge from the acute care hospital of 0 percent to 5 percent.<sup>8</sup> Nursing home residents with dementia have a CPR survival rate of 3 percent.<sup>9</sup> Not surprisingly, CPR is three times less likely to succeed in dementia patients in an acute care hospital, as opposed to cognitively intact patients, with success rates nearly as bleak as those with metastatic cancer.<sup>10</sup> In a sample of 114 elderly nursing home residents who underwent CPR, no one with an unwitnessed cardiac arrest was successfully resuscitated.<sup>11</sup> With such dismal survival rates in the evidence-based medical literature for this population in regard to the success of CPR, attending physicians generally have no difficulty in making this determination in accordance with the algorithm.

## Evidence-Based Rationale for DNI

The authors of a recent study that utilized the national repository of Minimum Data Set (MDS) assessments from 2000 to 2013 pertaining to the use of mechanical ventilation for hospitalized persons with advanced dementia and severe functional impairment noted that the usage of this modality increased significantly over time without evidence of substantially improved survival.<sup>12</sup> Based upon the lack of evidence-based medical data to support improved survival of such individuals near the end of life who are put on mechanical ventilators, the same rationale for withholding CPR can be applied to the withholding of intubation and mechanical ventilator support. In the algorithm outcome chart in Table 3, it is noteworthy that in all 25 cases, the attending physician withheld both CPR and intubation.

## No Tube Feeding

In 14/25 (56 percent) of the nursing home residents, the multidisciplinary ethics panels endorsed orders for no tube feedings. It should be noted that four of 25 (16 percent) of these nursing home residents were already receiving tube feedings for various reasons, including one who just required it to receive essential medications. As these four residents seemed to tolerate the feeding tube well, the multidisciplinary ethics panel chose to not recommend withdrawal of the tube feedings. It should be noted that in all 14 cases in which the ethics panels endorsed orders to withhold tube feedings, none was considered to involve the withholding of LST. Thus, step 9 of the Algorithm for the Unbefriended was not applied as all of these residents were in the advanced stage of dementia.

## Tube Feeding in Advanced Dementia Should Not Be Considered LST

Unlike CPR and intubation, tube feeding in individuals who are in the advanced stage of dementia should not be classified as LST, as there is no clinical evidence to support any benefit in terms of survival outcomes, prevention of aspiration pneumonia, prevention or improvement of pressure sores, improved overall functioning or even palliation.<sup>4, 13</sup> The current standard of medical care for patients with advanced stage dementia is to avoid tube feeding and to instead offer oral assisted feeding.<sup>14, 15</sup>

## Tube Feeding In Terminal Cancer Should Not Be Considered LST

Similar to the lack of efficacy of tube feeding in cases of advanced dementia, the evidence-based literature does not support the use of artificial nutrition in terminally ill cancer patients with anorexia and cachexia in terms of improved survival, which is an important and easily measurable clinical outcome.<sup>16</sup> The Lundholm *et al.* study carefully looked at the potential benefits to terminally ill cancer patients of both enteral (tube feeding) and parenteral nutrition. No evidence of a survival advantage was found in an intent-to-treat analysis.<sup>17</sup>

## Fully Palliative Plan of Care

The multidisciplinary ethics panels endorsed a *fully palliative plan of care* for six of 25 (24 percent) of these nursing home residents. All aggressive treatment modalities were withheld for these individuals in the terminal stage of their illness as orders for DNR, DNI, no tube feeding, no vasopressors, no central lines, no hemodialysis, no blood transfusions, no acute care transfers, and no further diagnostic testing were issued by the attending physician. This was accomplished mainly by applying step 9 of the algorithm. By 12/31/17, 5/6 (83.3 percent) of these residents had expired in their Coler nursing unit. The algorithm clearly provided a basis for the care team, in concert with the multidisciplinary ethics panel, to perform advanced care planning on these frail, elderly individuals, most of whom were in the advanced stage of Alzheimer dementia. According to the evidenced-based medical literature, advanced care planning is crucial to the effective management of this population with advanced dementia, as it is regarded as the single most consistent and modifiable factor linked to the avoidance of unnecessary and unwanted treatments.<sup>18, 19, 20, 21</sup>

## Limited Medical Intervention Plan of Care

The multidisciplinary ethics panels endorsed a *limited medical intervention plan of care*, which was considered mainly palliative, for 10/25 (40 percent) of these nursing home residents. This plan consisted of DNR, DNI, no cen-

tral lines, no vasopressors, no hemodialysis, along with either no acute care hospital transfers or a limitation on acute care hospital transfers for short-term treatments which could not be provided in the nursing facility. In such cases, the algorithm enabled more conservative, alternative medical treatments to be utilized in the nursing facility as more aggressive, but potentially burdensome treatments were withheld by the clinician. As viable alternative treatments existed, the attending physician in such circumstances was not withholding LST, and, thus, did not have to apply step 9 of the algorithm.

During these multidisciplinary ethics meetings, in accordance with steps 3 through 5 of the Algorithm, potential therapeutic interventions were identified which were unlikely to provide benefit as well as others that likely might increase suffering for no medical or health gain. For example, in many cases, central lines were withheld in those severely ill residents who were placed on DNR and DNI, as less aggressive but viable alternatives were used, such as inserting a peripheral intravenous line was utilized for the short-term, from which these residents could be administered intravenous fluids and antibiotics should the need arise. When feasible, in many situations oral antibiotics were used, which spared these residents painful needle sticks. By doing so, these nursing home residents at the EOL could be spared the burden of undergoing acute care hospital discharges, which would offer them little if any benefit, and which more likely would cause them further pain and suffering. Instead, the primary goal of the care plan was to provide palliation for these elderly, severely debilitated nursing home residents, many of whom were in the advanced stage of dementia, which is now widely recognized as a terminal condition.<sup>22</sup>

When treatments at the EOL were felt to not be clinically indicated, they were withheld in accordance with steps 3 through 5 of the algorithm as such were not considered beneficial, with the burdens outweighing the benefits. This was usually the case for hemodialysis in these residents, and consistent with the recommendations of the Committee for the Study of the Medicare ESRD Program, regarding the lack of benefit of dialysis for those with very limited survival potential and poor overall quality of life.<sup>23</sup>

Vasopressors are a powerful category of drugs that cause blood vessels to constrict and help to elevate or maintain arterial blood pressure.<sup>24</sup> Usage of such agents necessitate insertion of a central line and require an ICU level of care. For those frail, elderly and debilitated residents in the advanced stage of dementia, such agents would not offer any benefit and are routinely withheld at these multidisciplinary ethics panel discussions. A good case can also be made that such individuals would die

imminently with or without such treatment, in keeping with step 9 of the algorithm.

Finally, in regard to blood transfusions for such individuals in the advanced stage of dementia who require total nursing care and who are being hand fed, such is not generally considered to be beneficial. In cases of massive gastrointestinal hemorrhage, the clinical determination is generally made that with a reasonable degree of medical certainty, such individuals will die imminently with or without blood transfusions.

### Discussion of Outcome Results

The Algorithm for the Unbefriended was developed by bioethics consultants and legal advisers at New York City's public hospitals and nursing homes to serve as a quality improvement aid, aimed at helping clinicians make LST decisions for hospital patients and nursing home residents who lack decisional capacity and lack surrogate decision-makers. At Coler Rehabilitation and Nursing Care Center, the algorithm has improved the quality of care at the EOL by decreasing the use of medically inappropriate treatments (e.g., CPR) of great burden and little benefit. By using the algorithm, the care teams and CEC have gained confidence that their LST decisions not only conformed to best medical practices but also conformed to applicable policies, regulations, and laws.

What is quite noteworthy is that in 17/25 (68 percent) of these elderly, frail and debilitated nursing home residents, the multidisciplinary ethics panel endorsed either no acute care hospital discharges or limitation of acute care hospital discharges for short-term treatments that could not be provided in the nursing facility. As a result, unnecessary and unwanted treatments were largely avoided. In only 1/25 (4 percent) of these cases was the resident discharged to acute care at the very end of life. In that particular case, it was due to complications of hemodialysis which the resident's dialysis clinic chose to continue in accordance with his prior wishes. However, it should be noted that CPR and intubation with mechanical ventilator support were withheld at the time of death, in accordance with the prior advanced care planning determination made via the application of the algorithm.

In regard to tube feeding, in 14/25 (56 percent) of these residents, all of whom were in the advanced stage of dementia, the multidisciplinary ethics panel endorsed the decision to withhold tube feeding in keeping with the current standard of care, which recommends enhanced oral feedings as the more compassionate alternative.<sup>15, 16</sup>

One of the major goals in developing the algorithm to serve as a quality improvement aid was to help avoid unnecessary acute care hospitalizations at the very end of life, and to allow these nursing home residents to die

with the appropriate palliative advanced care planning measures in place, in relative peace and comfort, in the familiar surroundings of their nursing home units while being attended by dedicated and compassionate caregivers who know them best. Based upon the outcome results, such clearly appears to have been the case, as 11/25 (44 percent) of these nursing home residents expired at Coler as of 12/31/17, with CPR, intubation, and mechanical ventilator support withheld.

As for those residents who were still alive as of 12/31/2017, in all of the cases, appropriate palliative measures were put in place to help avoid burdensome and unnecessary treatments in their final days. Such was in stark contrast to earlier days when nursing home residents in the advanced stage of dementia commonly endured uncomfortable or aggressive interventions in their final days of life.<sup>22</sup> What perhaps is most telling from these results is that the algorithm appears to have facilitated advanced care planning, which is considered crucial to the effective management of such nursing home residents, many of whom are in advanced stage of dementia.<sup>18, 19, 20, 21</sup>

### Satisfaction Survey and Observations

Based upon the results of a satisfaction survey (Table 4) of care team members who participated in these multidisciplinary panel discussions, which were intended to gauge user feedback as to its effectiveness as a quality improvement aid, there was widespread agreement that the algorithm was, indeed, successful in its intended goals. Prior to implementation of the algorithm, members of the care team often felt uneasy and were reluctant to address such concerns on their own, without a supportive mechanism in place. The survey bore out that care team members felt that they were empowered by the algorithm to finally address EOL advanced care planning issues for this highly vulnerable population.

Among the observations of the ethics consultant at Coler and the director of social work is that the plight of these frail, elderly and debilitated residents, without any family or friends to comfort them in their time of greatest need, has a major impact upon the members of the interdisciplinary care team who are their caregivers. They note that these caregivers are often the only ones there to offer them comfort and emotional support over the long term, which serves to create a deep bond between them. They feel that in the eyes of these residents, the members of the care team, at times, seem almost like family, and that over the long haul, the caregivers, too, grow accustomed to being there for them. As a result, they surmise that these caregivers often become staunchly protective of these unbefriended residents, sometimes making it quite difficult to let go when their health declines. In their view, the algorithm, which relies on an inclusive, transparent, inter-

disciplinary process, allows the caregivers to act as stakeholders, which seems befitting as no one else knows these individuals better. The net effect, both strongly believe, is that it helps to ensure that the recommendations offered are truly in the best interests of these residents.

### Applicability of the Algorithm for the Unbefriended elsewhere

Whether or not the utility of the Algorithm for the Unbefriended as a quality improvement aid would be as beneficial, if applied elsewhere, remains to be seen. Its design was tailored to New York City's public hospitals and nursing homes which have a significant unbefriended population. The fact that it worked so well as a quality improvement aid at Coler, a very large nursing home with many unbefriended residents, does not necessarily imply that it will succeed elsewhere. Nevertheless, the fact that it was so effective at Coler is noteworthy and may encourage other facilities with a similar problem to consider such an approach.

### Conclusions

Based upon the experience at Coler, the authors view the algorithm as a very useful quality improvement aid to help address the EOL care needs of this highly vulnerable population in an ethical and compassionate manner with built in safeguards that greatly minimize the likelihood that arbitrary decisions are made. Prior to the implementation of the Algorithm for the Unbefriended, the medical staff at Coler was inclined to make EOL medical treatment decisions for the unbefriended without collaborating with the other members of the interdisciplinary care team. Due to the vulnerable nature of this population, the EOL care process tended to result in delayed decision-making, as more aggressive and burdensome medical treatments were initiated, resulting in multiple acute care hospitalizations with eventual death out of the facility. This all changed with the implementation of the Algorithm as evidenced by the outcome results and satisfaction survey.

According to the chief medical officer at Coler, the algorithm is aligned with the Patient Centered Care Model, which is a core value at Coler. It has proven to be an invaluable tool in de-emphasizing solo decision-making by the medical attending and in empowering the interdisciplinary care team with the lead of the ethics consultant to fully address the goals of care for the vulnerable unbefriended adult. The algorithm had provided guidance in addressing burdensome life sustaining treatment with limited clinical benefit to individuals at the EOL. At Coler, EOL care planning for this population has transitioned from prescriptions of aggressive treatment to palliative measures aimed at increasing comfort. The success of the algorithm can be attributed to a transparent interdisciplin-

ary panel approach, allowing each care team member to participate in decision-making geared to the patient's best interest while adhering to evidence-based best practices.

### **Table 2. New York City Health + Hospitals Clinical Ethics Consultation Guidelines:**

#### **GUIDELINES CONCERNING MANAGEMENT OF PATIENTS WITH POSSIBLY COMPROMISED DECISIONAL CAPACITY**

1. There is an ethical imperative to respect and enhance patients' decisional capacity to promote their autonomy and to ensure that they have a meaningful choice in their health care. Failing to detect impaired decisional capacity when it exists risks abandoning the patient and may leave the patient without the benefit of effective surrogate decision makers.
2. Many of our patients have impaired capacity to understand treatment options and interventions and to evaluate the risks and benefits of treatments. The first task for these patients is to determine their decision-specific decisional capacity. If the patient lacks capacity to make health care decisions, the attending physician with the support of other members of the health care team, must identify and work with surrogate decision makers when available. If there are no surrogates available and there are no known prior wishes of the patient, the care team must make decisions based upon notions of the best interest of the patient. The staff must continue to care for patients who may assent to or refuse care or vacillate between refusal and acceptance of treatment.

The determination of a patient's capacity is the responsibility of the patient's attending physician, the accuracy of whose judgment will be enhanced by consultation with members of the care team.

3. Determination of capacity involves the following considerations:
  - As an initial premise, every adult patient is presumed to have decision-making capacity.
  - Capacity is decision-specific. Complex decisions, consents to or refusals of standard of care, and consents to or refusals of critical or life-saving treatment and high-risk treatments, require a higher degree of capacity.
  - Decisional capacity may fluctuate with time of day, existence of pain, or change in setting.
  - Especially for elderly patients, consistency of a patient's choice with previous choices and

known values may serve as evidence supporting decisional capacity.

- Limited language skills or verbal fluency, limited knowledge of human anatomy and physiology, language barriers which are difficult to overcome, or limited literacy skills are not necessarily, by themselves or in combination, evidence of a lack of decision-making capacity.
4. Decision making capacity to make a health care decisions means the ability to understand and appreciate the nature and consequences of the proposed health care, including the benefits and risks of and alternatives to the proposed health care to reach an informed decision. An attending physician may consider using the following procedure during his or her assessment of a patient's decisional capacity:
    - A. Assess the patient's understanding – (e.g. "Please tell me in your own words what your doctor told you about: medical condition, treatment, benefits, risks, alternatives.)
    - B. Assess the patient's appreciation – (e.g. assess the patient's beliefs, perceptions and attitudes these must be assessed directly, e.g., "What do you believe is really wrong with you? What do you think this treatment will do to you or for you?")
    - C. Determine what the patient's choice is – (e.g. "Tell me what your decision is ...")
    - D. Assess the patient's reasoning – (e.g. "Tell me how you reached the decision you have made." "What things did you consider in making that decision?")
  5. Mental Illness. If the attending physician makes an initial determination that a patient lacks decision-making capacity because of mental illness, either such physician must be an appropriately trained and qualified psychiatrist or an appropriately trained and qualified psychiatrist must independently determine whether the patient lacks decision-making capacity.
  6. The experience or anticipation of pain may adversely affect decisional capacity and effective pain management can mitigate that effect.
  7. Beyond their role as potential surrogate decision makers, the participation of a supportive family, friend or clinician may improve the patient's ability to participate in decision-making and improve his or her decisional capacity.

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8. Lack of capacity is neither a sufficient ethical reason to treat over the objection of a patient nor (absent an emergency or court order) legally permissible.
9. Clinical Ethics Consultations with patients who have compromised decisional capacity should focus on continuing efforts to improve the patient's decisional capacity and maintain and optimize the patient's role in decision-making. These efforts should be documented in the CEC Chart Note.

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**Table 3. Outcome for 25 Residents with Care Guided by Algorithm for the Unbefriended (6/01/16 to 12/31/17)**

<b>End of life care for all residents whose care was guided by the Algorithm for the Unbefriended</b>	<b>Number of Residents (n=25)</b>	<b>Percent of all Residents</b>
DNR and DNI orders	25	100%
Do not use tube feeding orders	14	56%
Already using and tolerating tube feedings	4	16%
Full palliative care plan*	6	24%
Limited medical intervention/mainly palliative plan of care**	10	40%
Residents placed on either a limited medical intervention/mainly palliative or a fully palliative plan of care	16	64%
Residents with do not transfer to acute care orders	10	40%
Residents with limited acute care transfers	7	28%
<b>Number and treatment of residents deceased as of 12/31/2017</b>	<b>Number of Residents (n=12)</b>	<b>Percent of All Residents / Percent of Deceased Residents</b>
CPR, intubation/mechanical ventilator support withheld	12	(48%)/ (100%)
Died at Coler (without transfer); CPR, intubation/mechanical ventilator support withheld	11	(44%)/ (92%)
Died in acute care (receiving hemodialysis at time of death)	1	(4%)/ (8%)
<b>Number and status of surviving residents who remained unbefriended as of 12/31/2017</b>	<b>Number of Residents (n=12) †</b>	<b>Percent of All Residents / Percent of Surviving Residents who Remained Unbefriended</b>
DNR and DNI orders	12	(48%)/ (100%)
Residents on limited medical interventions/ (mainly palliative plan of care)	7	(28%)/ (58%)
Residents on fully palliative plan of care	1	(4%)/ (8%)
*Full palliative care comprises DNR, DNI, no tube feeding, no vasopressors, no central lines, no hemodialysis, no blood transfusions, no acute care transfers, and no further diagnostic testing.		
** Limited Medical Interventions/Mainly Palliative comprises DNR, DNI, no vasopressors, no central lines, no hemodialysis and either no acute care transfers or limited acute care transfers for short-term treatment that can't be provided in the nursing facility.		
† 1 Resident later found to have surrogate and a telephone conference was held with surrogate, who agreed to DNR.		

## GUARDIANSHIP AND SURROGATE DECISION-MAKING

**Table 4. The Algorithm for the Unbefriended are Team Survey Results\_**

**(Overall - 26 Respondents from NF Medicine, Social Work, Nursing and Food & Nutrition)**

1. Was the Algorithm for the Unbefriended beneficial in addressing the resident's end-of-life advanced care planning needs?	Extremely beneficial		Generally beneficial		Sometimes beneficial		Not sure		Not beneficial		Favorable Responses	
	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage
	15	57.7%	9	34.6%	2	7.7%	0		0		26	100.0%
2. During the meetings, all major concerns were adequately addressed.	Strongly agree		Somewhat agree		Neither agree nor disagree		Somewhat disagree		Strongly disagree		Favorable Responses	
	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage
	18	69.2%	7	26.9%	1	3.8%	0		0		25	96.2%
3. When the resident's prior wishes were unknown, the best interest standard was applied in accordance with the Family Health Care Decisions Act.	17	65.4%	8	30.8%	1	3.8%	0		0		25	96.2%
4. Utilizing the Algorithm for the Unbefriended at the interdisciplinary ethics case meetings helped allay or relieve any apprehensions that you may have had in regard to the type of decisions to be made.	16	61.5%	9	34.6%	1	3.8%	0		0		25	96.2%
5. I would recommend this tool and the process utilized to colleagues in other nursing facilities who care for similar types of residents.	19	73.1%	5	19.2%	2	7.7%	0		0		24	92.3%
6. The Algorithm for the Unbefriended helps to empower the attending physician and other members of the care team to make these difficult types of decisions in a transparent manner, in which all viewpoint may be shared, including the wishes and values of the resident when known, while demonstrating the utmost respect and compassion for these residents.	18	69.2%	8	30.8%	0		0		0		26	100.0%

## Endnotes

1. Chapter 8, Laws of 2010, adding N.Y. Public Health Law Article 29-CC ("The Family Health Care Decisions Act") and amending various other laws
2. PHL § 2994-a(19). "Life-sustaining treatment" means any medical treatment or procedure without which the patient will die within a relatively short time, as determined by an attending physician to a reasonable degree of medical certainty. For the purpose of this article, cardiopulmonary resuscitation is presumed to be life-sustaining treatment without the necessity of a determination by an attending physician.
3. PHL § 2994-g(5).
4. Zisfein, James, Finger, Howard J. and Dubler, Nancy Neveloff Tube Feeding in Advanced Dementia Should Not Be Classified as Life-Sustaining Treatment NYSBA Health Law Journal | Spring 2013 | Vol. 18 | No. 2
5. Clay-Williams R, Colligan L. Back to basics: checklists in aviation and healthcare. *BMC Qual Saf.* 2015;24:428-431.
6. PHL § 2994-a(5) "Decision-making capacity" means the ability to understand and appreciate the nature and consequences of proposed health care, including the benefits and risks of and alternatives to proposed health care, and to reach an informed decision.
7. Appelbaum PS. Clinical practice. Assessment of patients' competence to consent to treatment. *N Engl J Med* 2007; 357:1834.
8. Zweig SC. Cardiopulmonary resuscitation and do-not-resuscitate orders in the nursing home. *Archives of Family Medicine* 1997; 6:424-429
9. Dull SM, Graves JR, Larsen MP, Cummins RO. Expected death and unwanted resuscitation in the prehospital setting. *Annals of Emergency Medicine* 1994; 23(5):997-1002.
10. Ebell MH, Becker LA, Barry HC, Hagen M. Survival after in-hospital cardiopulmonary resuscitation. A meta-analysis. *J Gen Int Med* 1998; 13(12):805-816.
11. Ghush HF, Teasdale TA, Pepe PE, Ginger VF. Older nursing home residents have a cardiac arrest survival rate similar to that of older persons living in the community. *J Am Geriatr Soc* 1995; 43(5):520-527.
12. Teno, Joan MD, Gozalo, Pedro PhD, Khandelwal, Nita MD, MS, Curtis, J. Randall MD, MPH, Meltzer, David MD, PhD, Engelberg, Ruth PhD, and Mor, Vincent PhD Association of Increasing Use of Mechanical Ventilation Among Nursing Home Residents With Advanced Dementia and Intensive Care Unit Beds. *JAMA Intern Med.* 2016 Oct 10. doi: 10.1001/jamainternmed.2016.5964.
13. Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA* 1999; 282:1365-1370.
14. AGS Choosing Wisely Workgroup. American Geriatrics Society identifies five things that health care providers and patients should question. *J Am Geriatr Soc* 2013; published online: <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12226/pdf>.
15. Gillick MR. Rethinking the role of tube feeding in patients with advanced dementia. *N Engl J Med* 2000; 342:206-210.

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16. Timothy Moynihan, Darlene G. Kelly, and Michael J. Fisch To Feed or Not to Feed: Is That the Right Question? *Journal of Clinical Oncology* Volume 23 \_ Number 25 \_ September 1, 2005.
17. Lundholm K, Daneryd P, Bosaeus I, et al: Palliative nutritional intervention in addition to cyclooxygenase and erythropoietin treatment of patients with malignant disease: Effects on survival, metabolism and function. *Cancer* 100:1967-1977, 2004.
18. Mitchell, SL, MD, MPH Palliative care of patients with advanced dementia. UpToDate (last updated Feb 08, 2016) [www.uptodate.com](http://www.uptodate.com).
19. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* 2009; 361:1529.
20. Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med* 2011; 365:1212.
21. Goldfeld KS, Stevenson DG, Hamel MB, Mitchell SL. Medicare expenditures among nursing home residents with advanced dementia. *Arch Intern Med* 2011; 171:824.
22. Susan L. Mitchell, MD, MPH, FRCPC; Dan K. Kiely, MPH, MA; Mary Beth Hamel, MD, MPH Dying With Advanced Dementia in the Nursing Home *Arch Intern Med.* 2004; 164:321-326.
23. Rettig RA, Levinsky NG, eds.: *Kidney Failure and the Federal Government*. Washington DC, Committee for the Study of the Medicare ESRD Program, Division of Healthcare Services, Institute of Medicine, National Academy Press, 1991.
24. Scott Manaker, MD, PhD. Use of vasopressors and inotropes. UpToDate (topic last updated: Feb 08, 2018).

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