

Model Policy for DNR Orders in Dialysis Facilities

Developed by the ESRD Peer Workgroup of the Robert Wood Johnson Foundation
Promoting Excellence in End-of-Life Care Program
and endorsed by the RPA/ASN Quality Patient Care Committee

I. Policy

It is the policy of [*the name of the dialysis unit*] to respect the informed oral or written refusal of cardiopulmonary resuscitation (CPR) in the dialysis unit by patients with decision-making capacity or the health care agents for patients who lack decision-making capacity. In response to an informed refusal of CPR, [*the name of the dialysis unit*] will issue and honor a do-not-resuscitate (DNR) order for such patients.

II. Rationale for the Policy

CPR is not a successful therapy for most dialysis patients who undergo it. Patients who undergo and survive CPR may have major complications. Because dialysis patients already often bear considerable burdens as a result of dialysis and the frequent occurrence of co-morbid conditions, such as diabetes, congestive heart failure and peripheral vascular disease, many dialysis patients elect to limit the extent of life-prolonging medical care. Such limitations may include a decision to refuse CPR in the dialysis unit and request a DNR order. Honoring the decision of a patient with decision-making capacity (or the decision of a health care agent for a patient who lacks decision-making capacity) not to undergo CPR is ethically justified by the principle of respect for patient autonomy and legally justified by the doctrine of informed consent and the patient's right to self-determination. Furthermore, the performance of CPR on dialysis patients with significant co-morbid conditions who have an extremely poor prognosis with CPR violates the ethical principle of nonmaleficence.

III. Definitions

Advance Directive: An oral or preferably written statement by a patient with decision-making capacity expressing his/her preferences for a health care agent and/or for future medical care in the event he/she becomes unable to participate in medical decision-making. All 50 states have one or more laws or regulations recognizing written advance directives and the rights of patients to have their wishes respected. There are two types of written advance directives: a living will (an instruction directive in which the patient gives directions for future medical care in the event of particular medical conditions, such as a terminal illness or a persistent vegetative state); and a health care proxy (a proxy directive in which the patient designates a person to make decisions for him/her when the patient loses decision-making capacity). In some states the health care proxy is referred to as a medical power of attorney or a durable power of attorney for health care. In some states, both instruction and proxy directives may be combined into one advance directive form. All advance directives must comply with applicable state procedural and substantive laws.

Attending Physician: A licensed physician with staff privileges in the dialysis facility selected by or assigned to the patient who has primary responsibility for treatment of the patient. (In the case of dialysis patients, this physician is likely to be the nephrologist primarily assigned to the supervision of the patient's dialysis and related care.) If more than one physician shares the responsibility for care of the patient, any of those physicians may act as the attending physician under this policy.

Cardiopulmonary Resuscitation (CPR): A procedure performed to attempt to support and restore ventilation and circulation in a patient experiencing cardiac arrest (asystole, ventricular fibrillation, or pulseless electrical activity) or respiratory arrest (cessation of respiratory effort). It includes establishment and maintenance of an airway, assisted ventilation, chest compressions, establishment of intravenous access, cardiac monitoring, administration of medications, defibrillation or other control of arrhythmias, and immediate care after resuscitation.

Decision-Making Capacity: The capacity of a patient to 1) understand his/her medical condition; 2) appreciate the consequences (benefits and burdens) of various treatment options including non-treatment; 3) judge the relationship between the treatment options and his/her personal values, preferences and goals; 4) reason and deliberate about his/her options; and 5) communicate his/her decision in a meaningful manner. Assessment of decision-making capacity is a clinical judgment made by the patient's attending physician.

Do-Not-Resuscitate (DNR) Order: An order written in an appropriate document (medical record, specially formulated advanced care directive, standardized form according to applicable state law or regulation, etc.) that indicates the patient's (or health care agent's) decision to refuse CPR in the event of cardiac or respiratory arrest in the dialysis unit. This order does not restrict the provision of standard measures in dialysis treatment such as fluid resuscitation for intradialytic hypotension, nor does it preclude other forms of care meant to provide comfort and to relieve suffering. A DNR order only becomes effective when the patient has experienced a cardiac or respiratory arrest.

Health Care Agent, Proxy, Surrogate, Guardian, Medical Power of Attorney, or Durable Power of Attorney for Health Care: A person who, in accordance with applicable state laws, has been selected by a patient, or who, in accordance with applicable state laws, has been appointed, and has been given the authority to make informed health care decisions for the patient in the event the patient loses decision-making capacity. The appropriate terminology may vary from state to state, but the intent to allow an individual to pre-assign decision-making authority to another person is common among all such instruments. To the extent permitted by applicable state law, the health care agent may have the opportunity to be guided in his/her decision-making by prior knowledge of the patient's wishes through conversations and/or the stipulations in a written advance directive.

Living Will The living will, also known as an instruction directive, indicates a patient's wishes to be followed if he/she loses decision-making capacity. Wishes may refer to care in the event of particular medical conditions such as a terminal illness or a persistent vegetative state. The patient may indicate that he/she wishes under certain circumstances to have or continue

treatments such as dialysis or CPR or to discontinue or refrain from such treatments.

Patients Without Decision-Making Capacity: A patient who in accordance with the clinical judgment of the attending physician, clinical practice guidelines, and applicable state laws, has been declared to lack the capacity to: 1) understand his/her medical condition; 2) appreciate the consequences (benefits and burdens) of various treatment options including non-treatment; 3) judge the relationship between the treatment options and his/her personal values, preferences and goals; 4) reason and deliberate about his/her own options; and 5) communicate his/her decision in a meaningful manner.

IV. Statement of Principles

1. Patients with decision-making capacity have the same legal and ethical right to request DNR orders in dialysis facilities as they do in hospitals, nursing homes, and other medical or custodial facilities. Patients can better ensure that their legal and ethical rights are secured if they subsequently lose capacity to make medical decisions by executing an advance directive in which they designate a health care agent and state their preferences, including a preference for a DNR order in the dialysis unit if that is their wish. (See Appendix A)
2. For patients with decision-making capacity who have not appointed a health care agent, dialysis units should learn from them whom they wish to choose for a health care agent so that this person can participate in medical decisions for the patient in the event the patient loses decision-making capacity. When a patient has not designated a health care agent and temporarily or permanently lacks decision-making capacity to designate a health care agent, the dialysis facility must determine who has the legal authority to make medical decisions for the patient and take such actions as are necessary to secure the designation of the health care agent according to applicable state laws.
3. There is no legal or ethical difference between a patient requesting a DNR order in a dialysis facility or deciding to forgo dialysis therapy, each of these actions being legitimate manifestations of patient self-determination and the right to refuse therapy. On a clinical basis, a DNR order may be an entirely appropriate decision by a patient who recognizes that his/her quality of life may be quite adversely affected by even a “successful resuscitation” in the face of varying degrees of co-existing morbidity. Requesting a DNR in a dialysis facility may mean that the patient considers his or her quality of life to be adequate to continue dialysis treatment until cardiac or respiratory arrest occurs, even if this occurs while on dialysis, and possibly as a complication of the dialysis treatment itself.
4. Education of dialysis patients and their legal agents about the outcomes of CPR for patients with end-stage renal disease and other co-morbid conditions is essential for patients to make informed decisions about CPR.
5. Dialysis units are obligated to identify and respect the informed preferences of patients

regarding performance of CPR. Education about CPR and inquiry about patients' preferences may be conveniently conducted during required semi-annual long-term care planning meetings, though the process of advance care planning should begin as soon as medically indicated. Patients who request a DNR order in the dialysis facility should be encouraged to make advance preparations for their death to relieve the burden on their health care agent and family (See Appendix B).

6. To accommodate patients who refuse CPR in the dialysis unit and subsequently die there, dialysis units are obligated to have a procedure for treating such patients at and after the time of cardiorespiratory arrest with comfort, dignity, and respect (See V. Procedure).
7. A patient or the patient's health care agent has the right to revoke a DNR order at any time.
8. If the patient requests an in-facility DNR order, the dialysis facility is obligated to continue to provide the patient with the normal range of dialysis treatment and supportive services provided to all other patients.
9. Inherent in quality end-of-life care is the provision of bereavement support to the patient's family. Dialysis units should arrange for such support to be made available to the family either through the dialysis unit or through services available in the community.

V. Procedure

1. The dialysis unit personnel (physicians, nurses, social workers, dietitians, and patient care technicians) are to identify patients who want a DNR order in the dialysis unit through the long-term care planning process and/or in conversations that are appropriate as medical complications arise. Patients who request a DNR order in the dialysis unit are to be encouraged to complete an advance directive for a DNR order in the dialysis unit (See Appendix A), especially if they have not been issued DNR identification (card or bracelet) applicable under state law.
2. Attending physicians are to issue DNR orders for patients with decision-making capacity who want them or at the request of health care agents for patients who lack decision-making capacity. The DNR order is to be recorded in the patient's medical record, a DNR label is to be attached to the inside front cover of the chart, and the notation "DNR" is to appear in the special directions section of individual dialysis treatment sheets.
3. When a patient with a DNR order has a cardiorespiratory arrest in the dialysis unit, dialysis personnel are to screen the patient from other patients and move the patient to a private area of the facility as soon as possible and proper.
4. The dialysis nurse in charge is to notify the attending physician and follow the physician protocol to pronounce the death of the patient.

5. The dialysis nurse in charge and/or the social worker is/are to reassure other patients and staff that everything possible is being done to respect the affected patient's wishes and to promote his/her comfort and dignity.
6. The attending nephrologist, the nurse in charge, or the social worker is to notify the health care agent of the patient's death and to inquire about funeral home preferences, if not previously determined (See Appendix B).
7. Dialysis unit personnel are to notify the funeral home of the patient's death and request immediate pick-up of the body.
8. If required by state law, dialysis unit personnel are to notify the Medical Examiner (Coroner) and to inform him/her that the attending physician has been notified and the patient has been pronounced dead using the physician protocol for pronouncement of death (The Medical Examiner telephone number is to be readily available in the dialysis unit).
9. The nurse in charge is to document the death and procedures followed in the patient's progress notes and prepare an incident report, if appropriate, according to dialysis unit policy and procedure.

Appendix A

Advance Directive for a Do Not Resuscitate Order in the Dialysis Unit

Having considered the things that are important to me in life, my current medical condition, the probability that my medical condition will not improve in the future, and my feelings about life and the quality of my life, I hereby state my wishes.

I request that I not have cardiopulmonary resuscitation (CPR) performed on me when my heart or lungs stop functioning.

I understand that CPR will probably not be successful in prolonging my life, or if it is, that my quality of life will probably not be satisfactory to me.

Based on the above reasons and after discussion with family, friends, and health care professionals to the extent to which I wish to have such discussions, I've come to the conclusion that I do not want CPR, even though I still want to continue my dialysis treatments.

In this regard I hereby direct that if my heart or my breathing stops while being treated in the dialysis unit, I do not want to undergo CPR regardless of whether the stoppage of my heart or lungs is due to my underlying medical condition or a complication of the dialysis treatment.

Signature or Mark

Date

Witness

Date

Witness

Date

Notary (if required by state law)

Appendix B

Recommendations for Advance Preparation for Death*

Patients who request a DNR order in the dialysis unit are encouraged to provide the following information to their health care agent, family, close friends, and executor (where applicable):

1. A will.
2. Signed advance directive (living will, health care proxy, durable health care power of attorney, and/or an out-of-hospital DNR order) in accordance with applicable state law (provided also to dialysis unit, physician, and hospital).
3. A durable power of attorney complying with applicable state law (one that survives incompetency and death) designating someone to act on the patient's behalf on all matters other than medical, including legal, financial, banking and business transactions. The power of attorney can be made effective immediately or upon the occurrence of a defined set of circumstances.
4. An inventory, including the location of her/his bank, brokerage and other financial accounts, stock and bond holdings not in brokerage accounts, real estate and business records and documents, medical and other insurance policies, pension plans, and other legal documents.
5. A list giving the names, addresses and telephone numbers of the attorney, accountant, family members, close friends, and/or business associates who should be notified of the death or may have information that will be helpful in dealing with estate affairs.
6. Documentation and instructions concerning burial or cremation, including choice of funeral home, preferences for the funeral ceremony, and any decisions about organ, tissue, or body donation.
7. Written or video or audio taped message to the family, close friends, or business associates.

* Adapted and reprinted with permission from "Initiation or Withdrawal of Dialysis in End Stage Renal Disease: Guidelines for the Health Care Team" © National Kidney Foundation, Inc.

Addendum A to Model Policy and Procedure for
DNR Orders in Dialysis Facility

Advance Directive for a Do Not Resuscitate Order in the Dialysis Unit

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Based on the above reasons and after discussion with family, friends, and health care professionals to the extent to which I wish to have such discussions, I've come to the conclusion that I do not want CPR, even though I still want to continue my dialysis treatments.

In this regard, I hereby direct that if my heart or my breathing stops while being treated in the dialysis unit, I do not want to undergo CPR regardless of whether the stoppage of my heart or lungs is due to my underlying medical condition or a complication of the dialysis treatment.

Signature or Mark

Date

Witness

Date

Witness

Date

Notary (if required by state law)

Addendum B to Model Policy and Procedure for DNR Orders in Dialysis Facility

Recommendations for Advance Preparation for Death*

Patients who request a DNR order in the dialysis unit are encouraged to provide the following information to their health care agent, family, close friends, and executor (where applicable):

1. A will.
2. Signed advance directive (living will, health care proxy, durable health care power of attorney, and/or an out-of-hospital DNR order) in accordance with applicable state law (provided also to dialysis unit, physician, and hospital).
3. A durable power of attorney complying with applicable state law (one that survives incompetence and death) designating someone to act on the patient's behalf on all matters other than medical, including legal, financial, banking and business transactions. The power of attorney can be made effective immediately or upon the occurrence of a defined set of circumstances.
4. An inventory, including the location of her/his bank, brokerage and other financial accounts, stock and bond holdings not in brokerage accounts, real estate and business records and documents, medical and other insurance policies, pension plans, and other legal documents.
5. A list giving the names, addresses and telephone numbers of the attorney, accountant, family members, close friends, and/or business associates who should be notified of the death or may have information that will be helpful in dealing with estate affairs.
6. Documentation and instructions concerning burial or cremation, including choice of funeral home, preferences for the funeral ceremony, and any decisions about organ, tissue, or body donation.
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The Renal Palliative Care Initiative Memorial Service

The Renal Palliative Care Initiative was a demonstration project to integrate palliative care into the dialysis and transplantation settings. It was supported by the *Promoting*

Excellence in End-of-Life Care national program of The Robert Wood Johnson Foundation, and its medical director was Lewis Cohen, MD. This report was composed by Anne Woods, LICSW.

Introduction

The Service of Remembrance is an annual non-denominational program designed to remember the patients who have died during the year. It unites members of the renal community: family members, doctors, nurses, social workers, dietitians, technicians, van drivers, fellow patients and others impacted by the death. It is a collaborative effort to meet the bereavement needs of all. Remembrance can be simple or elaborate. It can be confined to one unit or area or cover a broader area. It should be designed in whatever format is thought to be appropriate for the needs of the bereaved community.

The following outline briefly describes components of the Service of Remembrance that is held in the Greater Springfield Area. This annual program includes participation of both a hospital-based dialysis facility and six freestanding treatment centers in the Connecticut River Valley region of New England. The service is intended to be an avenue of support for all that attend. Diversity of culture, ethnicity, religious belief, professional identity, age, and connectedness to the deceased is taken into consideration in developing the program. It is intended to be inclusive and welcoming.

Beginning

Once the participating facilities have been defined, committees can be formed and program planning can begin. An effort was made to include committee members representing each of the participating facilities. For the program to be a success, all members of the renal community need to feel a part of the process. It is also necessary at this point to consider resources. A budget is needed.

Committee Decisions: Planning the Event

Once a committee is formed, there are a number of decisions that are best made by the committee as a whole. First the population needs to be determined. Location is another major consideration. The facility needs to be large enough to accommodate the potential number of attendees, including loved ones, staff and patients. The final committee decision before breaking up into smaller task groups involves the consideration of symbols that touch upon remembrance. Some examples are candles, roses, rosemary, and bittersweet. Lists of patients to be remembered need to be obtained from whatever facilities are involved. The invitation needs to be drafted so it can be printed and mailed in a timely fashion. Printing arrangements for the programs need to be considered. Finally, evaluations and their stamped, addressed envelopes need to be prepared.

The Service

Program Committee decisions will be key in establishing the tone and content of the remembrance service. Inclusion of pastoral care, social work, administrative and nursing disciplines provide a balanced cross section of education and work experiences to contribute diversity of included elements. Drawing upon the various religious, ethnic and

racial backgrounds of members establishes the basis of a program with meaning to all participants and invitees.

Room Set Up

The room designated for the service should be media equipped if large enough to require microphones for speakers and musicians.

Equipment

Podiums are helpful for the readers so that they may have a place to put script to maximize eye contact with the audience. Table coverings, candleholders for large tapers, matches and a candle lighter and snuffer will be needed.

Service Participants

All service participants should arrive approximately 1½ hours before the scheduled time of the service. Participants will have their rehearsal during this time period. A group will also be needed to ensure that resources are collected and the facility is secure, neat, and clean after the event.

Welcome

As guests enter the facility, greeters and escorts should be available. The hospitality greeters' welcome will help to put guests at ease and set the tone for participants. If family members have a photograph for the **Collage of Loved Ones**, greeters take the photograph at this time. A quick check to make sure the name of the loved one is on the back of the picture will ensure its safe return. Family members are encouraged to retrieve their pictures at the close of the service. The guests may then be directed or assisted to the **Welcome Table** to sign the **guest books**. Guests requiring assistance can then be seated in the main room by a hospitality greeter. An ample number of greeters for the expected number of guests insure that people are transitioned smoothly.

The **welcoming speech** that begins the service is an important mechanism to bring together participants and guests by highlighting the role of the remembered loved ones in uniting the group.

Music will be a key piece of the service.

Readings - scripture, prayer, poetry, quotations may be interspersed with the musical selections to vary the tempo of the service.

Candle lighting as names of loved ones remembered are read provides a powerful symbol of love and hope.

At the conclusion of the service, program greeters are again stationed at exit doors to provide each family with an **evaluation form** in a self-addressed stamped return envelope.

The **Resource Table** requires staffers to assist families in selecting the materials most helpful for them.

The first Renal Palliative Care Initiative Service of Remembrance took place in Springfield on October 24, 1999. Anne Woods, LICSW, chaired the Organizing Committee, and the committee met repeatedly over the year. Deborah Hayes, LICSW, had organized earlier versions of a memorial service in Greenfield, MA during the previous several years.