

Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Clinical Practice Guideline

Second Edition



RPA

Renal Physicians Association

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About the Renal Physicians Association

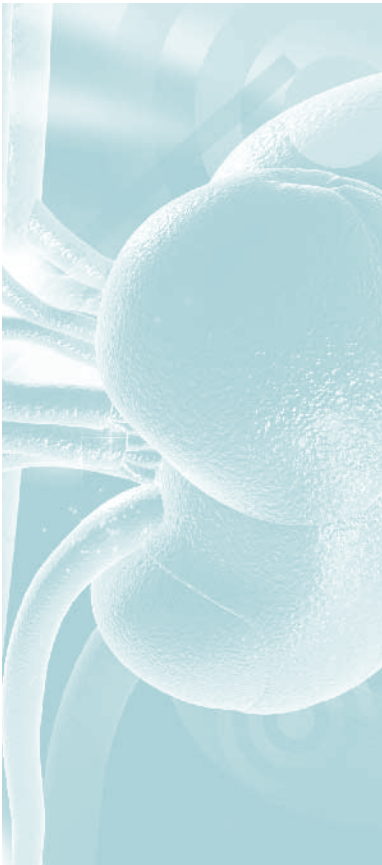
www.renalmd.org

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Section 9

Toolkit



Many validated tools can be used to assess depression, cognitive capacity, decision-making capacity, quality of life, and prognosis. Choice of a particular tool depends upon issues such as preferences, resources, and provider familiarity and training. The Working Group especially recommends the following instruments because they have been used and validated in dialysis patients or in patients with comparable age and cognitive disorders.

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1. General Checklist for Implementing Shared Decision-Making Recommendations

The Working Group developed the following checklist with examples of items that could be added to the Comprehensive Assessment and Plan of Care to monitor implementation of shared decision-making recommendations.

- yes no Patient has been screened for depression.
- yes no Patient score indicates possible depression.
- yes N/A If screened positive, patient has been referred for possible treatment.
- yes no Patient has been screened for mental status.
- yes no Patient score indicates possible cognitive impairment.
- yes N/A If cognitive impairment is indicated, have potentially reversible contributors been ruled out?
- yes no Patient has been assessed for decision-making capacity.
- yes no Patient's preference for a legal agent has been elicited.
- yes no Patient or designated legal agent has been given information on advance directives.
Date: _____ Staff: _____
- yes no Patient has a signed durable power of attorney for health care in chart.
- yes no Patient has a signed living will in chart.
- yes no Patient has completed a Physicians Orders for Life-Sustaining Treatment (POLST) Paradigm form.
- yes no Circumstances, if any, under which patient would desire discontinuation of dialysis have been documented in chart.
- yes no Circumstances, if any, under which patient would not want cardiopulmonary resuscitation, mechanical ventilation, or tube feeding documented in chart.
- yes no Patient or designated legal agent has been given prognostic information. Estimated survival prognosis is a range of _____ to _____ (state months or years) based on: _____ (e.g., table, model, clinician)
- yes no Present and projected future quality of life and/or functional status has been discussed. If assessed, instrument used _____, score: _____, date: _____.
- yes N/A Has an intervention been planned to improve quality of life or functional status?

2. Depression Assessment Tools

Many validated instruments can be used to screen for depression. A systematic review of nine of these instruments shows they all have approximately equal sensitivity in detecting depression.¹ Below is an example of a validated and easy-to-use depression screening instrument: the *Patient Health Questionnaire (PHQ-9)*.² Anyone who screens positive should have his or her diagnosis confirmed through a diagnostic interview.

Tool 2. Patient Health Questionnaire (PHQ-9)

Patient Health Questionnaire (PHQ-9)

Name: _____ Date: _____

Over the *last 2 weeks*, how often have you been bothered by any of the following problems? (use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or hurting yourself in some way	0	1	2	3

add columns: + +

(Healthcare professional: For interpretation of TOTAL, please refer to accompanying scoring card.)

TOTAL: _____

10. If you checked off *any* problems, how *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?

- Not difficult at all _____
- Somewhat difficult _____
- Very difficult _____
- Extremely difficult _____

PHQ-9 is adapted from PRIME MD TODAY, developed by Drs Robert L. Spitzer, Janet B.W. Williams, Kirt Kroenke, and colleagues, with an educational grant from Pfizer Inc. For research information, contact Dr. Spitzer at rfs8@columbia.edu. Use of the PHQ-9 may only be made in accordance with the Terms of Use available at <http://www.pfizer.com>. Copyright ©1999 Pfizer Inc. All rights reserved. PRIME MD TODAY is a trademark of Pfizer Inc.

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Fold back this page before administering this questionnaire

INSTRUCTIONS FOR USE

for doctor or healthcare professional use only

PHQ-9 QUICK DEPRESSION ASSESSMENT

For initial diagnosis:

1. Patient completes PHQ-9 Quick Depression Assessment on accompanying tear-off pad.
2. If there are at least 4 ✓s in the blue highlighted section (including Questions #1 and #2), consider a depressive disorder. Add score to determine severity.
3. **Consider Major Depressive Disorder**
—if there are at least 5 ✓s in the blue highlighted section (one of which corresponds to Question #1 or #2)
Consider Other Depressive Disorder
—if there are 2 to 4 ✓s in the blue highlighted section (one of which corresponds to Question #1 or #2)

Note: Since the questionnaire relies on patient self-report, all responses should be verified by the clinician and a definitive diagnosis made on clinical grounds, taking into account how well the patient understood the questionnaire, as well as other relevant information from the patient. Diagnoses of Major Depressive Disorder or Other Depressive Disorder also require impairment of social, occupational, or other important areas of functioning (Question #10) and ruling out normal bereavement, a history of a Manic Episode (Bipolar Disorder), and a physical disorder, medication, or other drug as the biological cause of the depressive symptoms.

To monitor severity over time for newly diagnosed patients or patients in current treatment for depression:

1. Patients may complete questionnaires at baseline and at regular intervals (eg, every 2 weeks) at home and bring them in at their next appointment for scoring or they may complete the questionnaire during each scheduled appointment.
2. Add up ✓s by column. For every ✓: Several days = 1 More than half the days = 2 Nearly every day = 3
3. Add together column scores to get a TOTAL score.
4. Refer to the accompanying PHQ-9 Scoring Card to interpret the TOTAL score.
5. Results may be included in patients' files to assist you in setting up a treatment goal, determining degree of response, as well as guiding treatment intervention.

PHQ-9 SCORING CARD FOR SEVERITY DETERMINATION

for healthcare professional use only

Scoring—add up all checked boxes on PHQ-9

For every ✓: Not at all = 0; Several days = 1;
More than half the days = 2; Nearly every day = 3

Interpretation of Total Score

Total Score	Depression Severity
1-4	Minimal depression
5-9	Mild depression
10-14	Moderate depression
15-19	Moderately severe depression
20-27	Severe depression

3. Cognitive Capacity Assessment Tools

Tool 3-1. The Montreal Cognitive Assessment (MOCA)³

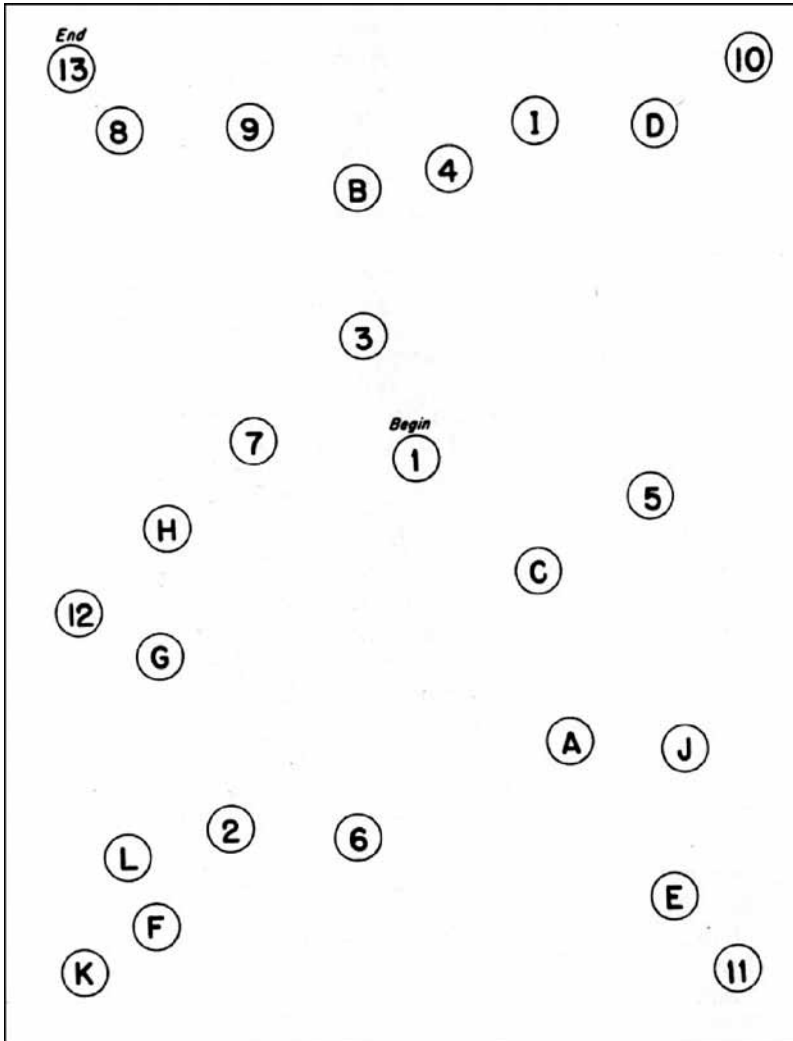
NAME : _____
 Education : _____ Date of birth : _____
 Sex : _____ DATE : _____

VISUOSPATIAL / EXECUTIVE		Copy cube	Draw CLOCK (Ten past eleven) (3 points)	POINTS			
		<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	___/5			
NAMING							
				___/3			
MEMORY	Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.	FACE	VELVET	CHURCH	DAISY	RED	No points
		1st trial					
		2nd trial					
ATTENTION	Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order	[] 2 1 8 5 4				___/2	
	Subject has to repeat them in the backward order	[] 7 4 2					
	Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors	[] FBACMNAAJKLBAFAKDEAAAJAMOF AAB					___/1
	Serial 7 subtraction starting at 100	[] 93	[] 86	[] 79	[] 72	[] 65	___/3
		4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt					
LANGUAGE	Repeat: I only know that John is the one to help today. []						___/2
	The cat always hid under the couch when dogs were in the room. []						
	Fluency / Name maximum number of words in one minute that begin with the letter F	[] _____ (N ≥ 11 words)					___/1
ABSTRACTION	Similarity between e.g. banana - orange = fruit	[]	train - bicycle	[]	watch - ruler	[]	___/2
DELAYED RECALL	Has to recall words WITH NO CUE	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only
		[]	[]	[]	[]	[]	
Optional	Category cue						
	Multiple choice cue						
ORIENTATION	[] Date	[] Month	[] Year	[] Day	[] Place	[] City	___/6
© Z.Nooreddine MD Version 7.0		www.mocatest.org		Normal ≥ 26 / 30		TOTAL ___/30	
Administered by: _____		Add 1 point if ≤ 12 yr edu					

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In research to study the Montreal Cognitive Assessment test on 90 normal controls, 93 patients with previously diagnosed mild cognitive impairment, and 94 patients with Alzheimer's disease, the mean scores for the three groups were as follows: normal controls 29, patients with mild cognitive impairment 22, and patients with Alzheimer's disease 16.³

Tool 3-2. The Trail Making Test Part B^{4,5}



In a study analyzing cognitive impairment in chronic kidney disease patients, normal individuals completed the Trail Making Test Part B in a mean of 92.7 ± 32.5 seconds; individuals with chronic kidney disease completed the test in a mean of 158.8 ± 74.1 seconds; and individuals with end-stage renal disease completed the test in a mean of 218.4 ± 83.9 seconds ($P < 0.001$).⁵

Tool 3-3. Short-Memory Questionnaire^{4,6}

Questions	Almost Never	Sometimes	Often	Almost Always
1. Can he/she remember what clothes he/she wore yesterday?	1	2	3	4
7. Can he/she remember where his/her ride will meet him/her?	1	2	3	4
8a. Can he/she recall his/her telephone number?	1	2	3	4
11. Can he/she shop for groceries without a list and not forget any items (5 items)?	1	2	3	4
12a. Does he/she usually remember where he/she put his/her glasses?	1	2	3	4
12b. Does he/she usually remember where he/she put his/her keys?	1	2	3	4
15. Does he/she forget birthdays in his/her family?	1	2	3	4
16. If someone calls him/her, can he/she give that person directions to his/her home?	1	2	3	4
17. After leaving, can he/she remember whether he/she locked his/her house?	1	2	3	4
20. When he/she leaves the supermarket, can he/she remember how much change he/she received?	1	2	3	4
21. Can he/she describe what he/she did last Sunday afternoon?	1	2	3	4
22. Does he/she have to be reminded of things that his/her spouse or someone else has asked him/her to do?	1	2	3	4
26. Is it difficult for him/her to find the words that he/she wants to use?	1	2	3	4
27. Can he/she recall all his/her financial obligations (bills, bank accounts, savings)?	1	2	3	4

⁴Item numbers are those of the original scale.⁷ Scoring key: almost never=1; sometimes=2; often=3; almost always=4. Scores on items 15 and 26 should be subtracted from the total because they have a reverse meaning. A total score of less than 40 is suggestive of disproportionate cognitive difficulties.

The Short-Memory Questionnaire has excellent specificity and sensitivity for identifying dementia in patients with Alzheimer’s disease.⁶ It has not been validated for dialysis patients, but reviewers have suggested that this questionnaire would be helpful for patients with limited visual capacity or limited manual skills who cannot write or draw.

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4. Decision-Making Capacity Assessment Tools

Decision-making capacity is the capacity to: 1) understand one’s 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 one’s personal values, preferences, and goals; 4) reason and deliberate about one’s options; and 5) communicate one’s decisions in a meaningful manner.

Lack of decision-making capacity is different from cognitive impairment. It is possible for someone to be mildly demented and have decision-making capacity. Traditionally, decision-making capacity has been assessed by clinical interview. In the past several years, a number of standardized instruments have become available. An example of one of these instruments is presented below.

Tool 4. Aid to Capacity Evaluation (ACE)⁸

Record the observations that support your score in each domain, including exact responses of the patient. Indicate your score for each domain with a checkmark.

1. Able to understand medical problem. Observations: _____ _____	YES <input type="checkbox"/> UNSURE <input type="checkbox"/> NO <input type="checkbox"/>
2. Able to understand proposed treatment. Observations: _____ _____	YES <input type="checkbox"/> UNSURE <input type="checkbox"/> NO <input type="checkbox"/>
3. Able to understand alternative to proposed treatment (if any). Observations: _____ _____	YES <input type="checkbox"/> UNSURE <input type="checkbox"/> NO <input type="checkbox"/>
4. Able to understand option of refusing proposed treatment (including withholding or withdrawing proposed treatment). Observations: _____ _____	YES <input type="checkbox"/> UNSURE <input type="checkbox"/> NO <input type="checkbox"/>
5. Able to appreciate reasonably foreseeable consequences of accepting proposed treatment. Observations: _____ _____	YES <input type="checkbox"/> UNSURE <input type="checkbox"/> NO <input type="checkbox"/>
6. Able to appreciate reasonably foreseeable consequences of refusing proposed treatment (including withholding or withdrawing proposed treatment). Observations: _____ _____	YES <input type="checkbox"/> UNSURE <input type="checkbox"/> NO <input type="checkbox"/>

NOTE: For questions 7a and b, a “Yes” answer means the person’s decision is affected by major depression or psychosis.	
7a. The person’s decision is affected by major depression. Observations: _____ _____	YES <input type="checkbox"/> UNSURE <input type="checkbox"/> NO <input type="checkbox"/>
7b. The person’s decision is affected by delusion/psychosis. Observations: _____ _____	YES <input type="checkbox"/> UNSURE <input type="checkbox"/> NO <input type="checkbox"/>

Overall Impression

- Definitely Capable
- Probably Capable
- Probably Incapable
- Definitely Incapable

Comments

(For example; need for psychiatric assessment, further disclosure and discussion with patient, or consultation with family)

The initial ACE assessment is the first step in the capacity assessment process. If the ACE definitely or probably indicates incapacity, the clinician should consider treatable or reversible causes of incapacity (e.g., drug toxicity). Repeat the capacity assessment once these factors have been addressed. If the ACE result indicates probable incapacity or probable capacity, then take further steps to clarify the situation. For example, if the clinician is unsure about the person’s ability to understand the proposed treatment, then a further interview that specifically focuses on this area would be helpful. Similarly, consultation with family, cultural, and religious figures and/or a psychiatrist, may clarify some areas of uncertainty.

Never base a finding of incapacity solely on an interpretation of domain 7a and 7b. Even if the clinician is sure that the decision is based on a delusion or major depression, it is always valuable to get an independent assessment.

Time taken to administer ACE: _____ minutes

Date: Day: ____ Month: ____ Year: ____ Hour: _____

Assessor: _____

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5. Advance Care Planning Including Advance Directives

Tool 5-1. Advance Care Planning Questions

The following table provides examples of questions that may be helpful in discussing end-of-life issues with patients.⁹

Potentially Useful Open-Ended Questions About End-of-Life Care
■ What concerns you most about your illness?
■ How is treatment going for you (your family)?
■ As you think about your illness, what is the best and the worst that might happen?
■ What has been most difficult about this illness for you?
■ What are your hopes (your expectations, your fears) for the future?
■ As you think about the future, what is most important to you?
Potentially Useful Questions With Which to Explore Spiritual and Existential Issues
■ Is faith (religion, spirituality) important to you in this illness?
■ Has faith (religion, spirituality) been important to you at other times in your life?
■ Do you have someone to talk to about religious matters?
■ Would you like to explore religious matters with someone?
More Direct Questions That May Be Useful with Patients Who Want to Discuss Spiritual and Existential Issues
■ What do you still want to accomplish during your life?
■ What thoughts have you had about why you got this illness at this time?
■ What might be left undone if you were to die today?
■ What is your understanding about what happens after you die?
■ Given that your time is limited, what legacy do you want to leave your family?
■ What do you want your children and grandchildren to remember about you?

Tool 5-2. Explanation of Advance Directives

Advance directives are oral or written statements by a patient with decision-making capacity, which express his/her preferences for a surrogate and 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 recognizing written advance directives.

There are two types of advance directives: a health care proxy and a living will. The health care proxy designates a person to make decisions for a patient when the patient loses decision-making capacity. The health care proxy is known in some states as a medical power of attorney or a durable power of attorney for health care. The living will, also known as an instruction directive, indicates a patient's wishes that are 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. In some states, both of these functions are combined in the living will.

The US Congress enacted the Patient Self-Determination Act¹⁰ to require that information concerning written directives be provided to all adults at the time of admission as a hospital inpatient, at the time of admission as a skilled nursing facility resident, in advance of coming under the care of a home health agency, or at the time of initial receipt of hospice care. State laws vary with regard to written directives.

Tool 5-3. Website Resources for Advance Care Planning and Advance Directives

The Kidney End-of-Life Coalition provides information and resources to help dialysis professionals, facilities, and patients complete advance care planning and advance directive completion. See <http://www.kidneyeol.org/>.

The Caring Connections website offers information about advance care planning and free downloads of state-specific, legal advance directives. See <http://www.caringinfo.org/stateadownload>.

The Physician Orders for Life-Sustaining Treatment (POLST) Paradigm program to convert patients' end-of-life wishes into easily identifiable, portable, and reviewable medical orders that are honored throughout the health care system is recognized as a preferred practice by the National Quality Forum in its *A National Framework and Preferred Practices for Palliative Care and Hospice Care Quality* (2006). The POLST Paradigm program was also recognized as a model practice for implementing advance care planning by RAND Health in their *Advance Directives and Advance Care Planning: A Report to Congress* (2009). The website link for the POLST Paradigm Program is www.polst.org.

Below is a model advance care planning policy that dialysis facilities may find helpful as they develop their advance directive policies and procedures to comply with the Conditions for Coverage published by the Centers for Medicare and Medicaid Services in 2008. Subpart C. Patient Care, Section § 494.70 Condition: Patients' Rights requires dialysis facilities to have advance directives policies.

Tool 5-4. Model Dialysis Unit Advance Care Planning Policy¹

I. Policy

It is the policy of (*name of the dialysis facility*) to respect the right of patients with decision-making capacity to execute advance directives documents and to have these documents respected by personnel of the dialysis facility.

II. Rationale for the Policy

Adoption of these policies and procedures enhances the dialysis facility's ability to provide the medical care sought by patients. Their implementation is a major step in assuring respect for patient autonomy and the patient's ability to exercise his or her right to self-determination concerning medical treatment.

¹ Adapted in part with permission from the Robert Wood Johnson Foundation's End-Stage Renal Disease Workgroup's Recommendations to the Field, Model Policy and Procedure for DNR Orders in Dialysis Facility. Refer to www.promotingexcellence.org/esrd for the Robert Wood Johnson Foundation's End- Stage Renal Disease Workgroup's final product.

This policy and procedure represents the work of the Kidney End-of-Life Coalition and does not necessarily represent the views of the above Foundations. It is reprinted here with permission of the Mid-Atlantic Renal Coalition and the Kidney End-of-Life Care Coalition.

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III. Definitions

Advance Care Planning: A process of communication among the patient, his/her family and friends, and the health care team in which the patient's preferences for a health care proxy and for future medical care determined prospectively (sometimes including the completion of a written advance directive), updated periodically, and respected when the patient no longer has the capacity to participate in medical decision-making.

Advance Directive: A statement by a patient with decision-making capacity expressing his/her preference for a health care proxy 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 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 durable power of attorney for health care. In some states both instruction and proxy directives may be combined into one advance directive form. Some patients may want to state their preferences verbally to their family and to dialysis staff and not put them into writing. Any expressed preferences should be documented in the patient's dialysis medical record. Such verbal statements constitute oral advance directives. (Since written advance directives are preferable from a legal perspective, the remainder of this policy and procedure refers to written advance directives.)

Attending Physician: A licensed physician with staff privileges in the dialysis facility 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.

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.

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.

Patient 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, preference and goals; 4) reason and deliberate about his/her own options; and 5) communicate his/her decision in a meaningful manner.

IV. Procedures

- A. _____ (facility should designate a specific individual, committee or category of health professionals, i.e. social worker, nurse, clinician) will assume ultimate responsibility for assuring compliance with the advance directive policies and procedures and assuring that each patient is advised of his/her rights under the policies. The responsible individual(s) will be well informed about advance directives and relevant state laws and will be comfortable with and capable of discussing issues related to death and dying. The individual(s) will also have an awareness of how cultural diversity affects the views and concerns of persons of different ethnic and religious groups towards death and dying. Designated staff should assure that their personal beliefs and values about death and dying are not imposed onto the patient and family.
- B. All clinical staff will be made familiar with advance directives and will be oriented with the facility's written policies and procedures.
- C. Upon adoption of these policies and procedures, a determination of decision-making capacity will be made by the patient's attending or rounding physician or other licensed professional as allowed by state law on the patient's admission to the dialysis unit, yearly, and whenever there is a change in the patient's neurological status.
- D. A determination will be made if each patient has previously signed any type of advance directive authorized by state law. Upon adoption of these policies and procedures, existing patients will be asked. A new patient will be asked upon admission to a dialysis facility for the initiation of dialysis treatment.
- E. If the patient has existing advance directives, he/she will be requested to provide a copy to the facility for placement in the patient's dialysis medical record.
- F. If the patient, either new or existing, is unable to participate in discussions with staff of the facility, an effort will be made through discussion with the patient's legal guardian or authorized health care proxy according to state law to determine if the patient has previously signed any type of advance directive. An effort will be made to obtain a copy of any such advance directive for placement in the patient's dialysis medical record.

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- G. Any existing advance directive document(s) will be reviewed and discussed with the patient if he/she is able to participate in such discussions. The patient will also be asked if he/she is comfortable with the existing advance directive or desires to execute a new one.
- H. If the patient has not signed advance directives, the responsible staff member(s) will have a discussion with and provide written information to the patient about advance directives and applicable state laws regarding advance directives.
 - a. If the patient does elect to complete an advance directive document, the following are helpful questions to ask during the advance care planning process:
 - I. If you had to choose between being kept alive as long as possible regardless of personal suffering or living a shorter time to avoid suffering and medical procedures such as breathing machines and feeding tubes, which would you pick and why?
 - J. Under what circumstances, if any, would you want to stop dialysis?
 - K. Under what circumstances, if any, would you not want to be kept alive with medical means such as cardiopulmonary resuscitation, a feeding tube, or mechanical ventilation?
 - L. Where do you prefer to die and who do you wish to be with you when you die?
 - a. (Applicable state forms for advance care planning can be obtained through Caring Connections, www.caringinfo.org)
 - b. Patients new to dialysis who have not signed advance directives will be approached within one month of initiation of dialysis therapy. Since the prospect of beginning dialysis is overwhelming to most individuals, patients who have not previously signed advance directives may not wish to discuss or sign advance directives at the time of admission. If at all possible, however, patients will be encouraged to complete a medical power of attorney to allow for a decision-maker in the event of an emergency.
- M. If it is determined that the patient has not signed advance directives and the patient's decision-making capacity is temporarily impaired due to a medical condition, e.g. uremia, the initial discussion of advance directives will be delayed until the patient can participate in the process.
- N. If the patient does not have advance directives and does not wish to discuss or sign advance directives the first time he/she is approached, the topic will be approached again within three months. However, regardless of whether the patient completes an advance directive, he/she will be asked to provide the name of a person he/she would want to make decisions for him/her in the event of incapacity. This person's name shall be documented in the advance directive section of the patient's dialysis medical record.
- O. If the patient still does not elect to complete advance directives, his/her decision will be respected. However, in conjunction with Comprehensive Assessment and Plan of Care completion, or if the patient's physical condition deteriorates, appropriate staff will once again offer to discuss advance care planning if the patient so desires.
- P. When a discussion regarding advance directives occurs with the patient, the discussion, as well as the patient's decision whether or not to sign advance directives, will be noted in the progress notes of the dialysis medical record. The patient's Comprehensive Assessment and Plan of Care will include pertinent information on advance directives that will be regularly updated as needed.

- Q. If the patient chooses to complete advance directives, the dialysis medical record will be marked in a manner that makes it readily apparent to staff that an advance directive exists. There will be a standardized section of the patient's dialysis medical record that is devoted to documenting end-of-life preferences. A copy of the advance directives document(s) will also be maintained in the dialysis medical record in a form that complies with applicable state law, if any.
- R. The patient's advance directives, if any, will be reported at periodic patient care meetings to ensure that staff members are familiar with the existence of that patient's advance directives.
- S. Staff assigned to deal with advance directives in the facility will promptly notify any third party designated to act under the advance directives if circumstances arise which are addressed by the patient's advance directive.
- T. The patient will be advised to discuss his/her advance directives and provide a copy of them to any person designated as a health care proxy or authorized to act under a health care power of attorney or similar advance directives. The patient will also be advised to discuss his/her advance directives and provide a copy of the advance directives to one or more of the following groups of people: his/her personal physician, significant other, family, friend, attorney or religious adviser. If the patient desires, a facility staff person will facilitate discussions with these individuals.
- U. Advance directives will be reviewed with the patient on a semi-annual basis, at approximately the time of the patient's Comprehensive Assessment and Plan of Care meeting, or more frequently if there is significant change in the patient's physical condition, to determine if changes in the advance directives are necessary. The facility will periodically review any health care proxy to ensure that the designated person can still act as proxy and that the contact information is current.
 - a. If the patient alters his/her advance directives, the facility should document that the superseded advance directive was revoked. If a copy of the revoked advance directive is maintained, it should be clearly marked to distinguish that it has been revoked. (Facilities should determine if applicable state law mandates how revocation is documented.)
- V. The dialysis patient or his/her health care proxy is responsible for giving a copy of his/her advance directive to health care professionals treating the patient. With a signed release from the patient or proxy, the dialysis facility will provide a copy of the advance directives to the following:
 - a. A hospital at the time of any future admission;
 - b. Another dialysis facility upon permanent transfer or transient treatments;
 - c. Any treating physician, home health agency, hospice, nursing home or health maintenance organization which provide service to the patient; or
 - d. Any ambulance service, transportation provider or EMT, which provides transport to the patient.

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6. Prognosis Tools

Tool 6-1. Integrated Prognostic Model for Dialysis Patients

Nephrology clinicians and other staff can use an Internet-based integrated prognostic model for dialysis patients to estimate 6-, 12-, and 18-month survival.¹¹ The model requires the user to enter patient age, serum albumin level, response to the surprise question, and presence or absence of dementia and peripheral vascular disease. The model is accessible at <http://touchcalc.com/calculators/sq>.

Tool 6-2. Modified Charlson Comorbidity Index¹²

Completed by _____

Date of completion _____ Time _____

Assigned Weights of diseases

Conditions

1	Myocardial Infarction (any form of coronary artery disease) Congestive Heart Failure Peripheral Vascular Disease Cerebrovascular disease Dementia Chronic obstructive pulmonary disease Connective tissue Disease Ulcer Disease Mild Liver Disease Diabetes
2	Hemiplegia Moderate or severe renal disease Diabetes with end-organ damage Any tumor Leukemia Lymphoma
3	Moderate or Severe Liver Disease
6	Metastatic solid tumor AIDS

For each decade over the age of 40 years, add a score of 1. Non-diabetic dialysis patients receive a minimum score of 2 for moderate to severe renal disease, and diabetic patients receive a minimum score of 4 (2 for diabetic end-organ damage and 2 for end-stage renal disease).

Total score of the patient ____/____.

Tool 6-3. Malnutrition Inflammation Score (M.I.S.)¹³

MALNUTRITION INFLAMMATION SCORE (M.I.S.)			
(A) Patients' related medical history:			
1- Change in end dialysis dry weight (overall change in past 3-6 months):			
0	1	2	3
No decrease in dry weight or weight loss <0.5 kg	Minor weight loss (>0.5 kg but <1 kg)	Weight loss more than one kg but <5%	Weight loss >5%
2- Dietary intake:			
0	1	2	3
Good appetite and no deterioration of the dietary intake pattern	Somewhat sub-optimal solid diet intake	Moderate overall decrease to full liquid diet	Hypo-caloric liquid to starvation
3- Gastrointestinal (GI) symptoms:			
0	1	2	3
No symptoms with good appetite	Mild symptoms, poor appetite or nauseated occasionally	Occasional vomiting or moderate GI symptoms	Frequent diarrhea or vomiting or severe anorexia
4- Functional capacity (nutritionally related functional impairment):			
0	1	2	3
Normal to improved functional capacity, feeling fine	Occasional difficulty with baseline ambulation, or feeling tired frequently	Difficulty with otherwise independent activities (e.g. going to bathroom)	Bed/chair-ridden, or little to no physical activity
5- Co-morbidity including number of years on Dialysis:			
0	1	2	3
On dialysis less than one year and healthy otherwise	Dialyzed for 1-4 years, or mild co-morbidity (excluding MCC*)	Dialyzed >4 years, or moderate co-morbidity (including one MCC*)	Any severe, multiple co-morbidity (2 or more MCC*)
(B) Physical Exam (according to SGA criteria):			
6- Decreased fat stores or loss of subcutaneous fat (below eyes, triceps, biceps, chest):			
0	1	2	3
Normal (no change)	mild	moderate	Severe
7- Signs of muscle wasting (temple, clavicle, scapula, ribs, quadriceps, knee, interosseous):			
0	1	2	3
Normal (no change)	mild	moderate	Severe
(C) Body mass index:			
8- Body mass index: BMI = Wt(kg) / Ht²(m)			
0	1	2	3
BMI>20 kg/m ²	BMI: 18-19.99 kg/m ²	BMI: 16-17.99 kg/m ²	BMI<16 kg/m ²
(D) Laboratory Parameters:			
9- Serum albumin:			
0	1	2	3
Albumin> 4.0 g/dL	Albumin: 3.5-3.9 g/dL	Albumin: 3.0-3.4 g/dL	Albumin: <3.0 g/dL
10- Serum TIBC (total Iron Binding Capacity): ♣			
0	1	2	3
TIBC> 250 mg/dL	TIBC: 200-249 mg/dL	TIBC: 150-199 mg/dL	TIBC: <150 mg/dL
Total Score = sum of above 10 components (0-30):			

* MCC (Major Comorbid Conditions) include CHF class III or IV, full blown AIDS, severe CAD, moderate to severe COPD, major neurological sequelae, and metastatic malignancies of s/p recent chemotherapy.

♣ Suggested equivalent increments for serum transferrin are: >200 (0), 170-200 (1), 140-170 (2), and <140 mg/dL (3).

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Tool 6-4. French Renal Epidemiology and Information Network Registry Clinical Score to Predict 6-month Prognosis¹⁴

Risk factors	Points
Body mass index (kg/m²)	
≥18.5	0
<18.5	2
Diabetes	
Absence	0
Presence	1
Congestive heart failure stage III or IV	
Absence	0
Presence	2
Peripheral vascular disease stage III of IV	
Absence	0
Presence	2
Dysrhythmia	
Absence	0
Presence	1
Active malignancy	
Absence	0
Presence	1
Severe behavioral disorder	
Absence	0
Presence	2
Totally dependent for transfers	
Absence	0
Presence	3
Initial context	
Planned dialysis	0
Unplanned dialysis (late referral)	2

The risk of death increases with the score. Patients with ≥9 points had a predicted 6-month mortality of 62% in the derivation sample (2,500 patients) and 70% in the validation sample (1,640 patients).

7. Quality of Life or Functional Status Assessment Tools

Patients and their providers may find it helpful to monitor patient-centered outcomes such as functional status or quality of life. The terms generally refer to functioning or well-being in one or more domains (e.g., physical, psychological, social, occupational, sexual). Poor functional

status is highly predictive of early death in dialysis patients (for a discussion of this evidence, see Recommendation No. 3 of this guideline).

Both generic and disease-specific instruments have been used to assess quality of life or functional status in hemodialysis patients. The most frequently used standardized and well-known instruments to assess dialysis patients include variations of the Karnofsky Performance Status Scale¹⁵, the Medical Outcomes Study 36-item Short Form (SF-36)¹⁶ or the Medical Outcomes Study 20-item Short Form (SF-20)¹⁷, the Beck Depression Inventory¹⁸, and the Sickness Impact Profile.¹⁹ Disease-specific instruments, such as the Kidney Disease Quality of Life (KDQOL) instrument,²⁰ have been used less frequently.

Tool 7. Karnofsky Performance Status Scale

The Karnofsky Performance Status Scale (KPS) is a well-established and widely used method of quantifying the functional status of cancer patients and was the most commonly used instrument to assess functional status in the Working Group’s systematic review of the renal literature.¹⁴ As originally conceived, the KPS has three alphabetic groups (A, B, and C) for classifying patients’ ability to work, carry on normal activity, and care for themselves.³³ These alphabetic groups are further divided into 11 categories, which cover all possible levels of functioning from completely normal (100) to dead (0).

Karnofsky Performance Status Scale Definitions Rating (%) Criteria²¹

A. Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
B. Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
C. Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead.

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8. National Kidney Foundation Dialysis Initiation and Withdrawal Tools

The National Kidney Foundation's *Initiation or Withdrawal of Dialysis in End-stage Renal Disease: Guidelines for the Health Care Team*²² included helpful checklists to follow in initiating dialysis, withdrawing dialysis, and in helping patients to prepare for dying.

Tool 8-1. Initiation of Dialysis Checklist

Patient's name, address, and telephone number:

Name, address, and telephone number of surrogate designated by advance directive, if applicable:

Names, addresses, and telephone numbers of significant other and family members (contact only with the consent of the patient if competent, or otherwise, the surrogate):

1. Pre-evaluation information:

- a. If applicable, attach a copy of the patient's advance directive(s) or other statement(s) of the patient's wishes and decisions regarding life sustaining medical treatment. State the type of directive executed.

- b. Materials should be reviewed for familiarization. The patient/surrogate should be asked to clarify any matters which may be unclear, incomplete or not in compliance with applicable state law. If the advance directive is only a treatment directive, ask if the patient wishes to designate a surrogate. If there is only a surrogate designation, ask if a treatment directive is considered appropriate.

- c. Assess whether the patient has the capacity to make medical decisions concerning initiation of dialysis and/or regarding other matters likely to require decisions in the foreseeable future (i.e. circumstances that would warrant a DNR order or discontinuation of dialysis). Document the methods used to determine capacity.

- d. If the patient lacks capacity, assess whether it is temporary or permanent or related only to one of more medical decisions. Document the methods used to determine capacity.

- e. If the patient lacks capacity and does not have an advance directive designating a surrogate, the physician or health care team treating the patient should consult with legal counsel to determine who can make medical decisions for the patient and what, if any, restrictions apply to such authority. The person who can act, the legal basis for that person's authority (i.e. health care power of attorney, health care proxy, court appointed guardianship, parent of minor) and the limitations on her/his authority are as follows:

- f. Date, time and place of the discussion and decision to initiate or withhold dialysis, including the name of the person(s) making the decision and who else was present.

- g. If there was a decision to withhold dialysis, identify any close family members/others who might object to withholding dialysis, and determine if the patient/surrogate has discussed not initiating dialysis with them. Explain why they might object to the decision to withhold dialysis.

2. Evaluation of Patient:

- a. Determine the reasons or conditions underlying the patient's/surrogate's desires regarding initiation of dialysis. Such assessment should include specific medical, physical, spiritual and psychological issues, as well as interventions which could be appropriate.

Some of the potentially treatable factors that might be identified by the assessment are:

Fear of dialysis, possibly due to a lack of information about treatment;

Underlying medical disorders, including the prognosis for short- or long-term survival on dialysis;

The patient's assessment of quality of life and ability to function before initiation of dialysis and preconceptions of anticipated quality of life and ability to function after initiation of dialysis;

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The patient's short- and long-term goals;

The burden that cost of treatment/medications/diet/transportation may have on the patient/family/others;

- The patient's psychological condition, including conditions/symptoms that may be caused by uremia;
- Undue influence or pressure from outside sources, including the patient's family;

Conflict between the patient and others.

- b. If the patient/surrogate does not want dialysis initiated, consideration might be given to the use of psychometric tools, such as the Beck Depression Inventory, the Karnofsky Scale, the SF 36 Health Survey or similar measurement instruments. They could aid in identifying specific problems which could impact the decision. Identify any such tools used and the results.

- c. 1. Have the patient/others received education about various ESRD treatment modalities and settings and the possibility of a trial period on dialysis to permit them to make an informed and knowledgeable decision on whether to initiate dialysis? Describe.

2. Have the patient/others spoken to dialysis patients with similar illnesses and/or cultural and socioeconomic backgrounds to learn the patient's/ other's perspective of the quality of life on dialysis?

- d. If the patient/surrogate does not want dialysis initiated, did he/she consent to referral to a counseling professional? (e.g. social worker, pastoral care, psychologist or psychiatrist) If yes, identify and describe any findings or recommendations.

- e. 1. If the patient/surrogate does not want dialysis initiated, are there interventions that could alter the patient's circumstances which might result in him/her considering it reasonable to initiate dialysis? Describe possible interventions.

2. Does the patient/surrogate desire the proposed intervention(s)?

3. A determination has been made that the following intervention(s) will be undertaken.

f. In cases where the surrogate has made the decision to either initiate or withhold dialysis, has it been determined that the judgment of the surrogate is consistent with the stated desires of the patient? Describe.

3. The Dying Process if ESRD Treatment is Withheld:

a. Have the patient/others been given advice and information on the clinical course of the patient dying of uremia or an underlying illness? Describe.

b. Have the patient/others been provided with counseling and information on bereavement issues? Describe.

c. Have the patient/others been advised that the health care team will attempt to provide them with all necessary emotional, spiritual, social and medical assistance and support possible? The following assistance and support have been offered:

d. Has the question of where the patient desires death to occur been discussed with the patient/surrogate? The patient/surrogate has made the following decision:

e. 1. If the patient desires to die at home, have the patient/care givers been offered assistance in obtaining supportive services from agencies and providers, including hospice and home health care? (List services offered and those that were accepted.)

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- 2. Has there been discussion about whether emergency medical services in the community will honor DNR orders or an advance directive?

- f. If the patient/surrogate has decided not to initiate dialysis at this time, has he/she advised that the decision can be reconsidered at a later date and given serious consideration by the physician?

Tool 8-2. Withdrawal of Dialysis Checklist

Patient's name, address, and telephone number:

Name, address, and telephone number of surrogate designated by advance directive, if applicable:

Names, addresses, and telephone numbers of significant other and family members (contact only with the consent of the patient if competent, or otherwise, the surrogate):

1. Pre-evaluation Information:

- a. If applicable, attach a copy of the patient's advance directive(s) or other statement(s) of the patient's wishes and decisions regarding life sustaining medical treatment. State the type of directive executed.

- b. Materials should be reviewed for familiarization. The patient/surrogate should be asked to clarify any matters which may be unclear, incomplete or not in compliance with applicable state law. If the advance directive is only a treatment directive, ask if the patient wishes to designate a surrogate. If there is only a surrogate designation, ask if a treatment directive is considered appropriate.

- c. Assess whether the patient has the capacity to make medical decisions concerning withdrawal of dialysis. Document the methods used to determine capacity.

- d. If the patient lacks capacity, assess whether it is temporary or permanent or related only to one or more medical decisions. Document the methods used to determine capacity.

- e. If the patient lacks capacity and does not have an advance directive designating a surrogate, the physician or health care team treating the patient should consult with legal counsel to determine who can make medical decisions for the patient and what, if any, restrictions apply to such authority. The person who can act, the legal basis for that person's authority (i.e. health care power of attorney, health care proxy, court appointed guardianship, parent of minor) and the limitations on her/his authority are as follows:

- f. If there was a decision to withdraw dialysis, indicate the date, time and place of the discussion and decision to withdraw dialysis, including the name of the person(s) making the decision and who else was present.

- g. If there was a decision to withdraw dialysis, identify close family members/others who might object to withdrawal of dialysis, and determine if the patient/surrogate has discussed withdrawing dialysis with them. Explain why they might object to the decision to withdraw dialysis therapy.

2. Evaluation of Patient:

- a. Determine the reasons or conditions underlying the patient/surrogate desires regarding withdrawal of dialysis. Such assessment should include specific medical, physical, spiritual and psychological issues, as well as interventions which could be appropriate.
Some of the potentially treatable factors that might be included in the assessment are:
Underlying medical disorders, including the prognosis for short- or long-term survival on dialysis;
Difficulties with dialysis treatments;
The patient's assessment of his/her quality of life and ability to function;
The patient's short- and long-terms goals;

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The burden that costs of continued treatment/medications/diet/transportation may have on the patient/family/others;

The patient's psychological condition, including conditions/symptoms that may be caused by uremia;

Undue influence or pressure from outside sources, including the patient's family;

Conflict between the patient and others;

Dissatisfaction with the dialysis modality, the time or the setting of treatment.

- b. If the patient/surrogate wishes to withdraw from dialysis, consideration might be given to the use of psychometric tools, such as the Beck Depression Inventory, the Karnofsky Scale, the SF 36 Health Survey or similar measurement instruments. They could aid in identifying specific issues which could impact the decision. Identify any such tools used and the results.

- c. If the patient/surrogate wishes to withdraw dialysis, did he/she consent to referral to a counseling professional? (e.g. social worker, pastoral care, psychologist or psychiatrist) If yes, identify and describe any findings or recommendations.

- d. 1. If the patient/surrogate wishes to withdraw dialysis, are there interventions that could alter the patient's circumstances which might result in him/her considering it reasonable to continue dialysis? Describe possible interventions.

2. Does the patient/surrogate desire the proposed intervention(s)?

3. A determination has been made that the following intervention(s) will be undertaken.

- e. In cases where the surrogate has made the decision to either continue or withdraw dialysis, has it been determined that the judgment of the surrogate is consistent with the stated desires of the patient? Describe.

3. The Dying Process if ESRD Treatment is Withdrawn:

- a. Have the patient/others been given advice and information on the clinical course of the patient dying of uremia or of the patient’s underlying illness? Describe.

- b. Have the patient/others been provided with counseling and information on bereavement issues? Describe.

- c. Have the patient/others been advised that the health care team will attempt to provide them with all necessary emotional, spiritual, social and medical assistance and support possible? The following assistance and support have been offered:

- d. Has the question of where the patient desires death to occur been discussed with the patient/surrogate? The patient/surrogate has made the following decision:

- e. 1. If the patient desires to die at home, have the patient/care givers been offered assistance in obtaining supportive services from agencies and providers, including hospice and home health care? (List services offered and those that were accepted.)

- 2. Has there been discussion about whether emergency medical services in the community will honor DNR orders or an advance directive?

- f. If the patient/surrogate has decided to withdraw dialysis, has he/she been advised that the decision can be reconsidered at a later date and given serious consideration by the physician?

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Tool 8-3. Preparation for Dying Checklist

(The physician might consider discussing and providing this checklist to the patient/surrogate after a determination has been made not to initiate or to withdraw dialysis.)

The patient/surrogate may wish to consult with an attorney, accountant, spiritual advisor or others to discuss these or other matters that may be important given the patient's particular circumstances. Consideration should be given to providing copies of the relevant documents, such as an advance directive, to the patient's surrogate, the patient's family/significant other, primary physician and/or attorney.

A patient who has decided not to initiate or to withdraw dialysis should have or consider preparing the following documents:

- A will.
- Signed advance directive (living will, durable health care power of attorney or health care proxy, DNR order) complying with applicable state law.
- A durable power of attorney complying with applicable state law designating someone to act on the patient's behalf on all matters other than medical, including legal, financial, banking and business transactions. (A power of attorney must be "durable" if it is to remain in effect even if the individual becomes unable to make his or her own decisions or dies.)
- 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.
- Names, addresses and telephone numbers of attorney, accountant, family members/significant other, friends and business associates who should be notified of the death or may have information that will be helpful in dealing with estate affairs.
- Documentation concerning preferences for funeral/memorial services, burial or cremation instructions and decisions about organ, tissue or body donation.
- Written or video or audio taped message to family/significant other, business associates and friends.

9. Pain and Symptom Assessment and Management for Dialysis Patients

Tool 9-1. Clinical Algorithm & Preferred Medications to Treat Pain in Dialysis Patients

The Mid-Atlantic Renal Coalition and the Kidney End-of-Life Coalition supported, in part, under CMS Contract #HHSM-500-2006-NW005C, developed, *Clinical Algorithm & Preferred Medications to Treat Pain in Dialysis Patients*, an evidence-based algorithm for assessing and treating pain in dialysis patients.²³⁻³²

The algorithm can be accessed at <http://www.kidneyeol.org/painbrochure9.09.pdf>.

Tool 9-2. Dialysis Symptom Index

The Dialysis Symptom Index is a validated tool for dialysis patients to assess symptom frequency and severity.³³

Instructions

Below is a list of physical and emotional symptoms that people on dialysis may have. For each symptom, please indicate if you had the symptom **during the past week** by circling “yes” or “no.” **If “yes,”** please indicate how much that symptom bothered you by circling the appropriate number.

During the past week: Did you experience this symptom?		If “yes”: How much did it bother you?				
		Not at All	A Little Bit	Some-what	Quite a Bit	Very Much
1. Constipation	No Yes →	0	1	2	3	4
2. Nausea	No Yes →	0	1	2	3	4
3. Vomiting	No Yes →	0	1	2	3	4
4. Diarrhea	No Yes →	0	1	2	3	4
5. Decreased appetite	No Yes →	0	1	2	3	4
6. Muscle cramps	No Yes →	0	1	2	3	4
7. Swelling in legs	No Yes →	0	1	2	3	4
8. Shortness of breath	No Yes →	0	1	2	3	4

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During the past week: Did you experience this symptom?		If "yes": How much did it bother you?				
		Not at All	A Little Bit	Some-what	Quite a Bit	Very Much
9. Lightheadedness or dizziness	No Yes →	0	1	2	3	4
10. Restless legs or difficulty keeping legs still	No Yes →	0	1	2	3	4
11. Numbness or tingling in feet	No Yes →	0	1	2	3	4
12. Feeling tired or lack of energy	No Yes →	0	1	2	3	4
13. Cough	No Yes →	0	1	2	3	4
14. Dry mouth	No Yes →	0	1	2	3	4
15. Bone or joint pain	No Yes →	0	1	2	3	4
16. Chest pain	No Yes →	0	1	2	3	4
17. Headache	No Yes →	0	1	2	3	4
18. Muscle soreness	No Yes →	0	1	2	3	4
19. Difficulty concentrating	No Yes →	0	1	2	3	4
20. Dry skin	No Yes →	0	1	2	3	4
21. Itching	No Yes →	0	1	2	3	4
22. Worrying	No Yes →	0	1	2	3	4
23. Feeling nervous	No Yes →	0	1	2	3	4
24. Trouble falling asleep	No Yes →	0	1	2	3	4
25. Trouble staying asleep	No Yes →	0	1	2	3	4
26. Feeling irritable	No Yes →	0	1	2	3	4

During the past week: Did you experience this symptom?		If "yes": How much did it bother you?				
		Not at All	A Little Bit	Some-what	Quite a Bit	Very Much
27. Feeling sad	No Yes →	0	1	2	3	4
28. Feeling anxious	No Yes →	0	1	2	3	4
29. Decreased interest in sex	No Yes →	0	1	2	3	4
30. Difficulty in becoming sexually aroused	No Yes →	0	1	2	3	4

Are there any other symptoms not mentioned on this questionnaire that you have experienced during the past week? _____

The University of Pittsburgh Medical Center



VA Pittsburgh Healthcare System

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10. ESRD End-of-Life Care Tool

In 2000 the Robert Wood Johnson Foundation National Program *Promoting Excellence in End-of-Life Care* assembled an interdisciplinary 23-person workgroup with expertise in nephrology and palliative care to assess the state of end-of-life care for dialysis patients and make recommendations to the field on ways to improve it.³⁴ This workgroup held a series of meetings, deliberated for 18 months, and issued a 96-page report.³⁵

The links below describe the findings of the workgroup and report the multiple recommendations they made to the Centers for Medicare and Medicaid Services, the NIH's National Institute of Diabetes and Digestive and Kidney Diseases, nephrology researchers, nephrology educators, nephrology clinicians, nephrology certifying boards, dialysis corporations, dialysis units, ESRD networks, public and private funders of nephrology research, and ESRD patient advocacy groups.

The Robert Wood Johnson Foundation National Program *Promoting Excellence in End-of-Life Care* ESRD workgroup webpage can be accessed at <http://www.promotingexcellence.org/esrd/>.

The specific reference for the workgroup report is http://www.promotingexcellence.org/downloads/esrd_full_report.pdf.

11. Communication Tools^{36,37}

Recommended Skill	Example
I. Identifying concerns:	
Eliciting concerns	
Open-ended questions	“What concerns you about your kidney disease?”
Active listening	Allowing patient to speak without interruption; allowing pauses to encourage patient to speak
Recognizing concerns	
Informational concerns	Patient: “I’m not sure about the treatment options”
Emotional concerns	Patient: “I’m worried about that”
II. Responding to informational concerns:	
“Ask-Tell-Ask”	Topic: communicating information about kidney disease
Ask	“What have others told you about what is going on with your illness?”
Tell	After learning what the patient knows, the physician can better tell the information in a way that addresses that patient’s concerns and needs.
Ask	“What questions do you have about what I just said?”

Recommended Skill	Example
III. Responding to emotional concerns:	
Nonverbal empathy: S-O-L-E-R	
S	Face the patient SQUARELY
O	Adopt an OPEN posture
L	LEAN toward the patient
E	Use EYE contact
R	Maintain a RELAXED body posture
Verbal empathy: N-U-R-S-E	
N	NAME the emotion: “You seem worried”
U	UNDERSTAND the emotion: “I see why you are concerned about this”
R	RESPECT the emotion: “You have shown a lot of strength”
S	SUPPORT the patient: “I want you to know that I will still be your doctor no matter what treatment plans we decide”
E	EXPLORE the emotion: “Tell me more about what is worrying you”

Clinical Scenarios in which expressions of wishes might be appropriate³⁸

Clinical Scenario	Sample Responses
Delivering very bad news	<i>I wish I had better news to give you.</i>
Responding to unrealistic hopes from patient or family	<i>I wish that were possible. It sounds like all of us would be a lot happier if that were so.</i>
Responding to expressions of loss, grief, and hopelessness	<i>It sounds like a terrible loss for you. I wish it hadn't turned out this way.</i>
Responding to disappointment in medicine or physician	<i>I can understand how disappointing this is for you. I too wish we had been able to do more for your loved one.</i>
Responding to demands or aggressive treatment when the prognosis is very poor	<i>It must be very hard to come to the intensive care unit every day and see so little change. I wish medicine had the power to turn things around.</i>
Responding to medical complications or errors	<i>This is so hard for you – just when our hopes were so high, for her to have this complication. I wish it had been otherwise.</i>

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