A Panel

ADVANCED CARE PLANNING

Richard Goldman, MD
Wendy Funk-Schrag, MSW
Glenda Harbert, RN
Frances Carroll, Mother
Linda Thompson, Daughter
ADVANCED CARE PLANNING
The Physician’s Role

Richard S Goldman MD
Conditions for Coverage

CENTER FOR MEDICARE AND MEDICAIDE SERVICES
PATEINT RIGHTS
494.70 (a) (6)
“Patients must be informed about their right to have advanced directives and inform patients of the facility’s policies regarding advanced directives”

MEDICAL RECORDS
494.170(b)(2)
“Required facilities to document in the patient’s medical record whether or not an advance directive has been executed by the patient.”
<table>
<thead>
<tr>
<th>Measure</th>
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<tbody>
<tr>
<td><strong>14a</strong> Percentage of patients aged 18 years and older with a diagnosis of ESRD on hemodialysis or peritoneal dialysis for whom there is documentation of a discussion regarding advance care planning</td>
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<tr>
<td><strong>14b</strong> Percentage of patients aged 18 years and older with a diagnosis of ESRD on hemodialysis or peritoneal dialysis who have advance directives and/or medical orders completed based on their preferences</td>
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<tr>
<td><strong>15</strong> Percentage of patients aged 18 years and older with a diagnosis of ESRD who withdraw from hemodialysis or peritoneal dialysis who are referred to hospice care within a 12-month period</td>
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Barriers to Effective Physician Involvement in Advanced Care Planning

- Insufficient time
- Insufficient knowledge about advanced care planning.
- Insufficient communication skills (begin discussion)
- Insufficient knowledge about how to handle “negative” emotions.
10 new or expanded guideline statements

12 new tools
10 GUIDELINE STATEMENTS
6 TOPICS

#1 • Establishing a Shared Decision-Making Relationship

#2, #3 • Informing Patients

#4 • Facilitating Advanced Care Planning

#5, #6 • Making decisions about initiating and discontinuing dialysis

#7, #8 • Resolving conflicts about which dialysis decisions to make

#9, #10 • Providing effective palliative care
Facilitating Advanced Care Planning

Recommendation No. 4  We recommend advance care planning.
Advanced care planning tool for dialysis facilities

Policy & Rationale

Definitions

Procedures

*Adapted in part from the National Kidney Foundation's booklet, Implementing Advance Directives: Suggested Guidelines for Dialysis Facilities.
ADVANCED CARE PLANNING ≠ ADVANCED CARE DIRECTIVES

Advanced Directives

Living Will
- Wishes to be followed after loss of decision-making capacity. Often “condition specific”

Health Care Proxy.
- Person to make decisions for a patient when the patient loses decision-making capacity. “Medical power of attorney” or “Durable power of attorney for healthcare”.

State by State
- Sometimes both of these functions are combined in the living will.
Learn about options
Implement a plan
Voice the plan to others
Engage others to LIVE

It’s about how you LIVE.

Free Downloads:
Caring Connections Brochures
State-Specific Advance Directives

Download Your State’s Advance Directives
Caring Connections provides free advance directives and instructions for each state that can be opened as a PDF (Portable Document Format) file.

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• HIPAA Privacy Rule Summary
• Appendix A: Glossary of Terms

Instructions for Downloading Your Advance Directive
• Opening a PDF requires a file viewer such as Adobe Acrobat Reader.
• If you already have this software installed on your computer, click on your state to proceed.
• Due to formatting and printing requirements, for some states a blank page will appear in the Acrobat Reader as the first page. This does not mean the document has not loaded correctly. Use the reader’s navigational toolbar to go to the next page.

If you have any questions call our Helpline at 800/658-8898 or email us at caringinfo@thecpa.org.

Click on the state below to get your state’s advance directives and instructions.

If you have any legal questions regarding these documents, we recommend contacting your state attorney general’s office or an attorney

Advance Care Planning

“ACP is a process that involves understanding, reflection, communication, and discussion between a patient, family/health care proxy, and staff ...”¹

- Designate a person to be primarily responsible
- Identify a surrogate (health care proxy), in a written State-accepted Advanced Care Directive (POLST)*
- Identify present condition, preferences and goals (shape future care)
- Develop individualized plans for care near the end of life.
- Update periodically

Questions for Advanced Care Planning to Help Discuss End-of-Life Issues

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

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

<table>
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<tr>
<th>Question</th>
<th>Answer</th>
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<tr>
<td>“If you become unable to make decisions for yourself, whom do you want to make decisions for you?”</td>
<td>“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 which would you choose?”</td>
</tr>
<tr>
<td>Under what circumstances, if any, would you want to stop dialysis?</td>
<td>“If your heart stops beating or you stop breathing, would you want to allow natural death?”</td>
</tr>
<tr>
<td>“If your heart stops beating or you stop breathing, would you want to allow natural death?”</td>
<td>“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?”</td>
</tr>
<tr>
<td>“Where do you prefer to die and who do you wish to be with you when you die?”</td>
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Physicians’ Role in Advanced Care Planning

- Medical Director
  - Everything ... including meeting Condition For Coverage requirements regarding advanced directives.

- Attending Practioners
  - Open the discussion skillfully
  - Provide, facilitate, oversee the process of advance care planning ... initially and ongoing†.
conversations
change lives
SOCIAL WORKER ROLE: ADVANCE CARE PLANNING

Wendy Funk Schrag, LMSW, ACSW
SW Role with Patients

- Initiating conversations
- Advance Directive information and completion
- Emotional/social support
- Linking with resources
- Involving family

Resources for patients/families: www.kidneyeol.org
- CPR brochure
- Patient/family brochures on not starting or stopping dialysis
- Info on advance directives and state specific forms
- Personal patient stories
- Book suggestions
SW Role with the Facility

- Educational inservices for staff
- Emotional support to staff/patients
- Care plan transition
- Assisting clinic manager with rituals to help staff, patients, family cope with patient deaths

Resources at [www.kidneyeol.org](http://www.kidneyeol.org):

- Education and webinar modules (understanding sw role: NASW w/ CEUs)
- Planning a memorial service
- Staff inservice trainings
- Model DNR policy, funeral home form, personal possessions form
SW Role with Community

- Building relationships with local hospice agencies
- Referrals to resources: support groups, bereavement counseling, etc.

- Resources at www.kidneyeol.org:
  - Information on hospice and dialysis coordination
SW Role with Policy

- Understanding hospice and dialysis Medicare benefit
- Advocating for state and/or federal legislation

Resources at [www.kidneyeol.org](http://www.kidneyeol.org):
  - State specific legislation related to advance directives and end of life planning
  - Information on CMS hospice and dialysis benefit
INTRODUCING THE STORIES

Glenda Harbert
Frances Carroll
Linda Thompson
Forgoing dialysis

- Medical management without dialysis
  - Instead of saying that a patient is withdrawing from dialysis or agreeing not to start
- Acknowledges that death is imminent, but also sends an important message

“We are not just sending people home to die. We are offering palliative CARE.”
Kidney specialists are pushing doctors to be more forthright with elderly people who have other serious medical conditions, to tell the patients that even though they are entitled to dialysis, they may want to decline such treatment and enter a hospice instead. In the end, it is always the patient’s choice.
Recent studies have found that dialysis does not prolong life for many elderly people with other serious chronic illnesses. One study found that the procedure’s main effect is to increase the chances that such patients will die in the hospital rather than at home.
A DAUGHTER'S STORY ABOUT HER MOTHER (IN LOVE) AND DIALYSIS

Linda Thompson