Wisconsin doctors get support to help patients complete advance directives

Social workers, chaplains and others will be trained to facilitate planning talks to avoid uncertainty about end-of-life care.

By KEVIN B. O'Reilly, amednews staff. Posted April 30, 2012.

The Wisconsin Medical Society is leading a statewide initiative to dramatically improve the rate at which patients complete advance care planning by training nonphysician health professionals to facilitate discussions with patients and encouraging community discussions of an often taboo subject.

The society already has raised $160,000 to fund the effort and lined up participation from most of the major health systems in Milwaukee and Madison, Wis. About 20% of Wisconsinites have designated a health care power of attorney, compared with 61% of physicians in the state, the medical society says. Nationwide, about 30% of patients say they have a living will. The goal of the advance care planning project is to close that gap and help make gut-wrenching end-of-life care decisions less stressful.

“All too often, you have family members who don’t know what the wishes of the patient would be, and they’re left guessing,” said George M. Lange, MD, a geriatrician, the medical society’s immediate past president and a leading force behind the project. “They’re really uncomfortable, and they just don’t know what to do.”

The lack of planning puts a burden on everyone involved, said Tim Barthlow, MD, the society’s chief medical officer.

“We’re all deeply invested in shared decision-making in the patient experience, and this is one of those places where we’ve heard from nurses, hospices, patients and frankly even our own physicians,” Dr. Barthlow said. “Why is it that we still have people showing up to the ICU and the emergency room, folks with chronic illnesses and other conditions who are predictably needing to have this conversation, and they have not?”

Most painful for physicians is that failure to plan can mean applying burdensome interventions at the end of life, he said.

“We’re required to, if we don’t know any other direction, to treat aggressively, even if it’s futile,” Dr. Barthlow said. “So the physician is in this position where sometimes folks who are really, really sick, we’re treating them more aggressively than they think the patient may have wanted.”

The money being raised from health systems, community nonprofits and other philanthropic organizations is principally going to help hospitals and clinics train nurses, social workers, chaplains and other nonphysicians on how to facilitate advance care planning discussions with patients and families. In the pilot phase, health systems will target middle-age patients with life-threatening conditions such as heart failure for planning referrals. Each site will have a point person to coordinate the effort.

Lessons from La Crosse

The training will be done through the Respecting Choices program, an educational curriculum that grew out of the success that the health system in La Crosse, Wis., achieved in improving advance care planning. The program, launched in 1991 in the Gundersen Lutheran Health System, was expanded to the other hospital in town as well as seven nursing homes, two hospices and a home-health agency. The most recent data, collected in 2007 and 2008, showed that of 400 La Crosse residents who died in a health care setting there, 90% had an advance directive. Of those, nearly all the directives were available in the patients’ medical records, and more than 99% of patients received care consistent with their instructions.

For advance care planning to happen reliably, it must be a priority, said Bernard Hammes, PhD, director of the Respecting Choices program. That means referring patients and their loved ones to professionals trained in talking through the many tricky questions that arise when discussing end-of-life care, people who have the time to give those issues the attention they deserve.

“It was really our assumption at the start that physicians would do this work,” said Hammes, director of medical humanities at Gundersen Lutheran. “We learned very quickly that didn’t work for a variety of reasons, the primary reason being that physicians don’t have enough time to do this. The primary care physician with 20 people in his waiting room, or who sees 30 people a day, can’t take an extra 30 to 60 minutes to have a robust, thorough conversation with patients about this stuff.”

Key questions covered in facilitated discussions include who will make decisions on behalf of the patient, how a permanent brain injury would change care goals, and how religious and personal beliefs influence care, Hammes said. While patients are walked through stating their instructions on specific life-sustaining interventions and naming a surrogate, the focus is on the conversation, not the form. Physicians are consulted on detailed clinical questions, review the plans once they are made, and check in with patients periodically to keep them up to date.

The Wisconsin Medical Society also is taking as inspiration the work done by the Twin Cities Medical Society through its Honoring Choices Minnesota initiative. Nearly 1,000 people in the Minneapolis-St. Paul area have been trained to facilitate advance care planning discussions since the project launched in 2008. The Twin Cities Medical Society worked to produce documentaries about end-of-life care that have aired on local public television. Engaging the community at large to talk and
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consider the choices they will face at the end of life is a key part of these initiatives.

ADDITIONAL INFORMATION:

How planning ahead affects end-of-life care

A randomized controlled trial at a Melbourne, Australia, hospital tested the facilitated advance care planning model the Wisconsin Medical Society is using as part of a new statewide initiative. Of the patients who died within six months, the 29 who had extra planning help received better end-of-life care than the 27 who got standard care.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Facilitated advance care planning</th>
<th>Usual care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completed advance care planning</td>
<td>86%</td>
<td>0%</td>
</tr>
<tr>
<td>Wishes known and followed</td>
<td>86%</td>
<td>30%</td>
</tr>
<tr>
<td>Wishes unknown</td>
<td>10%</td>
<td>63%</td>
</tr>
<tr>
<td>Died in ICU</td>
<td>0%</td>
<td>15%</td>
</tr>
<tr>
<td>Died in palliative care</td>
<td>24%</td>
<td>11%</td>
</tr>
<tr>
<td>Family very satisfied with quality of death</td>
<td>83%</td>
<td>48%</td>
</tr>
<tr>
<td>Family thought patient was very satisfied with end-of-life care</td>
<td>86%</td>
<td>37%</td>
</tr>
</tbody>
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Wisconsin Medical Society Advance Care Planning Project (www.wisconsinmedicalsociety.org/acp)

Honoring Choices Minnesota (www.honoringchoices.org/)

Respecting Choices advance care planning system (www.respectingchoices.org/)


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