A Better Way Coalition: Life on Our Own Terms and the Center for the Study of Aging at Boise State University collaborated in this effort to gather Idaho-specific data about views on end-of-life issues. Sponsoring members of the Coalition provided resources for printing, postage, and other costs while the Center matched these and managed the project. The objective of this project was to capture information that can help Idaho service providers and policy makers better understand the preferences and needs of people as they near the end of life.

The 12-page survey was mailed to a random sample of 3,003 Idaho residents over the age of 35 in February 2006. Over thirty-nine percent, or 1,181 people returned their surveys. The survey was designed to collect information on attitudes, beliefs, experiences, and behaviors related to end-of-life preferences and planning as well as basic demographic and health-status information. Similar surveys have been administered in other states and numerous communities around the country. The Idaho version was based on a questionnaire developed by the Missoula Demonstration Project and most recently adapted for the Massachusetts Commission on End-of-Life Care. The Idaho version contained only minor wording changes to reflect state specific laws, programs, resources, and a small number of additional items.

People are more likely to discuss end-of-life issues, perhaps due to recent media coverage and public policy debates. But the survey results suggest there is a gap between the acknowledgement of the issues and concrete action by individuals and organizations to assure that end-of-life wishes and preferences are honored.

People in Idaho are comfortable talking about death but often they have not had key end-of-life conversations.

- 47% remember their families talking about death and dying either often or occasionally when they were children
- 92% are comfortable or somewhat comfortable talking about death and 86% are likely to speak freely to love ones about death and dying
- 64% have talked about wishes for care near the end of life with family, but 80% want family to initiate a conversation regarding end-of-life issues
- 7% have talked with their primary care physician, but more than 1/3 (33%) want their primary care physician to initiate the conversation
- 4% talked to clergy/spiritual leaders, but almost 1/4 (24%) want clergy/spiritual leaders to initiate a conversation

They are familiar with advance care planning and may know about the tools but have not used them to express wishes.

- Only 35% have completed living wills that describe healthcare preferences at the end of life, but 98% have heard about them.
- Only 31% have completed a durable power of attorney for health care (healthcare proxy) that empowers someone to speak on their behalf if they are unable to speak, but 91% have heard about them.
Profile of Survey Respondents
3,003 surveys mailed
1,181 returned (39.3%)

Age
50% aged 45 to 64
18% 44 and younger
18% 65 to 74
13% 75 and older

Sex
42% male
57% female

Marital Status
72% married
10% divorced
10% widowed

Education
46% some college or technical training
20% high school diploma
18% college graduates
12% professional degree or postgraduate coursework

Employment
44% full time
30% retired and not working
15% part time
9% other, like homemaker
1% unemployed

Income
30% $20,000 to $39,000
29% $60,000 or more
21% $40,000 to $59,000

Health
33% very good
31% good
18% excellent
14% fair
3% poor

Region
43% western part of the state
40% eastern
17% northern

Race/Ethnicity
94% White
4% Hispanic or Latino
2% American Indian or Alaskan Native

*percentages may not add to 100 as all survey respondents did not complete all items

Communication Wishes

“You may think your wishes are what most people want and that your doctor would know what to do….our experience tells us that every person’s wishes are unique and different.”

<table>
<thead>
<tr>
<th></th>
<th>Have Heard About and Completed</th>
<th>Have Heard About and NOT Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living Will</td>
<td>35%</td>
<td>63%</td>
</tr>
<tr>
<td>Healthcare Proxy/Durable Power of Attorney for Health Care</td>
<td>31%</td>
<td>60%</td>
</tr>
<tr>
<td>Comfort One (DNR verification for emergency services)</td>
<td>4%</td>
<td>52%</td>
</tr>
<tr>
<td>Last Will &amp; Testament</td>
<td>43%</td>
<td>54%</td>
</tr>
<tr>
<td>Funeral Pre Plans</td>
<td>16%</td>
<td>80%</td>
</tr>
</tbody>
</table>

Next Steps

More and more people are aware of the difficult decisions that may need to be made at the end of life. They need to be encouraged and supported as they take action to formalize their wishes for end-of-life care. Public policy, professionals, and institutions can help empower individuals to make their wishes known and ensure that these preferences are respected.

1. Individuals, programs, and communities encourage people to discuss their wishes for care at the end of life with those near to them and appropriate professionals.
2. People in Idaho are given the support and encouragement they need to use the formal tools available to document their wishes and communicate their preferences (advance directives: living will and/or durable power of attorney for health care).
3. Once completed, advance directives will be registered and accessible to healthcare providers in the Idaho Health Care Directive Registry in the Secretary of State’s office (available January 2007).
4. A person’s stated desires for treatment and care at the end-of-life travels with them to all residential and care facilities.
5. The information in advance directive documents is used by physicians, nurses, social workers, and chaplains in developing plans that reflect and respect people’s preferences for care at the end of life.

Reference


More Information...

Additional copies of this focus brief, as well as three focus briefs on other topics, an executive summary of the project, the full report of the survey results are available in electronic formats from the websites of A Better Way Coalition (www.abetterwaycoalition.org) and the Center for the Study of Aging (aging.boisestate.edu). For additional information, please contact the Center at 208-426-5802 or aging@boisestate.edu.