

IDAHO END-OF-LIFE SURVEY

Fall 2006

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Compassionate Care

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.

Compassionate care for dying people involves taking care of the whole person – body, mind, spirit, heart, and soul. Sometimes called “palliative care,” it improves the quality of life people and their families experience when facing problems associated with life threatening illness and the end of life. Having adequate information and decisions honored is important for survey respondents as they shared thoughts about the role of social supports and medical treatment at the end of life.

A key part of the the social supports for people in Idaho are strong family ties. Many people said they would rely primarily on family, friends and their faith community to provide various types of end-of-life support.

- ◆ Family (“spouse/partner” and “children and other family”) was consistently the highest response in all categories of support
- ◆ People expect encouragement when they are down; 76% from spouse or partner, 86% from children or other family, 57% from friends or neighbors and 41% from their faith community
- ◆ 74% believe not being able to communicate their wishes and/or needs to family or friends would be worse than death
- ◆ 40% are afraid of dying alone and 56% said they are afraid of dying in an institution
- ◆ People in Idaho also want their spouse or partner (78%) and children and other family members (89%) to know what they want when they die

Much of what people want when they die can be provided by hospice. People in Idaho reported that they know about hospice care and would consider using this type of service at the end of life...

- ◆ 96% are aware of hospice services and 78% would use hospice support if needed
- ◆ ...but they may need more detailed information.
- ◆ Only 43% are aware that Medicare and Medicaid pay for hospice services

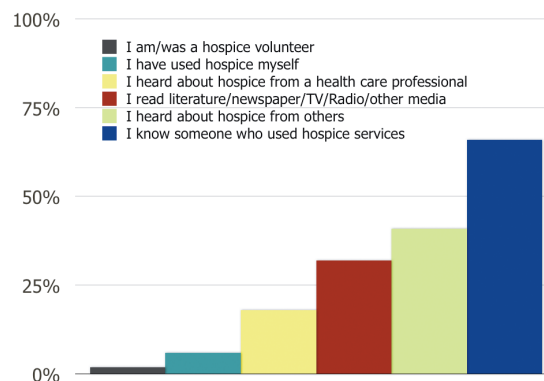
Hospice care

is most often provided in the patient's home, but also in hospice centers, hospitals, nursing homes and other long-term care facilities

is provided by a team including physicians, nurses, aides, social workers, clergy or other counselors and volunteers

focuses on caring, not curing including

- managing pain and symptoms
- assisting with the emotional, psychosocial and spiritual aspects of dying
- providing medications, supplies and equipment
- short-term inpatient care if needed



- ◆ Most of the information about hospice comes from talking with others (41%), the media (32%) or knowing someone who used hospice (66%)
- ◆ Just 18% heard about hospice from a healthcare professional

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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 post-graduate 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

Next Steps

The survey project clearly documents that many people are aware of various issues surrounding the end of life. There has been an increase in availability of services such as hospice and palliative care but this necessary growth is not yet sufficient to ensure improvements in outcomes the survey tells us are most important to the people of Idaho.

Specific activities suggested by survey outcomes provide an outline for the organization of future efforts to promote advance care planning and better care at the end of life in Idaho.

1. The medical community, faith leaders, and others recognize the importance of good end-of-life care and respond with compassion to dying people.
2. Effective pain management policies are created, approved and implemented and pain at the end of life is significantly reduced.
3. Palliative care is available and considered at the time of diagnosis of a life threatening illness.

"Care for people as they die obviously requires medical expertise, but care for our loved ones, friends and neighbors is, frankly, too important to leave to the experts. It is time for all of us, as families and as communities, to take back responsibility for our loved ones and our neighbors as they die"¹

4. Dying people are provided the information they desire, are included in decision making providing for autonomy and self determination.
5. Support is provided to family and friends so that people wishing to die at home or in another non-institutional setting are able to do so.
6. Hospice services are discussed and physicians make referrals earlier in the allowable 6-month time frame (expanding beyond the median of 22 days).
7. Hospice educational material is distributed through informal networks such as faith communities, community centers, libraries, etc.
8. Services for care at the end of life are designed for people without family or other support systems so that no one has to die alone.
9. The information in advanced directive documents is used by physicians, nurses, social workers, and chaplains in developing plans for treatment and care that reflect and respect people's preferences for care at the end of life.

Reference

1. Byock I. Dr. Byock's Potent Quotes: On the Community's Role in Care for the Dying. <http://www.dyingwell.org/dwquotes.htm>. Accessed August 10, 2006.

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.