

# IDAHO STATEWIDE END-OF-LIFE SURVEY

## EXECUTIVE SUMMARY

Fall 2006

In 2002 Idaho received a “D” in a report that graded each state on end-of-life care. The report was titled “Means to a Better End: A Report on Dying in America Today” and was produced by the Last Acts program of the Robert Wood Johnson Foundation.<sup>1</sup> This low rating, highly publicized cases, and personal experiences inspired many individuals

### Excerpt: Idaho End-of-Life Report Card and Update\*

Measures	Grade = D 2002	Update	Change
Advance directive laws support good advance care planning	3 out of 6 measures	6 out of 6 measures	↑↑
Hospitals with pain management programs	39%	58%	↑↑
Place of Death			
At Home	28.1%	29.2%	↔
In Hospitals	37.8%	35.7%	↔
In Nursing Homes	30.1%	31.5%	↔
Persistent Pain: Nursing home residents (worst in the US)	53.1%	53.4%	↔

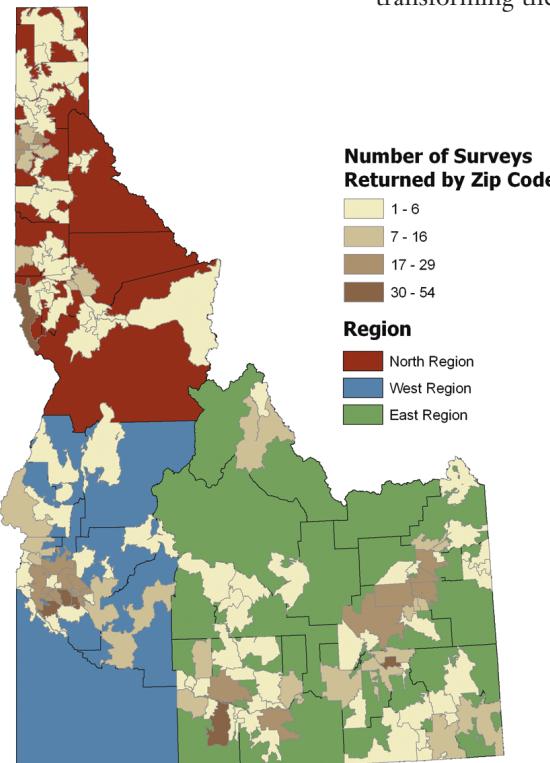
and organizations to take action. Selected examples of efforts in Idaho to improve care and help dying people and their families are included in the timeline that begins on the next page. The impact these efforts have had on end-of-life care in Idaho can be seen in the updated measures used in the original “report card.” Idaho’s state laws now meet the six criteria that support good advance care planning and more hospitals have pain management programs.

In 2005, A Better Way Coalition: Life on Our Own Terms, the Center for the Study of Aging at Boise State University, with the support of 18 sponsors, planned to field a survey collecting information to be used by healthcare providers, policy makers, advocates, and other stakeholders whose goals are to ensure people’s needs are met and their preferences honored at the end of life.

In March 2006, surveys were mailed to a random sample of 3,003 people living in Idaho who were 35 years of age or older. Over 39%, 1,181 people, returned completed surveys. The map on this page represents how many people participated from different regions of the state.

“More than anything else, we need reliability. We need a care system that we can count on, not just a virtuoso performance in a hospital operating room or an elegant diagnostic procedure, but enduring competence, from onset of serious illness through to death. We need home care, doctors, hospitals, pharmacies, hospices, nursing homes, and caregivers to work as one system.”

— Joanne Lynn, MD speaking about transforming the culture of dying.



\*The complete original report card as well as the update and the sources used for this information are available in Appendix A of the full report.

## **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

## **The Results**

The Idaho Statewide End-of-Life Survey was relatively long, including 12 pages of questions that required the respondents to reflect on their experiences, beliefs, and desires about death and dying...a topic that has been taboo in the past.

**The following summarizes the results and provides examples of the responses.**

**People in Idaho are comfortable talking about death and they are familiar with advance healthcare planning,**

- ◆ 92% are very comfortable or somewhat comfortable talking about death
- ◆ 98% have heard of living wills for end-of-life healthcare preferences

**but often they have not had key end-of-life conversations and many have not taken action to express their wishes.**

- ◆ 64% have talked with family about wishes for care near the end of life, but 80% want family members to initiate a conversation regarding end-of-life issues
- ◆ 7% have talked with their primary care physician, but 35% want them to initiate the conversation
- ◆ 63% are familiar with living wills, but have not completed one
- ◆ 60% know about healthcare proxies, but have not designated a proxy

## **Timeline**

<b>November 2002</b>	<b>2003</b>
Idaho receives overall "D" grade in Robert Wood Johnson Foundation Last Acts Report on Dying in America Today	Coalitions are formed: North Idaho End-of-Life Community Coalition Statewide end-of-life coalition A Better Way Coalition: Life on Our Own Terms

**People want to be involved in making decisions about their own death and they have strong preference about their own end-of-life care.**

- ◆ 97% say it is important to be able to understand and to choose treatment options
- ◆ 80% want to die in their own home
- ◆ 72% want no artificial life-sustaining procedures at the end of life

**They realize the importance of pain management but they have concerns.**

- ◆ 98% want information about options for managing pain
- ◆ 43% are afraid of becoming addicted
- ◆ 80% say they would take the lowest amount of medicine possible to save the larger doses for later when the pain is worse [Experts generally agree that this approach is not the most effective use of pain medication and does not produce the greatest reduction of pain.]

**They know about Hospice and would consider using this type of service at the end of life but they may need more detailed information.**

- ◆ 96% have heard a little or a lot about hospice
- ◆ 78% would use hospice support if needed
- ◆ 43% are aware that Medicare and Medicaid pay for hospice services

**People understand the meaning and value of the end of life and the importance of completing life well.**

- ◆ 92% say it is important to know how to say goodbye
- ◆ 86% hope to share time, gifts and wisdom with others

**They believe meaning and spirituality are important and play a significant role at the end of life to the extent that they want spiritual leaders and faith communities to be involved in their end-of life care.**

- ◆ 86% consider themselves very or somewhat spiritual
- ◆ 80% say being at peace spiritually is very important when they think about dying
- ◆ 52% report that their spiritual practice or religion affect end-of-life choices to a great extent

### **Survey Partners**

#### **A Better Way Coalition:**

**Life on Our Own Terms** is the Idaho statewide end-of-life coalition dedicated to promoting compassionate end-of-life care in Idaho. Members represent professional associations and organizations, citizen advocacy groups, concerned individuals, healthcare facilities, educational institutions, agencies, and local end-of-life coalitions.

**The Center for the Study of Aging**, established in 2004, is a joint project of the Colleges of Health Sciences and Social Sciences and Public Affairs at Boise State University. The Center's mission is to advance the well-being of older people by ensuring that Boise State University, our communities and our society prepare for the aging of the population.

### **2004**

### **2005**

### **CONTINUES... ▶**

First revision of Idaho Natural Death Act Statute by the Idaho State Legislature

Magic Valley Palliative Care Coalition formed

Comprehensive website with end-of-life resources sponsored by A Better Way Coalition: Life on Our Own Terms [www.abetterwaycoalition.org](http://www.abetterwaycoalition.org)

A Better Way Coalition awarded the Robert Wood Johnson Foundation Rallying Points Award of Excellence

Continued community and professional education offerings

Idaho Medical Consent and Natural Death Act statute is revised streamlining and combining the Living Will and Durable Power of Attorney for Health Care into one document

### **Summary**

The Idaho Statewide End-of-Life Survey project shows that contrary to past perceptions, many people in Idaho are willing to thoughtfully consider a wide range of issues related to end of life. They are talking with family and friends and want family, friends, and professionals to initiate conversations with them about dying and death. They know their wants and desires regarding issues such as honest answers from their doctors, choosing their treatment options, and not being a physical burden to loved ones. However, as in other states, significantly fewer people in Idaho have taken steps to formalize wishes for end-of-life care. Nearly all respondents want to die at home and most are familiar with hospice and would consider hospice care. In addition to all other end-of-life issues, financial difficulties related to death and dying concern many respondents and they need information about available resources.

### **Sponsors**

AARP Idaho

Compassion & Choices

First Choice Home Health and Hospice

Four Rivers Home Health and Hospice

Hospice of North Idaho, Inc.

Hospice of the Wood River Valley

Idaho Health Care Association

Idaho State Hospice Organization

Life's Doors Hospice

Magic Valley Palliative Care Coalition

Magic Valley Regional Medical Center

National Association of Social Workers, Idaho Chapter

Qualis Health

Saint Alphonsus Regional Medical Center

Sisson & Sisson, The Elder and Disability Law Firm

St. Luke's Regional Medical Center

The Interfaith Alliance of Idaho

XL Hospice, Inc.

## The Future

Ensuring good end-of-life care that honors preferences and meets needs requires both reforming institutions and changing individual behavior. Conducting a survey alone will not result in these changes. What the Idaho Statewide End-of-Life Survey does is provide insight into people's attitudes, desires, and behaviors. Survey results suggest the next steps in Idaho need to focus on two objectives and related goals.

**Objective: Help individuals move from awareness of end-of-life issues to actions that will increase the probability that their wishes and preferences will be honored.**

**Objective: Improve the range of care available at the end of life so that outcomes reflect the wishes and preferences of each individual.**

Achieving these objectives will require collaboration and the efforts of many. The following are only a few of the goals that must be met as part of future efforts to promote advance care planning and better care at the end of life in Idaho.

1. Individuals, programs, and our culture encourage people to discuss their wishes for care at the end of life.
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 (living will and/or durable power of attorney for health care.)
3. Information in advance directives is used by emergency services, physicians, nurses, social workers and chaplains in delivering treatment that reflect people's preferences for care at the end of life.
4. Policies to encourage effective pain management are created and approved. Effective pain management strategies are implemented.

5. Palliative care is considered at the time of diagnosis of a life threatening illness so that people can make informed choices among treatment options.
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. People seek to understand the needs of dying people in faith communities and provide support at the end of life.
8. Achieving spiritual peace is recognized to be as important as relief from pain and management of physical symptoms.
9. Future research collects information that could not be obtained from survey of a random sample of adults. For example, information is needed about the preferences of people with disabilities, for whom care at the end of life often involves a broad range of issues and a cultural history that differs from those experienced by their non-disabled peers.

## 2006

Idaho State Legislature creates the Idaho Advance Health Care Directives Registry in office of the Secretary of State

Idaho State Legislature passes Joint Concurrent Resolution 40 to address the need for portable Do Not Resuscitate Orders in Idaho

Continued community and professional education offerings

Strategies for improving pain management in Idaho are being developed

A Better Way Coalition and the Center for the Study of Aging at Boise State University release the Idaho Statewide End-of-Life Survey: Life on Our Own Terms, the first ever statewide research project surveying people in Idaho about their attitudes, knowledge, and wishes for end of life.

## 2007

Idaho communities mobilize to improve end-of-life care

People place their advance directive in the Idaho Health Care Directive Registry

Healthcare community uses the Health Care Directive Registry to access information about the wishes of people in Idaho

### More Information...

Additional copies of this executive summary, as well as four focus briefs, and the full report of the survey results are available in electronic formats from the websites of A Better Way Coalition ([www.abetterwaycoalition.org](http://www.abetterwaycoalition.org)) and the Center for the Study of Aging ([aging.boisestate.edu](http://aging.boisestate.edu)). For additional information, please contact the Center at 208-426-5899 or [aging@boisestate.edu](mailto:aging@boisestate.edu).

## References

1. Last Acts. Means to a Better End: A Report on Dying in America Today. Washington, DC: Last Acts; November 2002.
2. Open Society Institute. Transforming the Culture of Dying: The Project on Death in America 2004 p. 29.