

IDAHO STATEWIDE END-OF-LIFE SURVEY REPORT

2006

**A Better Way Coalition
Life on Our Own Terms**

**Center for the Study of Aging
Boise State University**

**Cheryl Simpson-Whitaker, MSW
Annette M. Totten, PhD
Carissa Moffat-Miller, MA**



**Center for the
Study of Aging**

A Better Way Coalition

LIFE ON OUR OWN TERMS

**Idaho Statewide End-of-Life Survey:
Life on Our Own Terms**

*First statewide research on end-of-life values,
priorities and concerns of people living in Idaho*

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

Sisson & Sisson, the Elder and Disability Law Firm

Saint Alphonsus Regional Medical Center

St. Luke's Regional Medical Center

The Interfaith Alliance of Idaho

XL Hospice, Inc.

October, 2006

IDAHO STATEWIDE END-OF-LIFE SURVEY REPORT

2006

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 whole person – body, mind and spirit, heart and soul – is the focus of our work. Advance care planning is a major coalition initiative with activities that range from policy to practice. ABetterWayCoalition.org is a content rich website that provides information for the public and professionals who want to improve the quality of life for terminally ill and dying people. A Better Way Coalition: Life on Our Own Terms is a proud recipient of the prestigious Robert Wood Johnson Foundation Rallying Points Award of Excellence.

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 assuring that Boise State University, our communities and our society prepare for the aging of the population. Such preparation requires research, education, and collaboration to: increase awareness of aging-related issues; build knowledge about how to maintain quality of life as we age; foster expertise among faculty, policy makers, and community organizations; and promote the study of gerontology and careers in aging. The Center for the Study of Aging applies an interdisciplinary approach to the study of aging and serves as a resource for Idaho and the rest of the nation.

Acknowledgements

The Idaho Statewide End-of-Life Survey is the result of collaboration between A Better Way Coalition and the Center for the Study of Aging at Boise State University. The survey is based on the Life's End Institute: The Missoula Demonstration Project's Community Survey. Charles Asp, PhD, of Asp Consulting, LLC, Barbara K. Spring, PhD, and Kaye Norris, PhD, formerly of Life's End Institute, provided technical assistance.

The Center for the Study of Aging, under the direction of Annette Totten, PhD, joined the project with a match of resources and research expertise. Thanks go to Carissa Moffat Miller, Holly Beard, Center researchers, and Komal Mehrotra, Paula Flacker, Jill Darlington and Dan Sigler, research assistants, for project management, data entry, analysis and tabulation of final survey results. Nancy Severance, RN, MS, chaired the Survey Implementation Committee comprised of Annette Totten, PhD, and coalition members Cheryl Simpson-Whitaker, MSW, Kim Martz RN, MSN, Magdalena Donaldson MAT, and Mary Kay Brunner, BSW. Lastly, deep appreciation is extended to project sponsors who contributed financial and in-kind support which turned a dream into reality.

Special thanks to the 1,181 people living in Idaho who took time to share their thoughts about dying and death so that Idaho communities would have the information they need to promote compassionate care at the end of life.

CONTENTS

PREFACE	II
TIMELINE	IV
DEMOGRAPHICS.....	1
KEY FINDINGS	5
COMMUNICATING WISHES.....	9
COMPASSIONATE CARE.....	15
MEANING & SPIRITUALITY.....	23
WHERE DO WE GO FROM HERE?	29
APPENDIX A - IDAHO END-OF-LIFE REPORT CARD.....	35
APPENDIX B - TECHNICAL DESCRIPTION.....	39
APPENDIX C - SURVEY AND COLLATERAL	45

Preface

In the spring of 2006, three thousand and three people in Idaho 35 years and older received a mail survey on end-of-life issues. They told us:

Who they are and how they feel,

What they know and what they want, and

**Who they would like to talk to about death, dying,
and the end of life.**

A Better Way Coalition and the Center for the Study of Aging collaborated on this first-ever effort to gather Idaho-specific data about views on end-of-life issues. Similar surveys have been administered in other states and numerous communities around the country. The Idaho 39% return rate is the highest statewide general response rate for similar surveys in the nation to date (1,181 of 3,003 people 35 years and older).

The Coalition, Center, and project sponsors were motivated to undertake this project in order to capture Idaho-specific information to help service providers and policy makers better understand how to meet the needs of people as they near the end of life and die.

People in Idaho face many challenges. Men and women in all regions of the state lack information about options and experience unnecessary barriers to realizing their wishes for the end of life. The pervasive focus on “cure” rather than “care” reflects lack of awareness of the special needs of this time of life and contributes to an already difficult experience for dying people and the ones they love.

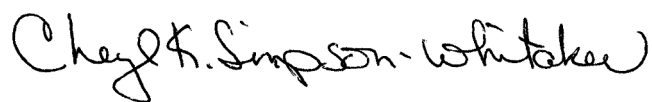
The Idaho Statewide End-of-Life Survey project shows that contrary to past perceptions, many people in Idaho are willing to thoughtfully consider a wide range of issues related to the end of life. They are talking with family and friends and also want family, friends, and professionals to initiate conversations with them about dying and death. Respondents are clear about their wants and desires regarding important issues such as honest answers from their doctors, choosing their treatment options, and not being a physical burden to loved ones. However, like people in other states, significantly fewer people in Idaho have taken steps to formalize their end-of-life concerns and desires. Nearly all respondents want to be able to die at home and most are familiar with hospice even if they do not have an in-depth understanding of how hospice actually functions. In addition to all other end-of-life issues, financial difficulties re-

lated to death and dying concern many respondents and they need information about available resources.

This report first presents a profile of survey respondents in the demographics section followed by key findings. Further details from the survey analysis are presented in Communicating Wishes, Compassionate Care, and Meaning & Spirituality. Necessary action steps suggested by the survey results and the current context in Idaho create a roadmap for change in the concluding section – Where do we go from here? An updated end-of-life “report card,” the technical report on the survey, and forms mailed to all participants, including a survey with response frequencies follow as Appendices.

In summary, this study reflects the desire by people living in Idaho to be fully engaged with family, friends, faith communities and health care professionals as they navigate the end of life. While the outcomes are a resounding affirmation of existing community and state efforts to promote compassionate end-of-life care, this study underscores the need to address significant issues which remain a challenge to Idaho professionals and the public.

This report attempts to both convey survey results and provide a context for their interpretation. All assertions, conclusions, and any errors are the responsibility of the authors and do not necessarily reflect the opinions of individual A Better Way Coalition members or project sponsors.



Cheryl K. Simpson-Whitaker, MSW
Executive Director, A Better Way Coalition: Life on Our Own Terms



Annette M. Totten, PhD
Director, Center for the Study of Aging, Boise State University

Timeline

Promoting Compassionate Care at the End of Life in Idaho

2002

Idaho receives overall “D” grade in Robert Wood Johnson Foundation Last Acts Report on Dying in America Today

2003

North Idaho Hospice, Inc. and Kootenai Medical Center form an end-of-life community coalition and receives a \$5,000 Robert Wood Johnson Foundation grant to conduct end-of-life research in three far north counties

Concerned people, organizations and associations form a statewide grass-roots end-of-life coalition. A Better Way Coalition: Life on Our Own Terms receives a Robert Wood Johnson Foundation \$10,000 grant for strategic planning consultation

2004

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

A Better Way Coalition receives a \$10,000 Rallying Points Development Grant and \$15,000 national Robert Wood Johnson Foundation Rallying Points Award of Excellence

Magic Valley Palliative Care Coalition forms to promote access to palliative care for people in Magic Valley

Comprehensive website with end-of-life resources for professionals and the public is sponsored by members of A Better Way Coalition: Life on Our Own Terms www.abetterwaycoalition.org

End-of-life and advance care planning are topics of community meetings, workshops and professional continuing education offerings

2005

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

Magic Valley Palliative Care Coalition receives a \$10,000 development grant from Glanbia Foods

End-of-life and advance care planning are topics of community meetings, workshops, and professional continuing education offerings

2006

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

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

End-of-life and advance care planning are topics of community meetings, workshops, and professional continuing education offerings

A Better Way Coalition, Center for the Study of Aging at Boise State University and project sponsors collaborate on the first statewide research project surveying people in Idaho about their attitudes, knowledge, and wishes for the end of life

Strategies for improving pain management in Idaho are being developed

Demographics

Who are the people behind the Idaho Statewide End-of-Life Survey data? This section will describe the people who filled out the 12-page questionnaire. Standing between the oldest and youngest respondent is a 58-year-old married woman. She lives in a household with an income of \$45,758 and has some college or technical training. Next to her are people from many different circumstances ranging from a 35-year-old married woman with a high school degree and a household income of \$35,000 to a 82-year-old married man who is a college graduate and has a household income of \$67,500.

What can you tell me about the other people that responded?

Marital Status

The vast majority of respondents were married (72%) while 10% were divorced and 10% were widowed. Only 3% were single or never married and another 3% were living with a partner. One percent of respondents noted they were separated.

Education Level

Almost half of the respondents reported some college or technical training (46%). Twenty percent had obtained a high school diploma or the equivalent, 18% are college graduates, and 12% have a professional degree or have completed post-graduate coursework. Only 4% reported having less than a high school diploma.

Employment

Almost 60% of the survey respondents were employed in some capacity. Forty-four percent of respondents were employed full time, 30% were retired and not working, 15% were employed part time and 9% noted the other category such as a homemaker. Only 1% of the respondents were unemployed and looking for work.

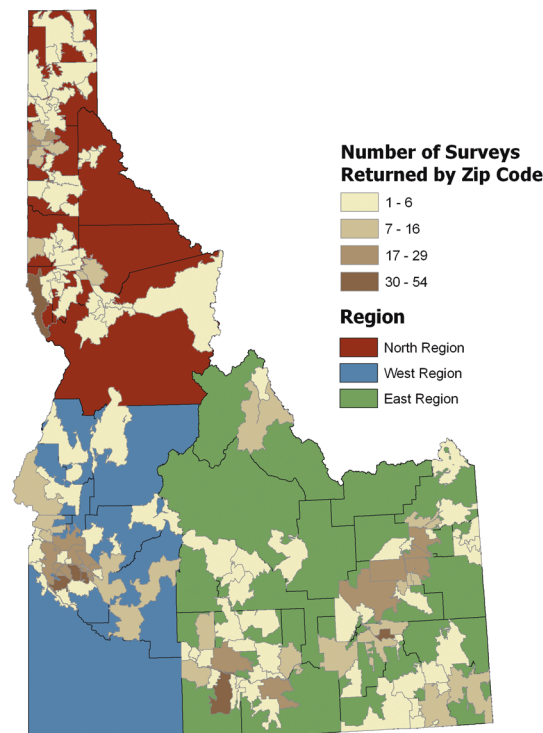
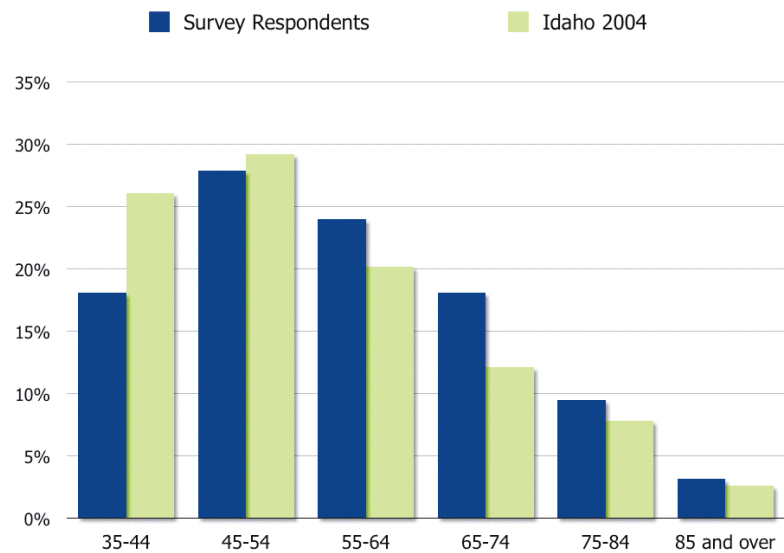
Are older people the only ones who filled out this survey?

No. The responses were fairly evenly spread across the different age groups. The survey was sent to 3,003 adults age 35 and older. People aged 45 to 64 composed half (50%) of the respondents. The greatest response was from people age 45 to 54 with 26% of the respondents in this age category and 24% in the 55 through 64 age group. The 44 and younger age group and ages 65 through 74 each comprised 18% of the total responses. People age 75 and older were 13% of the respondents.

The respondents that filled out the survey closely mirror the makeup of the general Idaho population except for the youngest age group which had a slightly lower response rate. In 2004, 28% of the Idaho population was age 35 to 44, 29% age 45 to 54, 20% age 55 to 64, 12% age 65 to 74 and 11% age 75 and older.

So, did only people who live in Boise fill out the survey?

No. People all over the state received the survey and respondents live in all corners of the state. Forty-three percent of the survey respondents were from the western part of the state, 40% from the east and 17% from the north.



Did men respond? It seems like this would be something only women would fill out.

Yes. In fact, 42%, of survey respondents were male and 57% female. This response rate is similar to Idaho's gender breakdown in 2004 for people age 35 and older which was 48% male and 52% female.¹

Do healthy people think about end of life issues?

Yes. The majority of respondents considered themselves to be in good to excellent health. Thirty-three percent rated their health as "very good," 31% rated it as "good" and 18% rated their health as "excellent." Fourteen percent reported being in "fair health" and 3% were in "poor health."

Yet, chronic illness was on the minds of some survey respondents. Eighteen percent of respondents reported having a serious chronic illness themselves and 18% said someone else in their household has a chronic illness.

How closely do the people who filled out the survey represent the population of Idaho?

The survey respondent population is similar to Idaho's population in race and ethnicity, income, education levels employment and marital status.

Income

The median income for a family of four ("standard family") in Idaho was \$39,859 in 2003.² Overall, survey respondents were older and had more varied household compositions than the "standard family". Thirty percent of respondents had an income level between \$20,000 and \$39,000; 29% had an income of \$40,000 or more and 21% of respondents reported an income of \$40,000 to \$59,000.

Race and Ethnicity

Ninety-four percent of the people who filled out the survey are White and 2% are American Indian or Alaskan Native. Four percent of the survey respondents are of Hispanic or Latino ethnicity compared to 5.25% of the Idaho population age 35 and older of Hispanic or Latino ethnicity.

Issues of Diversity

The Robert Wood Johnson Foundation Last Acts Diversity Committee addressed the complexity of the human condition and challenges to people engaged in end-of-life care.

In addition, we know that health-care for people with disabilities (including care at the end of life) often involves a broad range of issues and a cultural history not experienced by their non-disabled peers that deserves attention.⁴

The survey data are useful for gaining a better understanding about how people in Idaho view the end of life, but are not direct predictors of the wants and desires of an individual person or members of specific subgroups of Idaho's population.

"Diversity unavoidably shapes the death-and-dying experience not only because patients and their families are diverse, but also because their medical care providers are as well. The positive power of diversity in end-of-life care lies in acknowledging and respecting the differences among various racial, cultural, spiritual, ethnic and age groups, and also how individuals differ within these groups."³

— **Last Acts Diversity Committee, 2001**

References

1. U.S. Census Bureau. American Community Survey 2004: Detailed Tables: Idaho Sex by Age. June 28, 2005; Accessed August 29, 2006.
2. U.S. Census Bureau. Idaho QuickFacts. June 8, 2006; <http://quickfacts.census.gov/qfd/states/16000.html>. Accessed August 29, 2006.
3. Last Acts Diversity Committee. Last Acts Statement on Diversity and End-of-Life Care. Washington, DC: Last Acts National Program Office; Fall 2001.
4. Buckland K. Executive Director, Idaho State Independent Living Council. Interview with Simpson-Whitaker C, Boise, ID; 2006

Key Findings

The Idaho Statewide End-of-Life Survey was fielded as a joint project of *A Better Way Coalition: Life on Our Own Terms* and the *Center for the Study of Aging* at Boise State University. The survey provides data on the attitudes, preferences and behaviors of people in Idaho 35 years and older. The purpose of this project is to generate information that can support and inform policy initiatives, professional training, outreach to the public, and any other activity that promotes advance care planning and contributes to the improvement of end-of-life care in Idaho.

The survey was conducted February-April 2006 and 1,181 people responded for a response rate of 39%. A selection of the findings are outlined here and presented in more detail in the next sections of this report.

Communicating Wishes

People in Idaho are comfortable talking about death...

- ◆ Nearly 50% remember death and dying being talked about either occasionally or often in their families when they were children
- ◆ 92% are very comfortable or somewhat comfortable talking about death

...and they are familiar with advance health care planning

- ◆ 98% have heard of living wills that describe healthcare preferences at the end of life
- ◆ 91% have heard about a durable power of attorney for health care (health care proxy) that empowers someone to speak on their behalf if they are unable to speak
- ◆ 96% are familiar with funeral and burial pre-plans
- ◆ 95% know about donating organs and tissue

...but often they have not had key end-of-life conversations.

- ◆ 64% have talked about wishes for care near the end of life with family, 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
- ◆ 4% have talked to clergy/spiritual leaders, but 24% want them to initiate a conversation

...and many have not taken action to express their wishes.

- ◆ 63% have not completed a living will, even though they know what it is
- ◆ 60% have not designated a health care proxy
- ◆ 80% have not pre-planned their funeral or burial

Compassionate Care

People in Idaho want to be involved in making decisions about their own death...

- ◆ 92% would want to know if they had a serious illness
- ◆ 97% say it is important to be able to understand and to choose treatment options
- ◆ 93% would want to know if they only had a few months to live

...and they have strong preferences about their own end-of-life care.

- ◆ 80% want to die in their own home
- ◆ 72% want no artificial life-sustaining procedures
- ◆ 56% are somewhat or very afraid of dying in an institution
- ◆ 66% are concerned they will be a financial burden to family or friends
- ◆ 85% say it is very important to not be a physical burden on loved ones

They realize the importance of pain management...

- ◆ 96% believe good pain management is important
- ◆ 98% want information about options for managing pain
- ◆ 63% believe living with great pain would be worse than death

...but they have concerns.

- ◆ 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.]
- ◆ 37% are afraid they would be given too much pain medicine

They know about Hospice and would consider using this type of service at the end of life...

- ◆ 96% are aware of hospice services
- ◆ 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
- ◆ 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 health care professional

Meaning & Spirituality

People in Idaho understand the meaning and value of end of life ...

- ◆ 80% believe there is a special value in getting old
- ◆ 70% believe caring for people who are dying is a rewarding experience

...and the importance of completing life well.

- ◆ 70% rate reviewing their life history with family as an important end-of-life activity
- ◆ 86% hope to share time, gifts and wisdom with others
- ◆ 94% want to have relationship issues settled with their family
- ◆ 92% want to know how to say goodbye

People in Idaho believe meaning and spirituality are important...

- ◆ 86% consider themselves very or somewhat spiritual
- ◆ 62% are affiliated with an organized faith community
- ◆ 89% want to have a sense of their own worth at the end of their life

...and play a significant role at the end of life

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

...to the extent that people want spiritual leaders and faith communities to be involved in their end-of-life care.

- ◆ Between 24% and 41% indicated that their faith community should provide support ranging from encouraging them when they are down to providing transportation
- ◆ 24% want a spiritual leader/clergy to initiate a conversation with them about the end of life
- ◆ The presence of a spiritual leader is very important to 42% and somewhat important to 31% of people when they think about their own death

"FOR MOST PEOPLE, DEATH ISSUES ARE NOT PRIMARILY LEGAL MATTERS, BUT REFLECT CLOSELY HELD RELIGIOUS AND MORAL VALUES. THE PROBLEM IS THAT DEATH HAS BEEN SUCH A TABOO SUBJECT FOR SO LONG THAT PEOPLE ARE ONLY NOW STARTING TO DEVELOP A PERSONAL FRAMEWORK TO DISCUSS END-OF-LIFE ISSUES."¹

Communicating Wishes

That death is inevitable, and that a “good death” is something people want, is often discussed in the media, public policy debates, casual conversations and among family members. But, as advocates and healthcare providers point out, there is often a lag between acknowledging the importance of expressing wishes for end-of-life care and actually taking steps to effectively communicate these wishes.

The Idaho Statewide End-of-Life Survey provides a glimpse into adults’ experiences, attitudes, knowledge, and behavior concerning dying and planning for care at the end of life. At a time when these issues are on the public policy agenda, survey insights detail some of the opportunities and barriers to improving end-of-life care and suggest the next steps to be taken by individuals, advocates, and community leaders from government, healthcare and religious organizations in Idaho.

Experiences, Attitudes, and Knowledge

Although few respondents (6%) remember their families talking often about death and dying during their childhood, 41% reported that this happened occasionally. As adults, the majority (52%) state that they are currently very comfortable talking about death and another 40% selected “somewhat comfortable” making the topic not uncomfortable for 92% of respondents.

In addition to being comfortable discussing death, over 70% of survey respondents said they are likely to engage in activities related to death and dying such as attending funerals or memorial services (53% very likely; 34% somewhat likely), reading books and newspaper articles about the subject (35% very likely; 41% somewhat likely); or watching TV shows or movies (27% very likely; 43% somewhat likely).

The survey results also demonstrate that respondents have a general understanding of the issues surrounding end-of-life care and are familiar with

some of the services and resources that might be available for themselves or others. For example, 96% of respondents had heard of hospice services and respondents indicated that they would ask a wide range of people and organizations about insurance coverage for end-of-life care. Additionally, the vast majority of people had heard about the tools available for advance care planning including living wills, healthcare proxies, last will and testament, funeral pre-planning, and organ donation. Comfort One, an Idaho program that verifies to emergency medical personnel that a Do Not Resuscitate (DNR) order is in place for people living at home or in another non-skilled residential facility, is less well known.

	Have Heard About
Living Will	98%
Health Care Proxy/Durable Power of Attorney for Health Care	91%
Comfort One (DNR verification for emergency services)	56%
Last Will & Testament	97%
Funeral Pre Plans	96%
Organ & Tissue Donation	95%

Taking Action

The subject of dying and death is no longer quite as taboo as in years past. And yet childhood experience, comfort with discussions of dying, and knowledge of tools and programs have not yet translated into actual conversations and actions by most of the respondents to Idaho's survey. More than 90% of respondents have heard about the two basic advance healthcare planning tools to express wishes for end-of-life care: living will and durable power of attorney for health care. And yet 60% or more respondents said they have not taken steps to complete an advance directive. While there is much room to improve, with a 31% - 35% self-reported completion rate for these documents (data reported in table on page 12), the Idaho survey respondents are completing these at almost double the national average of 15% to 20% overall prevalence of completed advance directive documents.²

National attention was focused on advance care planning when the Advance Directives Improvement and Education Act was introduced on June 17, 2004, by Senator Bill Nelson (D-Florida) and reintroduced in 2005. This act recognizes the importance of physician participation in planning for the end of life. Included in the Act is Medicare Coverage of End-of-Life Planning and Consultations. The Act encourages advance healthcare planning by covering a consultation with the beneficiary's primary care physician (PCP). Together, the PCP and patient can discuss medical options, the Medicare hospice benefit, situations in which an advance directive (including living will and durable power of attorney for health care) would be useful, and other concerns. Provisions are also made to provide public education about the importance of advance health care planning.³

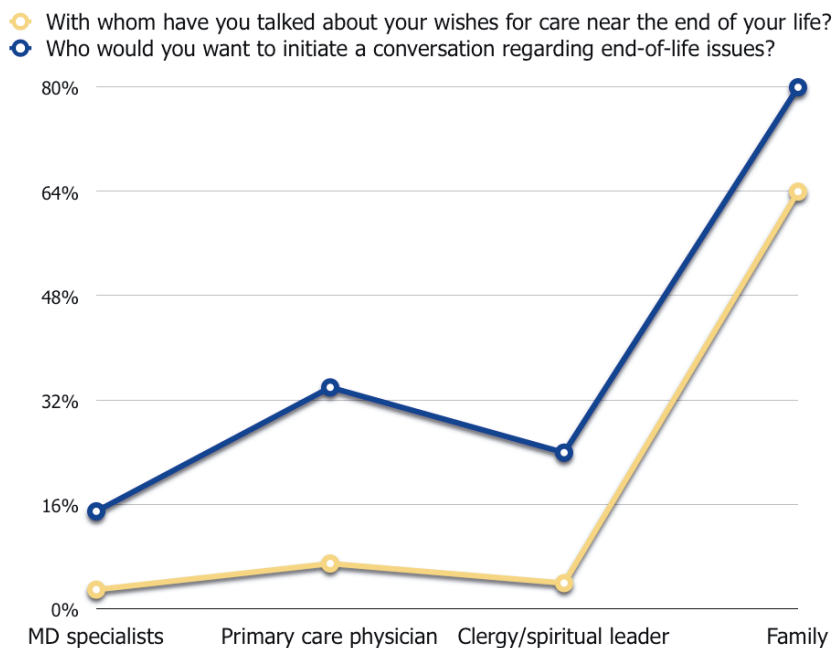
Lack of action to take control of situations related to the end of life may reflect an expectation, or hope, that death will come swiftly and not include the often complicated and emotional decision making involved in a dying process that may take weeks, months, or be the culmination of years of

chronic illness. This suggestion is supported by survey responses about fear related to death. Sixty-seven percent of respondents expressed fear about dying of a long-term illness compared to 20% who said they would be afraid of dying suddenly.

A century ago, most people died quickly living their last days at home, cared for by family members. Death was generally the result of sudden illness or injury. Now people live longer, healthier lives and the experience of dying and death often reflect advances in medical technology and public health.⁴ With these advances comes a host of new points of decision making which often complicates the last days of life for dying people and people near to them.

Considering that as recently as the 1960's (prior to advent of the hospice movement) dying and death was rarely talked about, the disconnect between knowledge and action evident in the responses to various survey items is not surprising. While 53% may be very comfortable talking about death, a smaller percentage

(45%) say they are very likely to speak freely to "loved ones" about death and dying. When asked about whom they had talked to about end-of-life issues, 87% of people reported talking to someone while 13% had not talked to anyone.



Interesting information emerged with a comparison between the percentage of respondents who had talked to someone about their own wishes for care near the end of life and the percentage who said they would like someone to initiate a conversation with them regarding end-of-life issues. (Multiple responses were allowed to each question).

The largest differences between who people had actually talked to and who they wanted to initiate a conversation were for family, clergy/spiritual leaders, physicians, and MD specialists. While only 7% of respondents had talked to their primary care physician, 35% wanted their primary care doctor to initiate a conversation

with them about issues related to the end of life. Three percent of respondents had talked to a specialist physician although 15% would want these doctors to raise end-of-life issues with them. In the case of clergy, 4% reported having a discussion with a spiritual leader compared to 24% who wanted the person in this role to initiate the discussion. Although many people had talked to family (64%), more wanted their family members to bring up end-of-life issues (80%).

"...if you want your wishes followed, there is nothing more important than talking with your doctor. 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."⁵

The difference between people who initiated conversations with MD specialists, physicians, clergy/spiritual leaders, family, and others about end-of-life issues and their desire to have others initiate the discussion is mirrored in the gap between knowledge about advance care planning tools and their use. As mentioned above, respondents are familiar with the tools currently available to express wishes for end-of-life care, but most have not made the leap from knowledge to action. There is a significant gap between the percentage of people who know about tools available to express wishes and those who have used them.

Karen, an Idaho hospice social worker spoke about the importance of advance care planning. People frequently tell her "I wish we had known about how to prepare for end of life before now..." She goes on to say she often encounters people who are not aware of resources and options for arranging for good end-of-life care and express regrets that so little time is left to attend to

	Have Heard About and Completed	Have Heard About and NOT Completed
Living Will	35%	63%
Health Care Proxy/Durable Power of Attorney for Health Care	31%	60%
Last Will & Testament	43%	54%
Funeral Pre Plans	16%	80%

Conflict in life is inevitable. Conflict in health care, given the stakes and the context, is endemic. Conflict in end-of-life decisions is sad and potentially destructive for surviving family members says Nancy Neveloff Dubler in **"Conflict and Consensus at the End of Life," Improving End of Life Care: Why Has It Been So Difficult.**⁶

important matters. She is asked about living wills, palliative care services, and as well as hospice benefits. As a hospice social worker she sees many adult children struggle with not knowing what their parents wishes would be for end-of-life care. "Without advance directives – or conversations that describe wishes for end-of-life care, family members are at a loss and sometimes divided when it comes to choosing care for dying parents. This can create distress and hard feelings at a time when being supportive is most important."⁷

Explaining specifically why few survey respondents have taken action to assure that their wishes and preferences are known and documented is beyond the scope of this survey project. However, at a time when people are expressing the desire to reclaim control of the end of life for themselves and those close to them, the survey suggests how attitudes might be translated into actions that would bring value to last days for self and others.

It's About How You Live: Learn ~ Implement ~ Voice ~ Engage*

Increasing the number of people who plan and communicate wishes is an important step in reforming care at the end of life in Idaho. Increased awareness and concern have led to more outreach activities by diverse organizations including healthcare providers, lawyers and financial planners, advocates, and membership organizations. In Idaho, state legislation was recently enacted to clarify the law surrounding advance healthcare directives and to establish a statewide healthcare directive registry in the office of the Secretary of State. Current initiatives include exploring ways to make Do Not Resuscitate orders (DNR) transferable across healthcare and residential settings and improving pain management.

"The fundamental problem with end-of-life care, however, may be structural and institutional in nature. [...] The informal culture of specialty medicine, the reward system, the range of choices people in extremis are being asked to make – each of these factors and more make up a system that is remarkably resistant to change."⁸

*The is title of a national consumer engagement initiative of Caring Connections at the National Hospice and Palliative Care Organization <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3285>

However, the burden cannot be placed solely on individuals. Education and improved communication with healthcare providers are not all that is needed to reform end-of-life care as is sometimes implied. As stated in the conclusion of the Hasting Center report titled Improving End of Life Care: Why has it been so difficult? reform is required on many levels, and changing systems as well as individuals will be required.

References

1. The Editors. Dying your way. Burlington Free Press. July 11, 2003.
2. Schwartz CEW, H. Brownell; Hammes, Bernard; Basque, Noreen; , Edmunds JR, George; Ma, Yunsheng; Li, Lynn; Tabloski, Patricia; Yanko, Julianne. Early Intervention in Planning End-of-Life Care With Ambulatory Geriatric Patients: Results of a Pilot Trial Archives of Internal Medicine. 2002;162(14):1611 - 1618.
3. Advanced Directives Improvement and Education Act of 2005 S.347. Sen. Bill Nelson (D-FL), 109th U.S. Congress.
4. Open Society Institute. Transforming the Culture of Dying: The Project on Death in America 2004.
5. Aging with Dignity. Next Steps: discussing and coping with serious illness 2001.
6. Dubler NN. Conflict and Consensus at the End of Life. Special Report Improving End of Life Care: Why Has It Been So Difficult? Vol 35 (6): Hastings Center Report; 2005:S19-S25.
7. Hoffman K. Hospice Social Worker, Saint Alphonsus Home Health and Four Rivers Hospice. Interview with Simpson-Whitaker C, Boise, ID; 2006.
8. Murray TH, Jennings B. The Quest to Reform End of Life Care: re-thinking assumptions and setting new directions. Special Report Improving End of Life Care: Why Has It Been So Difficult? Vol 35 (6): Hastings Center Report; 2005:S52-S59.

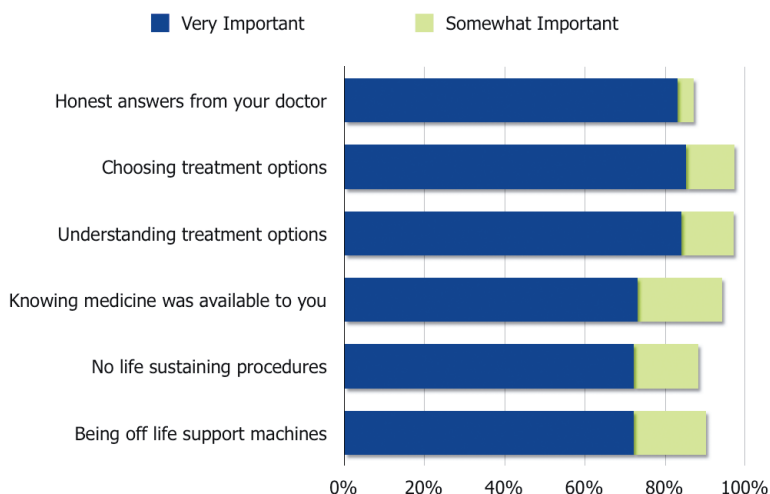
SUSTAINED CARE TO THE END — WHETHER WE PROVIDE IT WITH OUR OWN HANDS OR THROUGH OTHERS — IS WHAT WE OWE OUR LOVED ONES. BUT THE DYING GIVE BACK AN UNEXPECTED GIFT TO THOSE WHO WILL STAY BY THEM. THEY PREPARE THE CAREGIVERS FOR WHAT AWAITS THEM, TOO, AND THEY MAY EVEN HELP THEM TO FACE IT WITH HOPE.¹

Compassionate Care

Compassionate care for dying people involves taking care of the whole person – body, mind, spirit, heart, and soul. Sometimes called “palliative care,” it is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness.² Idaho respondents (88%) agree that death is an important part of life and 86% believe that sharing time, gifts, or wisdom with others would be important when they deal with dying. Additionally, having adequate information for decision making and having decisions honored is important for respondents as reflected in their thoughts about the role of medical treatment and pain management at the end of life.

Medical Treatment

Terri Schiavo’s story captured the attention of adults of all ages and brought the complexity of end-of-life decision making into living rooms, lunchrooms, and coffee shops across the country. Here in Idaho, similar conversations take place as people explore their wants and desires related to medical treatment at the end of life. This is reflected in two-thirds of respondents telling us they have talked about their wishes for care near the end of life with their spouse or partner. Idaho survey respondents told us issues related to medical treatment were very important when they think about dying.



Pain Management

Idaho is working to improve state pain policies, spurred on by the dismal report and “E” grade specific to pain policies received in the November 2002 Last Acts Report on Dying in America Today.³ The good news is that Idaho’s grade improved to a “C” when measured on the same indicators in 2003.⁴ Unfortunately, at this time, solutions have not been found to address persistent pain experienced by many people living in Idaho skilled nursing facilities which remains at 53%.⁵

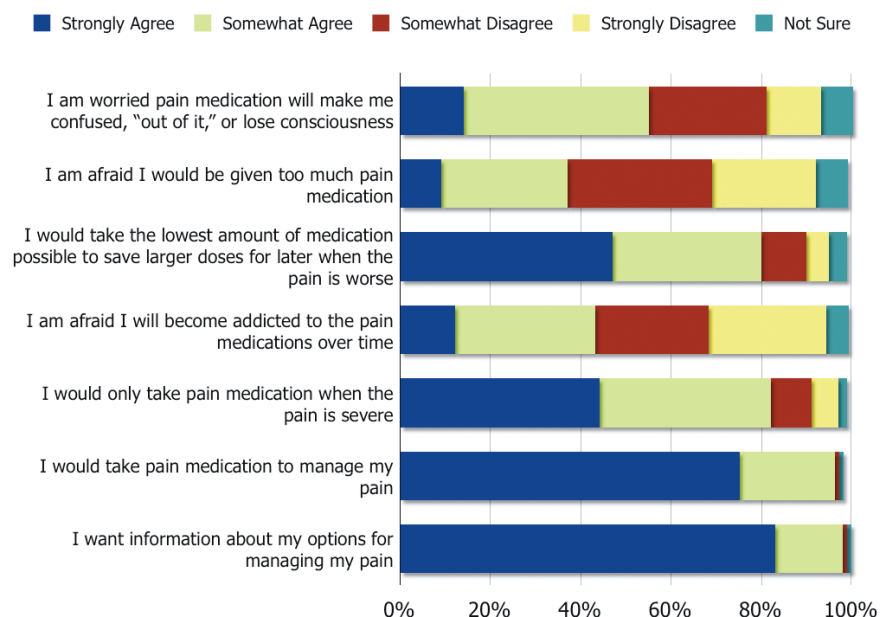
Recognizing the importance of pain management in end-of-life care, an entire section of the questionnaire was devoted to asking people about their thoughts and wishes related to pain at the end of life. Sixty-three percent of respondents said being free from pain was very important when they thought about dying and an equal number (63%) said living with great pain would be worse than death.

“Pain management is one of the most important aspects of care for terminally-ill persons. As with all healthcare issues, [it is important to] get a qualified medical opinion regarding any suggested treatments. Pain management is a medical specialty. [All people] have the right to obtain an opinion from a physician who specializes in pain management if [their] own physician seems unable or unwilling to provide adequate control for [their] pain.”⁶

PAIN CAN BE EXPERIENCED AS SHARP, ACHING, THROBBING, PRESSURE, BURNING, TINGLING, SHOOTING, STABBING

Large numbers of people state they want pain management information (83% strongly agree.) Seventy-five percent said they believe having good pain management available was very important and an equal number would take pain medicine to manage their pain.

These responses demonstrate awareness of pain and knowledge of the availability of treatment as an issue at the end of life. However, pain management is a complex issue as reflected in the fact 68% said it would be very important to be able to balance alertness and pain management while some are afraid of addiction (12% strongly agree), 44% would only take pain medication when pain is severe and 47% would save medication for when pain is worse. These results indicate a low level of understanding of various options for pain management and palliative care.



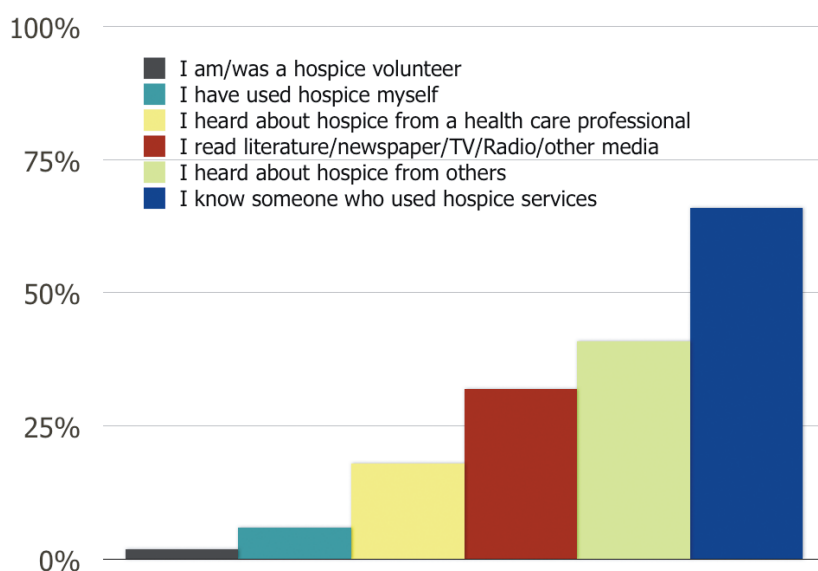
Lynne is an Idaho hospice supporter. In the early 1990's Lynne was living in Colorado and found herself not only with a terminally ill spouse, but also having to educate herself and her husband's doctor about hospice and the services it provides. "In my husband's case, his cardiologist was with him for 25 years and they were more friends than patient-doctor—his doctor could not bring himself to diagnose my husband as terminally ill," Lynne said. "I actually introduced my husband's cardiologist to hospice and even took him on a tour of the facility. It was the first time he'd ever been in a hospice and he's been practicing medicine for more than 30 years."¹⁰

Hospice Support

"Too many Americans die unnecessarily bad deaths – deaths with inadequate palliative support, inadequate compassion, and inadequate human presence and witness...When so many die without the support of good hospice or palliative care, we have not met our obligation to the most vulnerable in our society, and we have not kept faith with our highest moral ideals."⁷

In the survey, nearly all of the people (96%) said they have heard about hospice and 78% said they would consider using hospice support. Responding to the need for hospice care, members of the Idaho State Hospice Organization (ISHO) provide palliative end-of-life care in communities throughout Idaho such as Sandpoint, Twin Falls, Salmon, and Payette as well as other major population areas. While hospice services are available in many communities, ISHO President Paul Weil says lengths of stay in Idaho hospices hover around the national average, but in Idaho as in the nation many people receive services for a shorter period of time. Nationally, in 2005 one-third of the 2.4 million deaths occurred in a hospice programs where the median length of stay is 22 days, but 35% of people in hospice are in the program for seven days or less.⁸

Sixty-nine percent of respondents are worried their money won't last at the end of life. They expressed concern about becoming a financial burden to family and friends (66%) with almost an equal number (65%) concerned they will experience a financial burden paying for prescription drugs. However, only 43% said they were aware that Medicare and Medicaid paid for hospice services. The Medicare hospice benefit covers support for six months and allows for no more than \$5 to be charged to the patient for each prescription drug.⁹



While nearly all people know something about hospice when asked how they had heard about hospice, the most frequent sources were informal and perhaps more likely to provide very general information. Sixty-six percent know someone who has used services; 41% heard from others; and 32% the media as opposed to first-hand experience (6% have used hospice services; 2% were hospice volunteers). It is notable only 18% had received information about hospice from health professionals.

"Creating more efficient, visible pathways to hospice care from hospitals and nursing homes would help..." says

Richard Payne, MD, Director of the Duke Institute on Care at the End of Life. “This would require more coordination within healthcare systems and more training for doctors to recognize and affirm the needs of terminally ill patients... Faith leaders can play a role by encouraging conversations about hospice and end-of-life care... The result should be a better informed public in which people know when and how to choose hospice if this is right for them.”¹¹

Caring Communities

“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,” says Dr. Ira Byock. “We must ensure that competent medical evaluation is available, that appropriate treatments are offered and that comfort is ensured. But we can also ensure that people are visited, that their stories are heard and that they may know they are valued. We can bear witness to their lives, their frustrations, defeats and triumphs, and bear witness to their passing.”¹²

Most people who provide care for a family member, friend or neighbor near the end of life don’t think of themselves as a “caregiver.” However, persons providing support to someone who needs help, no matter how many hours per week, is considered a caregiver. According to Caring Connections, a national consumer engagement initiative to improve end-of-life care, “It doesn’t matter how many hours per week are spent providing support. Caregivers may live with the person they are caring for, providing assistance with daily needs, or may visit the person weekly or call regularly.”¹³

Nationally, more than 50 million people provide care for a chronically ill, disabled or aged family member or friend during any given year.¹⁴ People in Idaho shared their desire that if they needed care at the end of life it be provided primarily by family and friends. More than 80% of survey respondents indicated in seven of the eight categories they hoped family members would provide most of the support at the end of their life with friends/neighbors ranging from 27% to 54% in the eight support categories (see chart on page 20).

Carolyn, a hospice nurse in rural Idaho tells a story about caregiving – poignant but not unusual – a story being lived out daily in various ways in communities across Idaho.

There is a gentleman in our small, rural Idaho community who is 85 years old. His wife of 66 years died in the spring of cancer. He had cared for her for almost 9 months with the support of hospice volunteers. For many of us, this man’s life was difficult. He cut all of his own wood, hunted, fished, and repaired all of his own vehicles. At the same time, he was eager to keep his wife home, bring her coffee, make her soup, and sit by the log bed he had made and read to her. When she died, he didn’t call right away. He waited until morning and then calmly called to say... “My bride died last night. I didn’t want to bother you and I just wanted us to have a few more hours together.”¹⁶

Hospice care

is most often provided in 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
- bereavement care and counseling to surviving family and friends.

Hospice Programs can respond to the desires survey respondents expressed to

- die at home
- have good pain management
- be physically comfortable
- be with family and friends
- have relationship issues settled
- be at peace spiritually
- know how to say good-bye.

In 2003 in Idaho, there were approximately 119,625 family caregivers (including providing care at the end of life). Those Idaho family caregivers worked a net total of 128 million hours per year, equaling a market value of 1.129 billion dollars.¹⁵

A person may care for someone of any age who is impaired or dying, however, caregiving is often associated with support for older people eventually including care at the end of life. The aging of the baby boom generation, changes in family structures, and the increased numbers of people living to be 85 or older is straining informal and formal caregivers and presenting an ever increasing need for compassionate end-of-life care. Here in Idaho, the number of people 65 and older will more than double between the year 2000 and 2030 (146,000 to 361,000.) People 85 or older, those most in need of support for daily living and care at the end of life, will increase by 160%.

“The need for broad community involvement in caregiving and advance care planning is especially urgent as baby boomers age. We can’t just leave this in the hands of professionals. We own this together, and it is our responsibility to be present and offer support to each other.”¹⁷

Chronic illness often requires caregiving support for people at all ages. For Idaho survey respondents with a serious chronic illness themselves (18%) or with someone in the family diagnosed with a chronic illness (18%), caregiving may be a part of life that stretches over years and sometimes decades.

In the Idaho survey, three questions were asked related to “providing care” and being supportive to others at the end of life.

- ◆ 70% of respondents agreed that caring for people who are dying is a rewarding experience
- ◆ 86% would visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing
- ◆ 87% said they were likely to attend funerals or memorial services.

Since this study focused primarily on what people wanted or believed was important at the end of their life, it is possible to provide a comprehensive look into opportunities for creating and responding as caring communities. Items that asked about the importance of key types of care at the end of life and who should provide this care demonstrate the critical role people and caregiving communities play in providing quality care at the end of life. These responses reveal opportunities to reach out and create networks of support for people who are dying and their families in communities throughout Idaho.

Who Should Provide Various Types of Support

	Spouse/ partner	Children and other family	Paid caregivers	Friends/ neighbors	Community organizations	Health providers	Work associates	Faith community
Listen when I talk	79%	90%	38%	45%	5%	51%	9%	36%
Provide transportation	76%	84%	37%	38%	18%	17%	3%	26%
Help with chores	72%	81%	41%	34%	11%	11%	2%	24%
Do fun things with me	74%	84%	10%	54%	7%	4%	6%	25%
Know what I want when I die	78%	89%	17%	27%	2%	25%	3%	25%
Help care for other family members	61%	77%	18%	38%	9%	13%	3%	30%
Encourage me when I am down	76%	86%	21%	57%	7%	24%	9%	41%
Know about my illness	78%	89%	37%	46%	5%	48%	11%	35%

Family

Support from family (“spouse/partner” and “children and other family”) rated consistently high in all categories. When each issue is viewed separately, the highest percent expressed a desire for children and other family members to provide support. The higher numbers of respondents selecting children compared to spouses may reflect the fact that 24% of respondents reported they are widowed, divorced, separated, or were never married.

Friends and Neighbors

Support from “friends and neighbors” ranks after that of spouses and children as an important source of support near the end of life. Results ranged from 57% reporting they would like encouragement from friends and neighbors “when I am down” to a low of 27% in the category of “knowing what I want when I die.”

Faith Community

Support from “faith communities” follows that of family, friends and neighbors. It is interesting to note that 62% of respondents said they were affiliated with an organized faith community; however, many fewer said they expected support from their faith community near the end of life. Thirty-five percent expected their faith community to “know about my illness,” 36% want them to “listen when I talk,” and 41% to “encourage me when I am down.” Four of the support categories received responses ranging from 25% – 30% indicating a desire by some for various configurations of support.

References

1. Spohn WC. Caring to the End. *Issues in Ethics*. Winter 2003;14(1):11.
2. World Health Organization. WHO Definition of Palliative Care. 2006; <http://www.who.int/cancer/palliative/definition/en/>. Accessed August 28, 2006.
3. Last Acts. Means to a Better End: A Report on Dying in America Today. Washington, DC: Last Acts; November 2002.
4. University of Wisconsin Comprehensive Cancer Center. Achieving Balance in State Pain Policy: A Progress Report Card. Madison: University of Wisconsin; Updated February 2004.
5. Center for Gerontology and Health Care Research Brown Medical School. Facts on Dying: Policy relevant data on care at the end of life. <http://www.chcr.brown.edu/dying/idprofile.htm>. Accessed August 21, 2006.
6. Growth House Improving Care for the Dying. Pain. <http://www.growthhouse.org/pain.html>. Accessed September, 2006.
7. Jennings B, Rynes T, D'Onofrio C, Baily MA. Access to Hospice Care: Expanding Boundaries, Overcoming Barriers. *Hasting Center Report Special Supplement*. 2003;33(2):S3-S59.
8. Wharton School University of Pennsylvania. The Business of Hospice Care. Knowledge@Wharton; 2006.
9. Idaho Department of Insurance. Medicare Home Health Care and Hospice Benefits. <http://www.doi.state.id.us/shiba/shhomehlth.aspx>. Accessed September 14, 2006.
10. Eddy S. Hospice Workers Provide Special Service in Hard Times. *The Idaho Statesman*. April 10, 2006; Communities: 2.
11. Payne R. What Price Compassion? Rethink 'terrible choice,' remove hurdles to hospice care. *Orlando Sentinel*. April 20, 2006.
12. 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.
13. Caring Connections. Introduction to Caregiving. <http://www.caring-info.org/i4a/pages/index.cfm?pageid=3437>. Accessed August 15, 2006.

14. National Family Caregivers Association. Caregiving Statistics. Caregiving Population <http://www.thefamilycaregiver.org/who/stats.cfm>. Accessed September 5, 2006.
15. National Family Caregivers Association. Prevalence and Economic Value of Family Caregiving. State by State Statistics <http://www.thefamilycaregiver.org/who/stats.cfm#6>. Accessed September 5, 2006.
16. Nystrom C. A Day in the Life of a Rural Hospice Nurse. *Insights*. 2005(Winter '05-'06):36-38.
17. Brooks J. Caring Communities. *State Initiatives in End-of-Life Care*. May 2006(25):3.

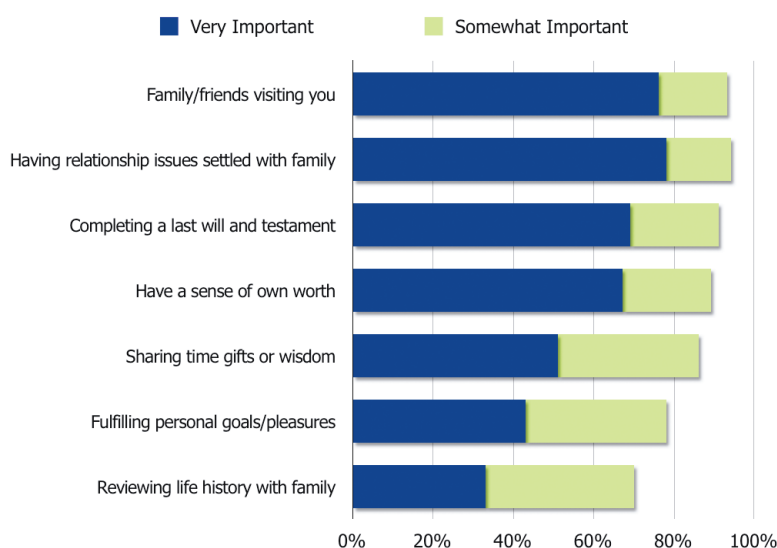
MOST OF US SEEK LIFE'S MEANING BEYOND THE BOUNDARIES OF OUR PHYSICAL LIFE... SUCH SEARCHING TAKES MANY FORMS. SOME PURSUE MEANING THROUGH THEIR RELIGIOUS FAITH, SOME IN FAMILY AND FRIENDS, OTHERS IN GOOD WORKS... HOWEVER YOU FIND MEANING, YOUR SEARCH FOR IT IS ORDINARILY ONE OF THE MOST IMPORTANT PROJECTS FOR THE END OF LIFE ¹

Meaning & Spirituality

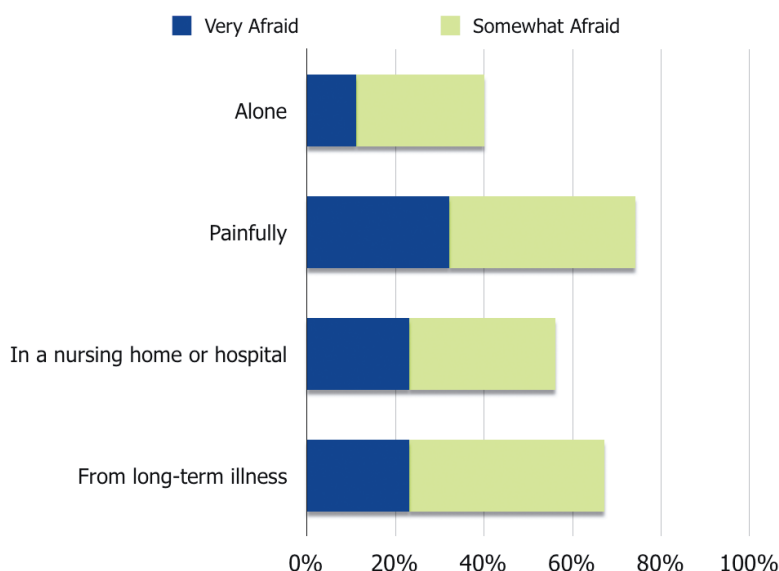
Meaning

“People’s understanding of the meaning of life may change over time and often comes into sharp relief with a terminal diagnosis or life threatening accident. Confronted with serious illness or our own dying we undergo... ‘a stripping away’ of many of the things that have brought meaning... While this ‘stripping away’ can be a difficult process, it is also an opportunity to explore and reframe ultimate meaning in our lives. The capacity to search for life’s meaning is common to all people. It is one of the things that connect us to each other.”²

In the end-of-life survey Idaho respondents shared thoughts about their desires to be valued, leaving a legacy and having a measure of control at the end of life. Activities and situations considered important by survey respondents include having a sense of worth, settling relationship issues, and spending time with family and friends. These provide insight about the nature of meaning at the end of life.



As presented in other sections of this report, the ability to make informed decisions about medical treatment and pain management, and the right to refuse life support were considered very important to most respondents. They expressed a desire to be involved in the significant decision making they will experience near the end of life. When asked to share their fears about dying 23% said they were very afraid of dying from a long-term illness and 23% said they were very afraid of dying in an institution such as a nursing home or hospital. Thirty-two percent are very afraid of dying painfully. Eleven percent were very afraid of dying alone.



When thinking about their death, respondents expressed a preference for environments conducive to spiritual comfort and well being. Eighty percent said they would want to be at home. Six percent would like to be in a residential hospice where palliative care could include attention to spiritual issues. Another 4% said they would like to die in a natural setting such as “in the mountains,” “fishing or hunting,” or “out of doors” with the remainder selecting a variety of other options.

Meaning and spirituality are closely related for many people. Last Acts Partnership developed Honoring the Mystery, which asks important questions about the role of meaning and spirituality at the end of life including:

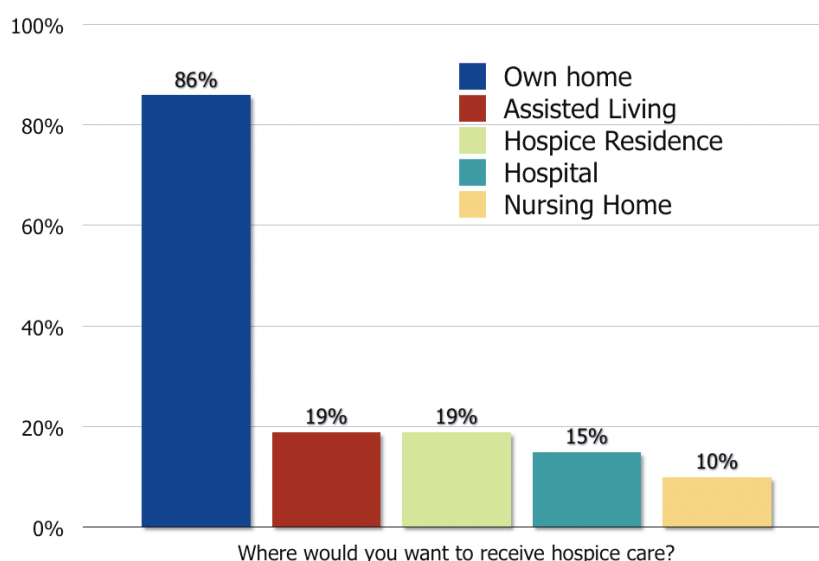
What are my values? Am I living them now?

What beliefs have sustained me in previous difficult times in my life? What are those beliefs now? Have they changed?

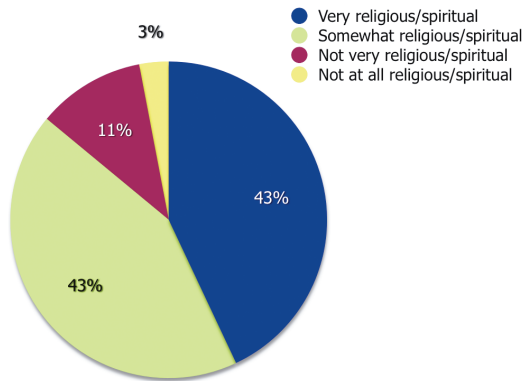
Where is the Divine in my life?

They go on to encourage people to “honor the mystery – accepting the unknown, even embracing it” in order to live a more full and rewarding life.³

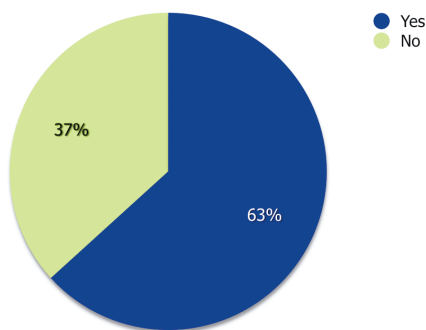
The Idaho Statewide End-of-Life Survey used “religious/spiritual,” “spiritual practice/religion,” and “clergy/spiritual leader” throughout the survey with the understanding that there is a distinction between religion and spiritual practice. Religion can be described as the totality of belief systems, an inner piety, an abstract system of ideas, and ritual practices. Spirituality can be understood as the personal and psychological search for meaning.⁴



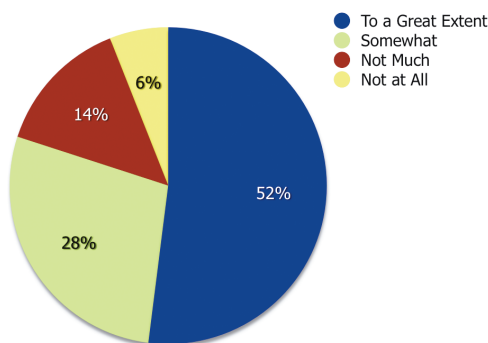
Do you consider yourself...



Are you affiliated with an organized faith community?



How does your spiritual practice/religion affect your end-of-life decision making?



Spirituality

“We must realize that dying is a spiritual process with medical implications, not a medical process with spiritual implications.”⁵

In 1996, the Nathan Cummings Foundation and the Fetzer Institute commissioned a Gallup national survey to investigate the relationship between spirituality and dying. George H. Gallup, Jr. states in the preface of the *Spiritual Beliefs and the Dying Process: A Report on a National Survey*, “The overarching message that emerges from this study is that the American people want to reclaim and reassert the spiritual dimension in dying.”⁶

Ten years later, results of the Idaho Statewide End-of-Life Survey support these national findings. Forty-three percent of respondents said they are very religious/spiritual and an additional 43% identified themselves as somewhat religious/spiritual. Sixty-two percent are affiliated with an organized faith community and spiritual practice/religion would affect end-of-life decision making to a great extent for more than half (52%). Twenty-eight percent anticipate their spiritual practice/religion would “somewhat” affect end-of-life decision making.

According to an article in the *New York Times*: “At the heart of hospice care... is the belief that dying is not simply the end of existence, but a time of important psychological, emotional and spiritual work. To promote self-examination and understanding, people involved in hospices emphasize controlling patients’ pain and then helping them come to terms with the approach of death.”⁷

Remembering, reassessing, reconciling and reuniting is the work of the spirit.¹

Nancy, an Idaho hospice chaplain talks about her role as a spiritual caregiver. “I often engage in life review so that as people are passing out of this life into what I consider to be another, they have a good sense that their’s has been full of meaning. It is a time to focus on beautiful things as well as express regrets and work towards resolution. I believe it is important for people approaching death to know their life has not been wasted.”⁸

The value of being at peace spiritually was recognized as very important for 80% of respondents with an additional 13% saying it was somewhat important. Forty-two percent

said the presence of a spiritual leader would be very important when dealing with their own dying and 31% said it would be somewhat important. While most survey respondents agree that being at peace is very important at the end of life, exactly how this is achieved is a highly individual matter. Exploring attitudes, beliefs, and traditions about religion and spirituality with people as they near the end of life is a way to provide compassionate care when it is needed most.

Physicians

Most Americans believe that physicians should consider their spiritual needs as part of their medical care.⁹ The role physicians and other medical professionals play in addressing spiritual issues with patients at the end of life has been the focus of increased interest in recent years. An April 2000 *Annals of Internal Medicine* article on Physicians and Patient Spirituality poses these questions,

Should the physician discuss spiritual issues with his or her patients?

What are the boundaries between the physician and patient regarding these issues?

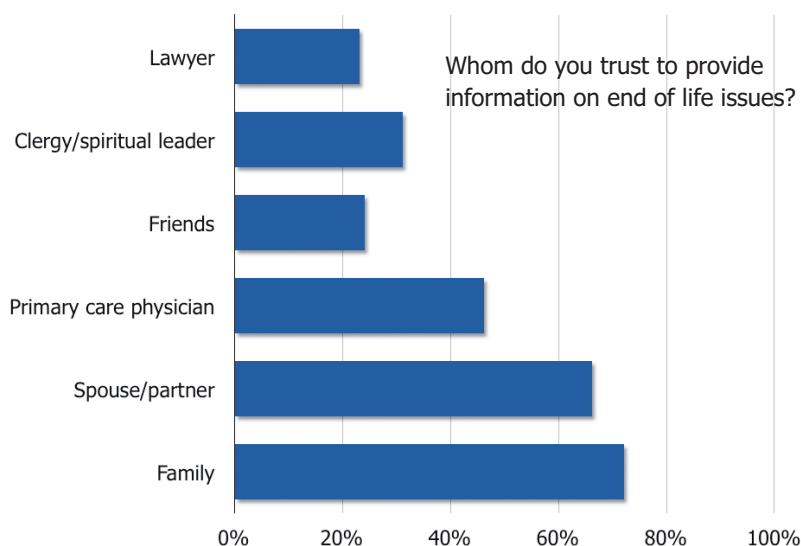
What are the professional boundaries between the physician and the chaplain?⁹

“While the medical community explores their role research results demonstrates that more than 75 percent of patients believe their physicians should address spiritual issues as part of their medical care. More than 40 percent actively want discussion of spiritual issues to take place.”¹⁰

Clergy and Spiritual Leaders

“We are talking about people’s need to assess life and its meaning, to solidify beliefs, to understand why they exist and what the future holds. The medical team and I are companions on this journey,”¹¹ said Robert A. Washington, MDiv, PhD, Chaplain.

Religious [and spiritual] leaders have historically served as both physical and spiritual healers. A trend to create a division between science and religion began in the mid-19th century progressively separating the clergy from significant roles in physical healing.¹² In the 21st century the divide between need for spiritual care and ability to provide this care continues to exist. Investigations throughout the country indicate that end-of-life topics are not included in



the clergy educational curricula regardless of faith or denomination. Therefore, clergy and spiritual leaders are often sent ill-prepared to provide care at the end of life.¹³

In Idaho, as a result of this survey, opportunities for clergy and spiritual leaders to be present in significant ways with people and their families as they approach the end of life have been identified. It is interesting that 24% of respondents would want clergy or a spiritual leader to initiate a conversation with them regarding end-of-life issues. However, only 4% of respondents have had a conversation with clergy or spiritual leaders. Even a higher number (31%) would trust clergy or spiritual leaders to provide information on end-of-life issues, exceeding the number that would trust friends (24%), MD specialists, such as cardiologists and oncologists (24%), lawyers (23%), or mental health professionals (12%.)

Survey respondents told us that end of life is more than being physically comfortable. Mending broken family relationships, finding peace and finally knowing how to say good-bye is just as important.

References

1. Lynn J, Harrold J. Handbook for Mortals: Guidance for People Facing Serious Illness. Oxford: Oxford University Press; 1999.
2. Life's End Institute. An Interview with Christina Puchalski, MD. Thyme. Vol Spring; 2005:1.
3. Meyer M. Exploring Spirituality at The End of Life. Voices: The Newsletter of Last Acts Partnership. Spring 2004;1(1):3.
4. Dickinson GE, Leming MR. Annual Editions: Dying, Death, and Bereavement. 8th ed. Burr Ridge: McGraw-Hill/Dushkin [Imprint]; McGraw-Hill Higher Education; Blacklick : McGraw-Hill Companies; 2006.
5. State Initiatives in End-of-Life Care. Shifting Reform Paradigms: Spiritual and Cultural Matters. State Initiatives in End-of-Life Care; 2006:4.
6. The Nathan Cummings Foundation. Spiritual Beliefs and the Dying Process: A Report of a National Survey: The Nathan Cummings Foundation, Fetzer Institute, The George H. Gallup International Institute; 2000.
7. Hagen C. Putting a Human Face on Death. The New York Times. January 19, 1997;Arts.
8. Gedney N. Chaplain, XL Hospice. Interview with: Darrington J., Boise; 2006.

9. Post SG, Puchalski CM, Larson DB. Physicians and Patient Spirituality: Professional Boundaries, Competency, and Ethics. *Annals of Internal Medicine*. April 4 2000;132(7):578-583.
10. Larimore WL. Providing basic spiritual care for patients: should it be the exclusive domain of pastoral professionals? *Am Fam Physician*. Jan 1 2001;63(1):36, 38-40.
11. Washington RA. *Spiritual Journeys. State Initiatives in End-of-Life Care*; 2006:4.
12. Norris K, Strohmaier G, Asp C, Byock I. Spiritual Care at the End of Life: Some Clergy Lack Training in End-of-Life Care. *Health Progress*. 2004(July-August).
13. Hospice Foundation of America. *Statewide Hospice Clergy End-of-Life Education Enhancement Project Final Report: Hospice Foundation of America*; 2006.

JOANNE LYNN, M.D. SPEAKS ABOUT TRANSFORMING THE CULTURE OF DYING: "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."¹

Where Do We Go From Here?

Assuring good end-of-life care that honors preferences and meets needs requires reforming institutions and changing individual behavior. Availability of palliative care in the healthcare system needs to be increased, religious communities and spiritual leaders need to be engaged in end-of-life planning and care, and people need to overcome their tendency to avoid confronting their own mortality – at least enough to make wishes and preferences clear to the family, friends, and professionals who will be involved in their care at the end of life.

Conducting a survey alone will not result in these profound changes. What a project like the Idaho Statewide End-of-Life Survey can do is provide insight into people's attitudes, desires, and behaviors. This insight then offers both direction and a foundation for future action.

Collecting information that adds momentum to improvements surrounding care at the end of life and dying in Idaho is particularly important at this point in time. Highly publicized legal battles concerning end-of-life decisions combined with the aging of population have moved the topic up on public, professional, and personal agendas. State laws have been changed to clarify and simplify advance care planning, more healthcare professionals and organizations are embracing palliative care, and attendance at community forums and educational sessions have markedly increased in the last few years.

In Idaho, several regional and statewide groups including A Better Way Coalition are poised to assist with the transformation of end-of-life care. The chronology of events listed in the Preface only highlights some of the many activities in Idaho since the release of the 2002 national report on dying in America.

These activities have begun to have an impact. The updated 'report card' included in Appendix A documents improvement in Idaho on several key indicators such as an increase in palliative care services and professionals and the improvement of policies that impact pain management. The impetus for the

Idaho Statewide End-of-Life Survey project was a desire to contribute information that could help all these stakeholders as they think about “Where do we go from here?”

The survey results reported in this document and the current status of end-of-life care in Idaho suggest that the next steps need to focus on two objectives:

1. Providing assistance so that individuals move from awareness of issues related to end-of-life to actions that will increase the probability that their wishes and preferences will be honored.

The survey project clearly documents that many people are aware of various issues surrounding the end of life. They know that decisions may need to be made about the use of life sustaining technology, pain management, and where they will die. They are also familiar with the tools that exist to formalize their wishes. Yet most have not taken action. They have not talked to all the people who could help or used the tools available. This is not an unusual situation. Many disciplines including psychology, health promotion, and education provide insights into how to help individuals make the leap from understanding to action and how to change habits and behaviors. The efforts to reform end-of-life care can build on this knowledge and strive not only to continue to educate the public, but also to empower individuals to take action.

2. Improving the range of care provided at the end-of-life so that the outcomes reflect the wishes and preferences of each individual.

Combined with the updated report card, the survey sheds light on another gap that needs to be the focus of future activities. There has been an increase in availability of services such as hospice and palliative care. While this increase is necessary for improvements in care, it is not sufficient. So far this increase in the structural supports for good end of life care has not resulted in improvements in the outcomes that the survey tells us are most important to the people of Idaho. Most people do not die at home and pain is still not adequately managed. Add to this the gap between the number of people who have talked to various professionals about end-of-life care issues and the number who want those in these roles to initiate conversations. Clearly there is much work to be done to assure that the services and professionals that support people at the end of life can actually produce the desired results.

Specific activities suggested by survey outcomes and related to these two objectives serve as a basis for the following outline of future efforts and goals as we work to promote advance care planning and better care at the end of life in Idaho.

Communicating Wishes

- ◆ Individuals, programs, and our communities encourage people to discuss their wishes for care at the end of life with those near to them and the appropriate professionals.

- ◆ 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).
- ◆ Once completed by adults 18 years and older, these tools are accessible to healthcare providers in the new Idaho Health Care Directive Registry (January 2007).
- ◆ People's stated desires for treatment and care at the end-of-life travel with them to all facilities and are followed by medical and emergency personnel.
- ◆ Information in advance directives 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.

Compassionate Care

- ◆ The medical community, faith leaders, and other professionals recognize the importance of good end-of-life care and obtain appropriate training and support. As a result they respond with compassion to the end-of-life wants and needs of people in Idaho.
- ◆ Policies that encourage effective pain management are created and approved and effective pain management strategies are implemented. Pain at the end of life is significantly reduced and eliminated when possible so that dying painfully is no longer something people fear.
- ◆ Palliative care is available and considered at the time of diagnosis of a life-threatening illness so that seriously ill and terminal patients can make informed choices among treatment options and benefit from palliative care if they choose.
- ◆ Support is provided to family and friends caring for dying people, allowing those who wish to die at home or in another non institutional setting to do so.
- ◆ Hospice services are discussed and physicians make referrals earlier in the allowable six-month time frame (expanding beyond the median of 22 days). More timely referrals allow dying people and their caregivers to benefit from additional hospice services.
- ◆ Hospice educational material is distributed through varied networks such as faith communities, community centers, libraries, etc.

- ◆ Dying people are provided the information they desire and are included in the decision making process providing for autonomy and self determination at the close of life.
- ◆ Services are designed for people without family or other support systems so that no one has to die alone.

Meaning & Spirituality

- ◆ Families, communities and the state of Idaho recognize the value of growing older which is demonstrated in behaviors, services, and policies.
- ◆ Dying and death are not viewed as “failure” but as an important part of life.
- ◆ Faith leaders learn about and acquire the necessary skills to respond to the unique spiritual needs of people nearing the end of life.
- ◆ People who do not identify with a specific faith community receive care that promotes spiritual peace.
- ◆ Listening to life stories of dying people is made a priority so they feel valued and recognized for a lifetime of contributions.
- ◆ People seek to understand the needs of dying people in their faith communities and provide various types of support at the end of life.
- ◆ Professionals providing care at the end of life recognize achieving spiritual peace can be as important as relief from pain and management of physical symptoms.
- ◆ Family and relationship issues are settled with people who are dying so that resolution can bring peace and people are able to say good-bye.

The results of this statewide research project provides rich information about a wide cross section of adults 35 years and older in Idaho. People responding to the 12-page questionnaire shared deeply personal feelings and concerns, asked for information and expressed wishes for care at the end of life. The significance of relationships was captured in one simple request recognized as important by almost all respondents, help in “knowing how to say good-bye.”

The ultimate goal of this survey project is to be part of reforming care at the end of life for people in Idaho; to promote compassionate care that tends to the entire person, body, mind and spirit, heart, and soul. Now it is time for Idaho communities to act on what people have said and take steps that make it possible for people to realize their own desires at end of life.

Reference

1. Open Society Institute. Transforming the Culture of Dying: The Project on Death in America 2004 p. 29.

Appendix A - Idaho End-of-Life Report Card

The Idaho End-of-Life Report card is reproduced with footnotes and references on the following page.

Appendix A

Idaho 2002 End of Life Report Card and Update

	Grade ¹	Report ¹	Update
Elderly patients spending a week or more in intensive care in the last six months of life	"B"	6.8% (2000)	7% ² (2003)
Place of death ^{3*}	"C"		
At home		28.1% (1997)	29.2% (2001)
In hospitals		37.8% (1997)	35.7% (2001)
In nursing homes		30.1 (1997)	31.5% (2001)
People 65+ who used hospice services the last year of life	"C"	20.8% (2000)	Unavailable
Quality of advance directive laws to support good advance care planning	"C"	(3 of 6 measures)	(6 of 6 measures) ⁴
Nurses certified in palliative care	"D"	15 (2000)	40 ⁵ (2006)
Hospitals reporting pain management programs	"D"	38.9% (2000)	57.5% ⁶ (2005)
Hospitals reporting hospice programs	"D"	30.6% (2000)	36.4% ⁶ (2005)
Hospitals reporting palliative care programs	"E"	8.3% (2000)	36.4% ⁶ (2005)
General primary care and primary care subspecialty physicians certified in palliative medicine	"E"	None (2000)	5 ⁷ (2006)
Policies in place to support appropriate pain control at the end of life [†]	"E"	None (2001)	C ⁸ (2003)
Nursing home residents in persistent pain - worst rate in the nation*	"E"	53.1% (1997)	53.4% ³ (2001)

* The numbers for 1997 included in the Means to a Better End report differ from those that are presented on the Facts on Dying profile currently available from Brown University Center for the Gerontology & Health Care research due to subsequent data updates and corrections. The numbers included here are from the profile on the website as this is more current.

[†] Idaho earned a D in the Achieving Balance in State Pain Policy, A Progress Report Card in 2000 and was listed as having an E in the Means to a Better End: A Report on Dying in America Today. The grade improved to a C in 2003 meaning policy changes were sufficient enough to produce a grade improvement. The grade given by Achieving Balance in State Pain Policy, A Progress Report Card comes from the full report based on 17 measures. Means to a Better End: A Report on Dying in America Today gives Idaho a grade based on 6 of the 17 measures

References

1. Last Acts. Means to a Better End: A Report on Dying in America Today. Washington, DC: Last Acts; November 2002.
2. Center for the Evaluative Clinical Sciences at Dartmouth. The Dartmouth Atlas of Health Care: Data Tools; Benchmarking. http://cecsweb.dartmouth.edu/release1.1/datatools/bench_s1.php. Accessed September 2006.
3. Center for Gerontology and Health Care Research Brown Medical School. Facts on Dying: Policy relevant data on care at the end of life. <http://www.chcr.brown.edu/dying/idprofile.htm>. Accessed August 21, 2006.
4. Simpson-Whitaker C. Assessment of Idaho Advance Care Directive Laws. Interview with Darrington J; 2006.
5. National Board for Certification of Hospice & Palliative Nurses. Certified Hospice and Palliative Nurse (CHPN) Certificants. http://www.nbchpn.org/Certificants_List.asp?Cert=CHPN. Accessed August 23, 2006.
6. American Hospital Association. AHA Hospital Statistics 2006 ed. Chicago: Health Forum; 2006.
7. American Board of Hospice and Palliative Medicine. ABHM Physician Directory. <http://www.abhpm.org/Locator.aspx?key=all&searchtext=Idaho>. Accessed August 23, 2006.
8. University of Wisconsin Comprehensive Cancer Center. Achieving Balance in State Pain Policy: A Progress Report Card. Madison: University of Wisconsin; Updated February 2004.

Appendix B - Technical Description

Introduction

The Center for the Study of Aging (Center) entered into a partnership with A Better Way Coalition: Life on Our Own Terms (Coalition) in December 2005 in order to conduct the Idaho Statewide End of Life Survey. Sponsoring members of the Coalition provided resources for printing, mailing, and other costs that were matched by Center resources including funds and staff time. The Center managed the project and this Appendix describes the technical aspects of the project.

Survey Instrument

The survey items and format were adapted from the Community Survey, developed by Life's End Institute. This questionnaire was originally developed for the Missoula Demonstration Project and was most recently adapted for the Massachusetts Commission on End-of-Life Care Survey. Life's End Institute held the copyright to the survey at the time permission was obtained to adapt it for use in Idaho. With the dissolution of Life's End Institute the copyright was transferred to The Duke Institute on Care at the End of Life at Duke University Divinity School.

Adaptations of the survey were kept to a minimum and reviewed by Life's End Institute prior to printing in order to assure the integrity of the instrument was maintained. This also allows comparisons with other states and communities that conducted this survey in the past or may use this instrument in the future. Wording in a few items was changed to reflect Idaho-specific laws, programs, and resources. Additionally, a small number of items were added (e.g., an item on the extent to which spiritual or religious beliefs impact end of life plans) to address issues of interest to Coalition members.

The survey was designed to collect basic demographic, socio-economic, and health status information as well as information on attitudes, beliefs, experiences, and behaviors related to end-of-life preferences and planning. Items were included on advance care planning, attitudes toward death, hospice services, preferences for medical practices and pain management, knowledge and/or use of planning tools such as wills and health care proxies, financial

concerns, and both current and desired sources of information and social support. The questionnaire form is reproduced in Appendix C.

Sampling

The Idaho end-of-life survey was sent to a random sample of 3003 adults 35 years and older who lived in private residences in Idaho and had phone service. The list of names and addresses was purchased from Accudata America, an independent list broker that was also used to produce samples for other state and community surveys in collaboration with Life's End Institute. Accudata lists are compiled from many sources including telephone directories, U.S. Census Bureau data, U.S. Postal Service information, birth records, warranty cards, mortgage data, other public records and are supplemented by door-to-door canvassing. For this project a sample was requested that included equal numbers of men and women and that represented the geographic distribution of the population across the state of Idaho.

Data Collection

Prior to contacting any persons in the sample, approval for the study was received from the Institutional Review Board (IRB) of Boise State University, which is the federally mandated mechanism used to protect human subjects in research. The cover letter for the survey stated that this research was approved by the IRB and provided phone and address information for both the Director of the Center for the Study of Aging and the IRB staff person who could be contacted with any questions.

The 3003 people living in Idaho who were included in the sample received two mailings. First, an announcement postcard was mailed on February 21, 2006. One week later, a packet was mailed including a cover letter, a survey booklet, a business return envelope, and an entry form for a drawing of five \$100 prizes. The announcement postcard, cover letter, and prize drawing entry form are also reproduced in Appendix C. Recipients were called and offered another copy of the survey if the survey was not returned within three weeks. No surveys were completed as phone interviews. No names or addresses were included on the surveys and the database with this information was maintained on a secure computer and was not merged with the survey response data. A study identification number was used to track completion during the time the survey was being fielded.

Surveys were returned to the Center for the Study of Aging at Boise State University. Envelopes were opened by Center staff and the survey booklet was immediately separated from the drawing entry form. Upon completion of the drawing, the entry forms were shredded.

Response Rate and Sample & Respondent Characteristics

Of the 3003 surveys mailed, 1181 or 39.3% were returned with the survey form completed totally or in part. With 1181 respondents, the survey has a sampling error estimated to be +/- 2.9% at the 95% confidence level.¹

Four surveys were returned blank with a completed drawing form. These individuals were included in the prize drawing, but were not counted as respondents. Information on gender, estimated age, and the mailing address were provided by Accudata on all sample members. This information from Accudata was used to produce Table B-1 on the gender, age, and regional distribution of entire sample, the non-respondents, and respondents.

Table B-1

	Idaho Population over 35 years old	Sample Sent Survey N=3003	Respondents N=1181	Non-Respondents N=1822
	(2004) ¹			
Male	48.3%	50%	44.3%	53.7%
Female	51.7%	50%	55.7%	46.3%
	(2004) ¹			
Age 35-44	27.9%	20.9%	18.0%	22.9%
Age 45-54	29.3%	26.7%	25.9%	27.3%
Age 55-64	20.2%	21.5%	24.1%	19.9%
Age 65-74	12.1%	16.4%	17.8%	15.5%
Age 75-84	7.8%	10.7%	10.4%	10.8%
Age 85>	2.7%	3.6%	3.8%	3.5%
	(2000) ²			
North	24.0%	17.2%	17.3%	17.1%
West	35.6%	44.9%	42.9%	46.1%
East	40.4%	37.9%	39.8%	36.8%

For respondents, self-reported demographic and additional socio-economic information is available from the survey. The responses to these items are provided in Table B-2 on the following page.

Table B-2: Respondent Characteristics

Gender		%	Marital Status		%
	Female	57.2		Single, never married	3.4
	Male	42.2		Married	72.1
				Living with a partner	3.4
Age				Separated	0.6
	44 and under	18.0		Divorced	9.9
	45-54	26.2		Widowed	9.7
	55-64	24.0	Live alone		
	65-74	18.0		Yes	18.2
	75-84	9.5		No	80.4
	85 and older	3.2			
			Self-Rating of Health		
Hispanic	Yes	3.5		Excellent	18.2
	No	94.8		Very Good	33.3
Race				Good	31.4
	White	94.4		Fair	13.8
	Asian	0.3		Poor	2.5
	Black	0.2			
	Native American	2.4	Have a serious chronic illness		
Income				Yes	18.3
	Less than 10K	4.7		No	79.3
	10K to under 20K	10.2	Another member of household with a serious chronic illness		
	20K to under 30K	14.9		Yes	17.8
	30K to under 40K	15.3		No	79.4
	40K to under 50K	12.4	Covered by any Health Care Insurance		
	50K to under 60K	8.6		Yes	89.7
	60 to under 75K	9.8		No	8.7
	75K or more	19.0			
	Missing	5.2			
Education			Employment status		
	Less than high school	4.0		Full time	44.3
	HS or equivalent	20.0		Part time	14.9
	Some College	45.6		Retired and not working	30.0
	College Graduate	18.0		Other such as homemaker	8.6
	Post-grad or professional degree	11.8		Unemployed and looking for work	1.4

Data Preparation and Analysis

Survey responses were entered using SPSS Data Entry Station into a database provided by Life's End Institute that was written using SPSS Data Entry Builder. Data entry was performed by Center for the Study of Aging staff. Data entry checks were conducted as staff members were trained and on a random sample of forms after data entry was completed. From this sample, it is estimated that the data entry error rate before data cleaning was approximately 0.13 %.

Prior to analysis, data were checked for out-of-range values, appropriate skip patterns and patterns of missing responses. This data preparation included collapsing some variable and coding open-ended responses. For example, age reported in years was collapsed into age ranges; organized faith affiliations were coded and open-ended "other" responses to items were reviewed and classified.

All analyses were conducted by staff at the Center for the Study of Aging using the statistical software SPSS v.14. The coding of open-ended responses and preliminary analyses were reviewed with the survey committee of the Coalition in order to verify classifications and identify additional analysis questions.

A weighting schedule was constructed to match the age and gender distribution of the Idaho population based on US Census data from the American Community Survey in 2004 as this was the most recent data available at the time of analysis. Application of the resulting weights would require eliminating 13 surveys that were missing age or gender information and produced frequencies that differed only slightly from the results that were not weighted. The survey committee decided to report actual unweighted responses in this report given that the differences were minor and using weights would require the assumption that variance in responses is primarily due to differences in the characteristics used for weighting (in this case gender and age.)

In addition, the results included in this report are the actual numbers of responses and the actual, (not the valid) percentages. This means that the percentages are calculated including the missing values for each item. As a result the percentages for a particular question may add to less than 100%, with the remainder being the percentage of respondents who provided no response to that item. This allows the percentages provided in the report to be multiplied by the number of respondents (1,181) and result in the actual number of people who provided each response.

For more information on the management of this study, contact Annette Totten, Director, Center for the Study of Aging, Boise State University, at aging@boisestate.edu or 208.426.5899.

Notes

1 In theory, with a sample of this size, one can say with 95 percent certainty that the results have a statistical precision of plus or minus 2.9 percentage points of what they would be if the entire adult population over 35 had been surveyed with complete accuracy. However there are several other possible sources of error in all surveys that may be more important than theoretical calculations of sampling error that are difficult or impossible to quantify.

2 The differences between Table B-1 and Table B-2 result from the use of different data sources. Table B-1 is based on the information provided by Accudata, while B-2 is what survey respondents reported. There are several possible explanations for these differences: the survey may have been answered not by the person to whom it was addressed but by someone else in the household; the information from Accudata may have been from a different time period or incorrect; or the person completing the survey may have provided inaccurate information.

References

1. U.S. Census Bureau. American Community Survey 2004: Detailed Tables: Idaho Sex by Age. June 28, 2005;. Accessed August 29, 2006.
2. U.S. Census Bureau. Census 2000, Summary File 1 (SF1): generated by Jill Darrinton using American Factfinder; <http://factfinder.census.gov>. Accessed September 5, 2006.

Appendix C - Survey and Collateral

1. Survey form with frequencies of responses

Note: the frequencies reported in this appendix are rounded to the nearest whole number and represent the actual percentages. This means that the percentage is calculated by dividing the number of people who endorsed a response by the total number of respondents. Using this method, respondents who did not answer the particular item (the response was missing) are included in the calculation. Including the missing means that the total of the reported percentages for each item may be less than 100.

2. Cover Letter

3. Additional materials mailed to potential respondents

Announcement Card

Prize drawing entry

Idaho End of Life Survey

This survey is about end-of-life issues. It includes questions about your attitudes, beliefs and experiences concerning topics that may be sensitive. Your responses will help us gain a better understanding of what is important to people in Idaho when they think about the end of life. The survey should take only 20 minutes. We would really appreciate your participation.

For each survey item below, ☒ check the box that best represents your opinion or experience.

Thoughts about Death and Dying

1. Thinking back on your childhood, how often were death and dying talked about in your family?

- 6% Often
- 41% Occasionally
- 38% Rarely
- 10% Never
- 3% Can't remember

2. How comfortable are you with...

	Very comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable	Not sure
a. Talking about death	52%	40%	6%	1%	1%
b. Writing your own will	57%	27%	10%	3%	2%
c. Appointing a health care proxy to act for you if you were unable to speak	56%	28%	10%	2%	3%

3. How likely are you to...

	Very likely	Somewhat likely	Not very likely	Not at all likely	Not sure
a. Attend funerals or memorial services	53%	34%	9%	3%	0%
b. Read books, newspaper articles or other information that deal with the subject of death and dying	35%	41%	19%	5%	1%
c. Watch television programs or movies that deal with the subject of death and dying	27%	43%	23%	7%	1%
d. Avoid medical checkups because you are afraid the doctor will find "something serious"	5%	12%	26%	56%	1%

	Very likely	Somewhat likely	Not very likely	Not at all likely	Not sure
e. Use integrative medicine such as massage, acupuncture, music, exercise, relaxation, etc.	31%	33%	23%	11%	1%
f. Speak freely to loved ones about death and dying	45%	41%	11%	2%	0%
g. Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing	51%	35%	10%	2%	0%
h. Preplan your own funeral	34%	36%	19%	6%	3%

4. How afraid, if at all, are you of...

	Very afraid	Somewhat afraid	Not very afraid	Not at all afraid	Not sure
a. Dying	3%	27%	33%	33%	3%
b. Dying from a long-term illness	23%	44%	19%	9%	3%
c. Dying suddenly	4%	16%	31%	44%	2%
d. Dying alone	11%	29%	28%	26%	4%
e. Dying in an institution such as a nursing home or hospital	23%	33%	25%	13%	5%
f. Dying painfully	32%	42%	15%	6%	4%

5. How strongly do you agree or disagree that...

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Not sure
a. There is a special value in getting old	42%	38%	11%	6%	2%
b. Death is an important part of life	62%	26%	5%	3%	2%
c. You would want to know if you had a serious illness	74%	18%	4%	1%	2%
d. You would want to know if you only had a few months to live	76%	17%	2%	2%	2%
e. Caring for people who are dying is a rewarding experience	32 %	38%	13%	8%	9%

6. When you think about death and dying, how concerned are you that...

	Very concerned	Somewhat concerned	Not very concerned	Not at all concerned	Not sure
a. Your (or your spouse/partner's) money won't last	30%	39%	20%	9%	1%
b. Your family's money won't last	27%	38%	22%	10%	2%
c. You will be a financial burden to your family or friends	32%	34%	21%	11%	1%
d. You will experience a financial burden paying for prescription drugs	32%	33%	21%	11%	1%

7. Which of the following health conditions, if any, do you think are worse than death?
Check ALL that apply.

- 63% Living with great pain
- 86% Total physical dependency on others, such as being in a coma
- 74% Not being able to communicate my wishes and/or needs to family and friends
- 77% Severe mental deterioration or severe memory loss
- 5% Nothing is worse than death

Advance Planning and Preparation

Advance Directives allow people to make their health care choices known in advance of an incapacitating illness, life threatening condition or death.

8. Which of the following advance directives and other pre-plans have you heard about and completed?

	Have heard about <u>and</u> completed	Have heard about but <u>not</u> completed	Have not heard about
a. A health care proxy or durable power of attorney for health care in which you name someone to make decisions about your health care in the event you are unable to speak	31%	60%	8%
b. A living will or other written instructions in which you state the kind of health care you want or don't want under certain circumstances	35%	63%	1%
c. A Comfort One form and bracelet to verify that you have a valid Do Not Resuscitate ("DNR") order and thereby authorize emergency services personnel to honor your DNR status when they are called to a non-hospital setting for emergency transport	4%	52%	43%

	Have heard about <u>and</u> completed	Have heard about but <u>not</u> completed	Have not heard about
d. A last will and testament that controls how your money and other property are to be distributed	43%	54%	1%
e. Funeral or burial pre-plans in which you plan or purchase in advance any goods or services for yourself	16%	80%	2%
f. Authorization to have your organs and/or tissue donated after you die for use by others in need of transplants	51%	44%	2%

9. Whether you have completed any advance directives/pre-plans or not, with whom have you talked about your wishes for care near the end of your life? Check ALL that apply.

68%	Spouse / partner	7%	Primary care physician
64%	Family	3%	MD specialists, such as: cardiologist, oncologist
27%	Friends	2%	Mental health professional, such as: social worker, psychologist, or psychiatrist
4%	Clergy/spiritual leader		Disease-specific organizations, such as:
12%	Lawyer	1%	American Cancer Society, Alzheimer's Association, American Heart Association
5%	Estate planner		
5%	Funeral director	13%	No one

10. Who would you want to initiate a conversation with regarding end-of-life issues? Check ALL that apply.

71%	Spouse / partner	35%	Primary care physician
80%	Family	15%	MD specialists, such as: cardiologist, oncologist
29%	Friends	5%	Mental health professional, such as: social worker, psychologist, or psychiatrist
24%	Clergy/spiritual leader		Disease-specific organizations, such as:
17%	Lawyer	5%	American Cancer Society, Alzheimer's Association, American Heart Association
9%	Estate planner	5%	No one
12%	Funeral director		

11. Who would you trust to provide information on end-of-life issues? Check ALL that apply.

66%	Spouse / partner	46%	Primary care physician
72%	Family	24%	MD specialists, such as: cardiologist, oncologist
24%	Friends	12%	Mental health professional, such as: social worker, psychologist, or psychiatrist
31%	Clergy /spiritual leader		Disease-specific organizations, such as:
23%	Lawyer	15%	American Cancer Society, Alzheimer's Association, American Heart Association
13%	Estate planner	2%	No one
13%	Funeral director		

Dealing with Dying

12. How important would each of the following be to you when dealing with your own dying?

		Very important	Somewhat important	Not very important	Not at all important	Not sure
a.	Family/friends visiting you	76%	17%	3%	1%	1%
b.	Being able to stay in your home	66%	27%	4%	1%	1%
c.	Honest answers from your doctor	93%	4%	1%	0%	0%
d.	Presence of spiritual leader	42%	31%	14%	8%	2%
e.	Knowing medicine was available to you	73%	21%	3%	1%	0%
f.	Planning your own funeral	35%	36%	20%	6%	1%
g.	Being able to complete a Last Will and Testament	69%	22%	4%	1%	1%
h.	Fulfilling personal goals/pleasures	43%	35%	14%	5%	1%
i.	Reviewing your life history with your family	33%	37%	20%	6%	1%
j.	Having a good relationships with your health care providers	58%	32%	7%	1%	0%
k.	Getting your finances in order	73%	22%	2%	1%	0%
l.	Understanding your treatment options	84%	13%	1%	0%	0%
m.	Choosing your treatment options	85%	12%	1%	0%	0%
n.	Sharing with others your time, gifts, or wisdom	51%	35%	9%	3%	1%
o.	Having good pain management available	75%	21%	2%	0%	0%

13. How important is each of the following to you when you think about dying?

	Very important	Somewhat important	Not very important	Not at all important	Not sure
a. Being physically comfortable	66%	32%	1%	0%	0%
b. Being free from pain	63%	34%	3%	0%	0%
c. Being off life support machines	72%	18%	4%	1%	3%
d. No artificial life-sustaining procedures	72%	16%	6%	1%	4%
e. Not receiving artificial nutrition/hydration	54%	26%	9%	3%	6%
f. Being able to balance alertness and pain management	68%	28%	2%	1%	1%
g. Having relationship issues settled with my family	78%	16%	4%	1%	1%
h. Being at peace spiritually	80%	13%	4%	2%	0%
i. Not being a physical burden to loved ones	85%	13%	1%	0%	0%
j. Knowing how to say goodbye	71%	21%	4%	2%	1%
k. Having a sense of your own worth	67%	22%	7%	3%	1%

14. Do you consider yourself...

43% Very religious/spiritual
 43% Somewhat religious/spiritual
 11% Not very religious/spiritual
 3% Not at all religious/spiritual

15. How does your spiritual practice/religion affect your end of life decision making?

52% To a great extent
 28% Somewhat
 14% Not much
 6% Not at all

Hospice is a program that provides care for terminally ill patients. Once enrolled in a Hospice program, patients are given services designed to relieve pain and make them as comfortable as possible during the last six months of life. Hospice services can be provided in a person's home, their hospital room, long-term care or in a separate hospice facility. The Hospice staff works to address the medical, nursing, emotional, social, financial, and spiritual needs of their patients and families.

16. If you were terminally ill and could choose where to die, where would you MOST want to be?
Check ONE answer only.

- | | | | |
|-----|--------------------------------|----|----------------------------------------------------------------------------------|
| 80% | In your own home | 1% | In a nursing home |
| 2% | In an assisted living facility | 6% | In a residential hospice (hospice services provided by a hospice owned facility) |
| 5% | In a hospital | 4% | Other : _____ |

17. Have you heard of hospice services?

- 4% I have never heard of hospice service. **IF NEVER, SKIP TO QUESTION 21**
44% I have heard a little about hospice services.
52% I have heard a lot about hospice services.

18. How did you learn about hospice services? Check ALL that apply.

- | | | | |
|-----|-------------------------------------------|-----|---------------------------------------------------|
| 66% | I know someone who used hospice services. | 18% | I heard from a health care professional. |
| 6% | I have used hospice services myself. | 32% | I read literature/newspaper/TV/radio/other media. |
| 2% | I am/was a hospice volunteer. | 41% | I heard from others. |

19. Would you consider using hospice support?

- 78% Yes
4% No **————→ IF NO, SKIP TO QUESTION 21**
14% Don't know/not sure

20. Where would you want to receive hospice support? Check ALL that apply.

- | | | | |
|-----|------------------------|-----|---------------------------------------------------|
| 19% | In a hospice residence | 19% | In a residential facility such as assisted living |
| 15% | In a hospital | 86% | In my own home |
| 10% | In a nursing home | | |

21. Are you aware that Medicare and Medicaid pay for hospice services?

- 43% Yes
40% No
17% Not sure

22. Below are some statements related to pain near the end of life. How strongly do you agree or disagree with each statement?

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Not sure
a. I want information about options for managing my pain.	83%	15%	1%	0%	1%
b. I would take pain medicine to manage my pain.	75%	21%	1%	0%	1%
c. I would only take pain medicines when the pain is severe.	44%	38%	9%	6%	2%
d. I am afraid I will become addicted to the pain medicines over time.	12%	31%	25%	26%	5%
e. I would take the lowest amount of medicine possible to save larger doses for later when the pain is worse.	47%	33%	10%	5%	4%
f. I am afraid I would be given too much pain medicine.	9%	28%	32%	23%	7%
g. I am worried pain medication will make me confused, “out of it” or lose consciousness.	14%	41%	26%	12%	7%

Support from Others

23. When people are near the end of life, they may need support from others. Which of the following types of support do you expect to need when near the end of your life, and who should provide it to you?

a. Listen when I talk

96% Yes
2% No



If YES, who should provide this type of support?
Check ALL that apply.

79%	Spouse/partner	5%	Community organizations
90%	Children and other family	51%	Health providers
38%	Paid caregivers	9%	Work associates
45%	Friends/neighbors	36%	Faith community

b. Provide transportation

92% Yes
3% No



If YES, who should provide this type of support?
Check ALL that apply.

76%	Spouse/partner	18%	Community organizations
84%	Children and other family	17%	Health providers
37%	Paid caregivers	3%	Work associates

		38%	Friends/neighbors	26%	Faith community
c. Help with chores					
92% Yes	→	If YES, who should provide this type of support? Check ALL that apply.			
4% No		72%	Spouse/partner	11%	Community organizations
		81%	Children and other family	11%	Health providers
		41%	Paid caregivers	2%	Work associates
		34%	Friends/neighbors	24%	Faith community
d. Do fun things with me					
87% Yes		If YES, who should provide this type of support? Check ALL that apply.			
8% No		74%	Spouse/partner	7%	Community organizations
		84%	Children and other family	4%	Health providers
		10%	Paid caregivers	6%	Work associates
		54%	Friends/neighbors	25%	Faith community
e. Know what I want when I die					
94% Yes	→	If YES, who should provide this type of support? Check ALL that apply.			
3% No		78%	Spouse/partner	2%	Community organizations
		89%	Children and other family	25%	Health providers
		17%	Paid caregivers	3%	Work associates
		27%	Friends/neighbors	25%	Faith community
f. Help care for other family members					
84% Yes		If YES, who should provide this type of support? Check ALL that apply.			
9% No		61%	Spouse/partner	9%	Community organizations
		77%	Children and other family	13%	Health providers
		18%	Paid caregivers	3%	Work associates
		38%	Friends/neighbors	30%	Faith community
g. Encourage me when I am down					
90% Yes		If YES, who should provide this type of support? Check ALL that apply.			
5% No		76%	Spouse/partner	7%	Community organizations
		86%	Children and other family	24%	Health providers
		21%	Paid caregivers	9%	Work associates
		57%	Friends/neighbors	41%	Faith community
h. Know about my illness					
91% Yes	→	If YES, who should provide this type of support? Check ALL that apply.			
3% No		78%	Spouse/partner	5%	Community organizations
		89%	Children and other family	48%	Health providers
		37%	Paid caregivers	11%	Work associates
		46%	Friends/neighbors	35%	Faith community

About You

The following questions are for classification purposes only and will be kept entirely confidential.

24. In general, how would you rate your own health right now?

18%	Excellent health	14%	Fair health
33%	Very good health	3%	Poor health
31%	Good health		

25. Do you have a serious chronic illness? 18% Yes 79% No

26. Are you currently covered by any health care insurance or program including insurance through work/retirement, the military, Medicare, Medicaid or some other government program?

90% Yes
9% No
1% Not sure

27. In the last 12 months, about how much did you spend *each month* out of your own pocket for insurance and doctor visits?

30%	Less than \$50 per month	6%	\$500 to less than \$1,000 per month
34%	\$50 to less than \$200 per month	2%	\$1,000 or more per month
23%	\$200 to less than \$500 per month	3%	Not sure

28. In the last 12 months, about how much did you spend *each month* out of your own pocket for prescription drugs?

56%	Less than \$50 per month	2%	\$500 to less than \$1,000 per month
31%	\$50 to less than \$200 per month	0%	\$1,000 or more per month
9%	\$200 to less than \$500 per month	1%	Not sure

29. Does any *other* member of your household have a serious chronic illness?

18% Yes **→** If yes, are you incurring costs for: *Check ALL that apply.*

2 %	Caregivers or home health aides
15 %	Medicines
12 %	Insurance
6 %	Transportation and/or parking for appointments
2 %	Lost wages for missing time at your work

79% No

30. Who would you ask to find out whether end-of-life care services are covered by insurance, Medicare, Medicaid? Check ALL that apply.

I would contact:

14% SHIBA - Senior Health Insurance
Benefit Advisors Program
18% Area Agency on Aging
9% Local home care agency
11% Local senior center/council on aging
51% My doctor
65% My health plan
56% Medicare
30% Medicaid

16% My friends/neighbors
22% My relatives
7% Community organizations
9% Social worker
8% Faith community
5% Work associates
15% My employer
10% 211 Idaho CareLine

31. Are you...? 42% Male 57% Female

32. What was your age at your last birthday?

Lowest through 44 - 18%	55 through 64 - 24%	75 through 84 - 10%
45 through 54 - 26%	65 through 74 - 18%	85 through Highest - 3%

33. Do you live alone? 18%Yes 80% No

34. What is your current marital status?

3% Single, never married	1% Separated
72% Married	10% Divorced
3% Living with a partner	10% Widowed

35. What is the highest level of education that you completed?

4% Less than high school	18% College graduate (4 years)
20% High school graduate or equivalent	12% Post-graduate or professional degree
46% Some college or technical training beyond high school	

36. Which of the following best describes your current employment status?

44% Employed or self-employed <u>full-time</u>	9% Other, such as homemaker
15% Employed or self-employed <u>part-time</u>	1% Unemployed and looking for work
30% Retired and not working	

37. Are you Hispanic or Latino? 4% Yes 95% No

38. Which one or more of the following would you say is your race? Check ALL that apply

94.4% White	0.3% Don't know/not sure
0.2% Black or African American	1.2% Other
0.3% Asian	1.1% Refused
2.4% American Indian or Alaskan Native	

39. In what language do you prefer to read or discuss information related to death and dying?

99% English
0.3% Spanish
0.3% AllOther

French
Japanese
Serbocroatian

Portuguese
Vietnamese
German

40. What was your annual household income before taxes in 2005?

5%	Less than \$10,000	12%	\$40,000 to under \$50,000
10%	\$10,000 to under \$20,000	9%	\$50,000 to under \$60,000
15%	\$20,000 to under \$30,000	10%	\$60,000 to under \$75,000
15%	\$30,000 to under \$40,000	19%	\$75,000 or more

41. Are you a member of AARP? 34% Yes 66% No

42. Are you a United States Veteran? 20% Yes 79% No

43. Are you affiliated with an organized faith community?

62% Yes If so, which denomination? 36% No

44. Have you visited the web site created by the Idaho statewide end-of-life coalition – A Better Way Coalition – to access a living will or other information about the end of life care and care giving at www.abetterwaycoalition.org? 1% Yes 98% No

45. What is your 5-digit zip code? (WRITE IN YOUR ZIP CODE) ____ ____ ____ ____ ____

A Better Way Coalition: Life on Our Own Terms is all about promoting compassionate end-of-life care in Idaho. We are a statewide end-of-life coalition providing knowledge, tools, and mechanisms for palliative end-of-life care. The whole person - body, mind, and spirit, heart and soul is the focus of our work. We promote advance care planning and provide a wealth of information for the public and professionals on our website. You can download Idaho's Advance Directive (living will and durable power of attorney for health care) at no cost on our website in both English and Spanish. A wallet card is also available. If you would like more information visit our website, <http://www.abetterwaycoalition.org>, or contact the A Better Way Coalition at 5572 N. Turret Way, Boise, Idaho 83703.

The mission of the *Center for the Study of Aging* at Boise State University is to promote the well being of Idaho's growing population of older citizens. For more information visit us at <http://aging.boisestate.edu/>

Thank you for completing the survey!

A Better Way Coalition

LIFE ON OUR OWN TERMS

February 22, 2006

Dear

You have been selected to receive this survey from A Better Way Coalition (an Idaho statewide end-of-life coalition), and the Boise State University Center for the Study of Aging. The survey is part of our effort to identify ways to improve quality of life at the end of life for people in Idaho. It should take about 20 minutes to complete.

You are part of a small group of people 35 years and older in Idaho that are being asked for their opinion on end-of-life issues. Answering this survey gives you a chance to tell us about your values, priorities and concerns. We want to know how you feel, what you know and think about the choices available during the last days of life.

This survey has been administered in several other states and numerous communities around the country. The results have been used to develop community and statewide programs addressing issues such as pain management, access to services and family support at the end of life. Information from the Idaho survey will make it possible to tailor programs to specific needs in Idaho and more effectively promote compassionate end-of-life care.

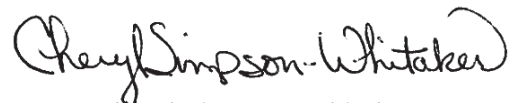
Please complete this survey and return it in the pre-paid envelope by March 15, 2006. If you choose to return the enclosed green card along with your completed survey, your name will be entered in a drawing for 1 of 5 \$100 prizes. This card will be separated from the survey upon receipt and will be destroyed after the drawing on March 22, 2006. All survey responses will be kept completely confidential and no individual responses will be reported.

If you have any comments or questions about this survey, please contact Dr. Totten at (208) 426-5802, or the Institutional Review Board at Boise State University, Office of Research Administration, 1910 University Drive., Boise, ID 83725-1135 or (208) 426-1574.

We thank you for your time and appreciate your assistance with this important project.



Annette Totten, MPA, PhD
Director, Center for the Study of Aging
<http://aging.boisestate.edu/>



Cheryl Simpson-Whitaker, MSW
Executive Director, A Better Way Coalition
<http://www.abetterwaycoalition.org/>

Project Sponsors

AARP Idaho,
First Choice Home Health and Hospice, Four Rivers Home Health and Hospice,
Hospice of North Idaho, Inc., Hospice of the Wood River Valley,
Idaho Chapter National Association of Social Workers,
Idaho Health Care Association, Idaho State Hospice Organization,
Life's Doors Hospice, Magic Valley Regional Medical Center,
Sisson & Sisson - the Elder and Disability Law Firm,
Saint Alphonsus Regional Medical Center,
The Interfaith Alliance of Idaho,
Qualis Health

Live Life On Your Own Terms

Within the next few days, you will receive an important survey from A Better Way Coalition and the Boise State University's Center for the Study of Aging. This survey is part of our effort to identify ways to improve the quality of the end of life. You are one of a small group of people over the age of 35 in Idaho we are asking about their opinions and preferences.

- The survey will take only a short time to complete
- All survey responses will be kept completely confidential
- Respondents will be entered in a drawing for \$100

**We would appreciate your response and we
thank you in advance for your help.**

Cheryl Simpson-Whitaker

Executive Director

A Better Way Coalition:

Life on our own terms

www.abetterwaycoalition.org

* * *

Annette Totten

Director

Center for the Study of Aging

Boise State University

aging.boisestate.edu

**Please enter me in the drawing for
\$100.00!!**

Thank you for taking time to complete the End-Of-Life Survey.
Please provide the following information to enter the drawing.
(Please print)

Name: _____

Mailing Address: _____

Phone Number: _____

*Your personal information will be kept confidential and will be used only to select the winners. This card will be separated from the survey upon receipt and destroyed after the winners are identified.

Colophon

Designed by Jeremy Speer
under guidance from the
authors and produced in
Quark Xpress 7.01 on a
MacBookPro laptop.

The body is set in Janson,
sidebars, tables, and legends
are set in Tahoma, and all
accents including the title use
Emigre's Matrix.

All charts were reproduced
from the original survey data
in Apple Computer's Keynote
presentation software,
exported as images, and
post-processed in Adobe
Photoshop.

The map showing response
distribution was produced at
The Center for the Study of
Aging from actual response
data.

Printed at Table Rock Print-
ing, Boise, Idaho on an HP
Indigo digital press.

