Nebraska End of Life Survey Report

Thoughts of Nebraskans about
living at the end of life
—and implications for those
working to improve end of life care
and conditions for all Nebraskans

January, 2004

Nebraska Coalition for Compassionate Care

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Nebraska Coalition for
Compassionate Care
www.nebrccc.org

Sponsoring Organizations

The Nebraska Coalition for Compassionate Care (NCCC) formed in 1997 to improve Nebraska end of life conditions so that no Nebraskan need ever feel compelled by physical pain, loneliness, neglect, or other factors to artificially end their lives. NCCC sponsors an annual conference, publishes the Compassionate Care Journal, maintains a web site at www.nebrccc.org, and has created the 118-page Educational Guide on End-of-Life Care Law & Public Policy in Nebraska. NCCC and NHPCA (below) are partners in a Quality of Life at the End of Life Community Engagement Campaign, of which this survey is a part.

The Nebraska Hospice and Palliative Care Association (NHPCA), whose members include all 29 hospice programs and both hospice residential facilities in Nebraska, champions the highest quality end of life care across Nebraska by providing professional education, pursuing community engagement activities, addressing legal and regulatory barriers, and entering into collaborative relationships with other organizations concerned about end of life issues. A contact list of Nebraska's hospice programs can be found at www.nebrccc.org. NHPCA maintains an automated hospice information line at 800-967-7288.

The Robert Wood Johnson Foundation, the world's largest foundation focused on health care issues, has made end of life care a priority for several years. Principal sponsor for the national end of life coalition now known as Last Acts Partnership, the Foundation has funded the Rallying Points program of Last Acts to support initiatives of state and local end of life coalitions, including this Nebraska Survey.

Acknowledgements

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The principal researcher for this study was Kaye Norris, PhD, of the Life's End Institute of Missoula, Montana, a national leader in end of life research and innovative end of life programming. Jennifer Eurek of Grand Island's Saint Francis Medical Center and the Grand Island Coalition for End of Life Care chaired the Nebraska Survey Task Force. Task Force members included Cathy Brockmeier with Saint Francis Medical Center in Grand Island; Linda Todd and Sally Smith with Hospice of Siouxland in Sioux City; Phyllis Heimann and Sister Mary Beth Prinz with Saint Francis Memorial Hospital in West Point, Greg Schleppenbach with NCCC; and Jonathan Krutz, executive director of both NCCC and NHPCA and principal author of this survey report. Others who assisted include Bill Brennan with Saint Francis Medical Center and the Grand Island Coalition for End of Life Care, Denise McNitt and Bonnie Brown with Alegent Health Systems, Heather Leschinsky with the Lincoln LIFE Office and the Lincoln End of Life Coalition, September Stone with the Nebraska Health Care Association, Aloha Schmid with Tabitha Health Care Services, LaDonna VanEngen with Saint Elizabeth Regional Medical Center, and Barb Nitzche with Hospice of Siouxland.

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Definitions

Hospice services involve an interdisciplinary team of a doctor, nurse, social worker, chaplain (if desired), various therapists (as needed), and volunteers. Paid by Medicare and many private insurance carriers, hospice helps families and the health care system know and respect the wishes of the terminally ill. Available wherever a dying person calls home—including assisted living and nursing facilities and hospitals—hospice assesses and addresses physical, social, spiritual and psychological issues to improve the quality of life of those near the end of life. While hospice does not serve as caregiver for a terminally ill person, hospice is available on call 24/7 to address and assist with needs and issues whenever they arise. Hospice supports both the dying person and his/her family or other caregivers with practical expertise on pain and symptom management, living arrangements, identifying and meeting end of life wishes, the dying process and issues to expect, end of life financial considerations, relationship and spiritual issues, and access to respite care and other resources. Hospice also provides bereavement services for up to a year after the death of a loved one.

Palliative Care means comfort care. It is an extension of the hospice philosophy for those with chronic but not terminal conditions. Palliative care goes beyond palliative medicine—which seeks to provide comfort for the physical symptoms of a person's condition(s)—to identify and address broader issues of how an individual's quality of life is being impacted by their medical condition(s).

I. Background and Introduction

Roughly ten percent of American deaths happen unexpectedly. The rest of us will see the end coming. But we may not be prepared—and we may not be in control.

Anecdotally we know that too often the end of life approaches with pain, with an erosion of personal dignity, with family in-fighting over care decisions made in crisis situations, with wishes disregarded, with difficult adjustments to deteriorating physical and mental abilities, with family members carrying a heavy load, with family tensions over assets and debts, with relationships and spiritual issues unaddressed, and with loneliness in unfamiliar surroundings. We know, too, that our health care system, so effective at healing and curing, is not designed to address many of these critical issues for dying Nebraskans who end up there by default as they pass beyond healing and beyond cure.

"Seventy percent of Americans want to die at home, free from pain, surrounded by family and friends; 70 percent will die in an institution, in pain, without family and friends," said Drew Edmonson, president of the National Association of Attorneys General, at the November, 2002, release of Means to a Better End: A Report on Dying in America Today. In that report, available on-line at www.lastacts.org, Nebraska received the following grades:

- "A" for having in place good policies to support appropriate pain control at the end of life,
- "C" because nearly 10 percent of elderly patients spend a week or more in intensive care in their last six months of life,
- "C" because 37 percent of nursing home residents report persistent pain,
- "D" for having only 19 percent of Nebraskans die at home,
- "D" for having only 24 percent of Nebraska hospitals report having a pain management program (this percentage is rising),
- "D" because only 20 percent of deaths use hospice services (now over one third),
- "D" because less than 1 percent of physicians and nurses are certified in palliative care, and
- "D" because the state does not have strong policies in place to support good advance care planning.

There is work to be done to improve end of life care and conditions in Nebraska.

Many activities are underway. Some have been evolving over decades, such as the hospice movement, which has developed specific programs and expertise to meet the unique physical, emotional, spiritual, and social needs of end-of-life patients and their families, and now reaches nearly one million dying Americans each year and over one third of those dying in Nebraska. Other activities are just now emerging, like the new initiative for improved end of life education in nursing facilities recently announced by the Nebraska Medical Directors Association, the Nebraska Health Care Association, and the Nebraska Hospice and Palliative Care Association. Or the recent formation of local end of life coalitions in communities across the state like West Point, Grand Island, Lincoln, Cass County, Custer County, Omaha, York, and North Platte, and others.

The Nebraska Coalition for Compassionate Care conducted the Nebraska End of Life Survey to find out Nebraskan's views on end of life issues, to identify baseline measures for efforts to improve end of life care and conditions in Nebraska, and to help those involved in such efforts to focus their activities and set appropriate priorities.

To better understand how Nebraskans deal with end of life issues, both privately and within their communities, this survey explores Nebraskans'
- Talking and thinking about death and dying,
- Perceptions of pain, spiritual issues, and end of life fears,
- Wishes and preparation for death, and
- Need for support and awareness of resources.

The results of the survey indicate that many Nebraskans have thought about and talked to their immediate family about end of life issues. However, fewer have taken steps to ensure that their end of life concerns and desires are addressed. Only one third have completed an advance directive, and only 39 percent have talked about their end of life wishes with someone in addition to a family member.

While many say they will want their health providers or faith community to listen and understand when they near the end of life, few have talked about their wishes for care with their physicians or clergy. Many report that they are afraid of dying painfully but, at the same time, many also indicate that they are afraid of over-medication and/or addiction to pain medicines. Half have heard little or nothing about hospice though most are concerned about being a burden to their families. Two thirds are also concerned about their money running out but less than one fifth know that Medicare pays for hospice. Few are aware of or expect help from community organizations.

In summary, the Nebraska End of Life Survey shows that Nebraskans are willing to think and talk about end of life issues, but they need some help to start conversations, to be aware of the resources available, and to understand end of life care issues.

This report first shares highlights of the survey responses, then discusses steps suggested by the survey results, and finally provides a more detailed look at the responses. The methodology of the research and a set of bar graphs with responses to the complete set the survey questions are each included for reference as an appendix.

To find out about and participate in current efforts to improve end of life care and conditions across Nebraska, contact the Nebraska Coalition for Compassionate Care at www.nebrccc.org, email NebraskaHospice@aol.com or call 402/540-3128.

II. Significant Results

1. <u>Talking and thinking about death and dying</u>

- Ninety percent of Nebraskans report being at least somewhat comfortable talking about death. Ninety-one percent would want to know if they would likely have six months or less to live.

- Half indicate they have not talked about their own wishes for end of life care with anyone other than family; more than two thirds (three fourths of those over age 65) would want their spouse or family members to initiate such a conversation.

- Only 5 percent overall and only 11 percent of those over age 65 report that they have talked with their primary physician about their wishes for end of life care; 35 percent (40 percent over age 65) would want their physician to initiate such a conversation; 71 percent would trust their physician to provide end of life information

- At least eight in ten Nebraskans rate the following as <u>very</u> important when dealing with their own dying or thinking about dying:
    - Honest answers from doctors (95 percent)
    - Understanding treatment options (89 percent)
    - Having things settled with family (86 percent)
    - Being at peace spiritually (85 percent)
    - Not being a burden to loved ones (83 percent)
    - Knowing medicines are available (82 percent)

2. <u>Perceptions of pain, spiritual issues, and end of life fears</u>

- While 98 percent say being free from pain is somewhat or very important, three-quarters say they would only take pain medicine when the pain is severe and that they would take the lowest amount of medicine possible, saving larger doses for later when the pain is worse.

- One-third fear becoming addicted to pain medicine

- Nearly half fear that their doctor will not believe they are in pain

- Eighty-eight percent of Nebraskans rate themselves as at least somewhat spiritual/religious; half attend religious services regularly, with higher percentages for women and those 65 and older.
    - In dealing with their own dying, 85 percent (90 percent of women) say it is <u>very</u> important to be at peace spiritually and 64 percent say it is <u>very</u>

    - important to have comfort from spiritual or religious persons. Even among those who rarely or never attend services, 60 percent feel it is at least somewhat important to receive comfort from spiritual or religious persons.
    - Only 4 percent overall and only 6 percent of those age 65 or older have spoken with clergy about their end of life wishes, yet 32 percent (40 percent over age 65) report wanting clergy to initiate a conversation on end of life issues and 50 percent say they would trust clergy to provide information on end of life issues.
    - Roughly one third look to faith communities to provide support of various kinds at the end of life, with women more likely than men to do so.

- Nebraskans are concerned about various end of life scenarios:
    - Eighty-four percent say that total physical dependency is worse than death, 72 percent say that not being able to communicate their wishes is worse than death, and 66 percent (73 percent of women) say that living with great pain is worse than death.
    - Eighty-one percent of Nebraskans fear dying in pain, 69 percent fear dying from a long illness, and 62 percent fear dying in a hospital, nursing home, or other institution
    - Ninety-nine percent say not being a burden to loved ones is important; 72 percent are concerned that they will be a burden to family and friends.

3. Wishes and preparation for death

- Two thirds would want to die at home; only 10 percent would want to die in a hospital, nursing home, or assisted living facility; 18 percent have no preference

- Two thirds (71 percent of women) would want to die in their sleep; 17 percent (24 percent of men) would want to die suddenly; only 1 percent would want to die from a long term illness

- Over 25 percent of Nebraskans say they are likely to avoid medical checkups for fear the doctor will find something serious.

- Although 96 percent of Nebraskans say it is important to be off machines that extend life, such as life support,
    - Only 30 percent overall and only 54 percent of those over age 65 have a health care power of attorney
    - Only 30 percent overall and only 52 percent of those over age 65 have a living will.
    - Sixty-six percent have neither a health care power of attorney nor a living will.

4. Need for support and awareness of resources

- When asked about support they expect to need near the end of their lives, Nebraskans report a variety of needs:
  - Over 90 percent expect to need someone to listen to them (97 percent), to know what they want when they die (95 percent), to help with chores (95 percent), to know about the illness (94 percent), to provide transportation (93 percent), and to encourage them when they are down (92 percent)
  - Over 80 percent expect to need someone to help with care for other family members (86 percent), to do fun things with them (85 percent), and to understand what they are going through (82 percent)

- Nearly all with children or a spouse/partner expect those family members to provide each type of support. Roughly half (56%) expect such support from other family members and slightly less (46%) expect it from friends and neighbors. Only 11 percent expect to get such support from community organizations, 28 percent from health providers, and 29 percent from faith communities.

- Half say they have heard little or nothing about hospice; just over half would want to hear more about hospice. Of those who have heard a lot about hospice
  - Three-quarters know someone who used hospice services
  - Eighty-three percent would want hospice themselves if they were dying
  - Sixty two percent do not know that Medicare pays for hospice services.

5. Nebraska - North Carolina Comparison

- One third of Nebraska survey takers were AARP members. In 2003, a similar survey was conducted among North Carolina AARP members. A comparison of the AARP member responses reveals overall similar results, with a few interesting differences:
  - Ninety-three percent of Nebraska AARP members but only 38 percent of North Carolina AARP members would want to know when they have six months or less to live
  - Twice as many Nebraskan AARP members are likely to read books or articles related to death or dying (88 percent to 41 percent)
  - Three times as many Nebraska AARP members are likely to avoid medical checkups for fear the doctor will find “something serious” (30 percent to 10 percent)
  - North Carolina AARP members are more likely to have completed an advance directive (health care power of attorney or living will): 55 percent in North Carolina compared with 34 percent in Nebraska
  - Twice as many Nebraskans (37 percent to 17 percent) have heard of hospice from a health care professional

III. Steps Suggested by the Results

Survey results suggest several areas in which specific activities could be initiated to improve the quality of life at the end of life for Nebraskans and their families.

1. Encourage end of life conversations and decision-making in advance

There is a huge disconnect when 96 percent of Nebraskans say they would not want artificial means to prolong their lives, yet only 34 percent have completed an advance directive—a health care power of attorney or living will—to make their wishes known.

Nebraskans (90 percent) are willing to talk about death. Eighty-two percent have talked about end of life issues with someone in their family (though very few have had such a conversation with their physician). But, as court cases from Nancy Cruzan in Missouri to Terri Schiavo in Florida illustrate, to ensure that wishes are both known and respected, they should be both* written and discussed with all family members. Such preparation for the end of life is the exception rather than the rule in Nebraska today.

Until end of life decision-making in advance becomes the norm, a majority of Nebraskans are at risk for receiving treatment that they do not want at the end of life, treatment that takes them out of the familiar and comfortable surroundings of their own homes (where two thirds would prefer to die), treatment that isolates them from families and friends, and treatment which often both increases pain and reduces personal dignity.

Organizations including AARP, Nebraska's Area Agencies on Aging and other branches of the Health and Human Services System, Nebraska's health care providers and nursing facilities, Nebraska's faith communities, Nebraska's VA System, Nebraska's local end of life coalitions, NCCC, and NHPCA are well positioned to encourage and support both the creation of advance directives and conversations about them within families. Programs and publicity to support such efforts should be encouraged.

2. Improve education on pain issues

A disconnect exists when 81 percent of Nebraskans say they fear dying in pain and 98 percent agree that being free from pain is important, yet three fourths say they would take only minimal pain medications and one third fear addiction to pain medications.

Experts say that 95 percent of pain is controllable and that addiction to pain medications at the end of life is extremely rare. Pain management expertise has been evolving rapidly with the advent of new medicines, new routes for the delivery of medicines, and better ways to minimize once-typical side effects like nausea and constipation. Yet, as of 1999, 37% of Nebraska nursing home residents were reported to experience persistent, severe pain, according to a Brown University study of Medicare data. And that's a good result: 48 other states had percentages even higher than Nebraska's.

The health care system has been making great strides to improve pain management. Hospitals have been embracing pain as the fifth vital sign. Nursing facilities have begun using pain scales as a quality of life indicator. The finding of this study that two thirds of Nebraskans say living with great pain would be worse than death provides additional impetus to improve pain education among health care professionals.

At the same time, public confidence in appropriate pain management approaches also needs to be bolstered so that those nearing the end of life will not limit their activities and quality of life because of pain that is controllable but that they are afraid to control.

3. Improve awareness and access to hospice and other resources

Nebraska's hospice professionals see daily what this survey reveals: Nebraskans want to die at home (96 percent); they do not want to die in pain (98 percent) or in an institution (62 percent); they do not want to be totally physically dependent (84 percent), or on machines that artificially extend their lives (96 percent), or a burden to their families (72 percent). The disconnect is that what people want is not what they get.

Hospice is the one service designed to be responsive to each person's wishes. Hospice provides a team of professionals to address the range of physical, emotional, spiritual, and social needs confronted at the end of life. For instance, hospice allows people to stay in their own homes when they so desire by helping families modify their homes to be livable for those with decreasing physical or mental abilities, by training caregivers to monitor signs and administer medications, and by providing 24/7 access to nursing expertise. This care results in a higher quality of life at the end of life. As a positive side effect, this care is also less demanding on the resources of the health care system. In particular, it minimizes hospitalizations of those who do not wish to be hospitalized.

But hospice is not reaching those who need it. Only one third of dying Nebraskans use hospice, and one third of that group receive hospice care only within their last seven days of life, when it is too late to realize the most significant benefits hospice offers.

"Why didn't we learn about hospice sooner?" is the single most common question asked by those under hospice care. And some populations in Nebraska do not have access to hospice at all. Residents of North Central Nebraska are not currently served by hospice. Nor, unlike those in nearly every other state, are Nebraska Medicaid recipients, although a Medicaid hospice benefit would both improve the quality of life of the recipients and result in financial savings to the state. (Significant work toward such a benefit has been accomplished in the past year and half by the Department of Health and Human Services, the Nebraska Health Care Association, NCCC, NHPCA, and others.)

This survey indicates that one half of Nebraskans know little or nothing about hospice and most do not know that hospice services are covered under Medicare—an important consideration for the two thirds who are concerned that their money won't last. Work toward greater hospice awareness, earlier hospice referrals, and making hospice available to those on Medicaid and those in North Central Nebraska would all help Nebraskans better meet their desires for the end of life as reflected in this survey.

Greater awareness of other resources would help, too. Although those at the end of life do not want to burden their families, they overwhelming expect family members to do fun things with them, to encourage them, to understand them, to listen, to help with chores, to help with transportation, and to help care for other family members.

Only twenty percent or less of Nebraskans expect this kind of help from community organizations. Yet, in addition to hospice services, resources are available through programs of Nebraska's Area Agencies on Aging, Nebraska's Respite Network, and others. Increasing awareness and use of these resources is critical to addressing the growing problems related to caregiver burnout in Nebraska and across the country.

4. Improve awareness of end of life issues among clergy and faith communities

Spiritual issues matter to Nebraskans. Overall, 89 percent of Nebraskans say that it is important to have comfort from religious or spiritual services or persons at the end of life and 97 percent say it is important to be at peace spiritually.

In trust, clergy rank second only to physicians with 50 percent of Nebraskans saying they would trust their clergy members to provide information on end of life issues. Nebraskans look to their faith communities for support at the end of life. Half look to faith communities for encouragement; one third look for listening, knowledge of the illness, understanding, and help with care for other family members. Women tend to look for such support slightly more than men.

A significant percentage (37 percent) of Nebraskans say they would want clergy to initiate conversations about end of life issues, yet only 4 percent have had such conversations with their clergy. Among those age 75 and older this disconnect is even clearer: 49 percent would want their clergy to initiate such a conversation, but only 2 percent have had such a conversation with their clergy.

5. Improve awareness and training in end of life issues among health care professionals and within health care systems

Results of a national survey published in the January, 2004, issue of the *Journal of the American Medical Association* illustrates the end of life care challenges facing America's health care professionals and health care systems.

"Nursing homes and hospitals, where most Americans spend their final days, regularly fail to treat dying patients with respect or provide needed emotional support," reported a *Boston Globe* summary of the report. "Nearly one-quarter of those dying in nursing homes didn't get relief for labored breathing, nearly one-third didn't get enough care for pain, and nearly 20 percent suffered because of the staff's incomplete knowledge of the patient's medical history."

The Nebraska survey provides critical information about Nebraskans that health care providers need to consider:

- 66 percent of Nebraskans think living in great pain is worse than death,
- 84 percent think total physical dependency on others is worse than death, and
- 72 percent think not being able to communicate wishes is worse than death

In addition:

- 47 percent fear that physicians will not believe they are in pain, and
- 28 percent are likely to avoid medical checkups for fear of finding something serious.

While 35 percent of Nebraskans say they would want their physicians to initiate a conversation with them about end of life issues, only 5 percent have actually had such a conversation with their doctor. At the same time, 88 percent want to know their treatment options, 71 percent would trust their physician to provide information on end of life issues, 91 percent would want to know if they had six months or less to live, 87 percent want health care professionals to visit their homes at the end of life, and 95 percent say that honest answers from their doctors would be <u>very</u> important.

While many end of life issues are not primarily health care related, a health care perspective tends to dominate end of life considerations. For this reason, more training is needed in Nebraska that focuses health care professionals on end of life issues, such as the American Medical Association's EPEC (Educating Physicians on End of Life Care) program—which the Geriatric Section of the University of Nebraska Medical Center is conducting in modules across the state—and the similar ELNEC (End of Life Nursing Education Consortium) course for nurses, as well as professional certification programs in hospice and palliative care. Enhancing key communication skills, including how to break bad news and how to set realistic treatment goals, would help clinicians as they work with patients near the end of life. Hospice rotations in training programs of physicians, nurses, social workers, and pharmacists would also be beneficial

Reflective of the national trend, palliative care programs are beginning to emerge in a number of Nebraska hospitals. Encouragement and support for these and for initiatives like the Nebraska Medical Directors Association, the Nebraska Health Care Association, and the Nebraska Hospice and Palliative Care Association's collaborative effort to provide end of life training for nursing facility staff is recommended.

IV. Detailed Findings

1. Talking and Thinking About Death

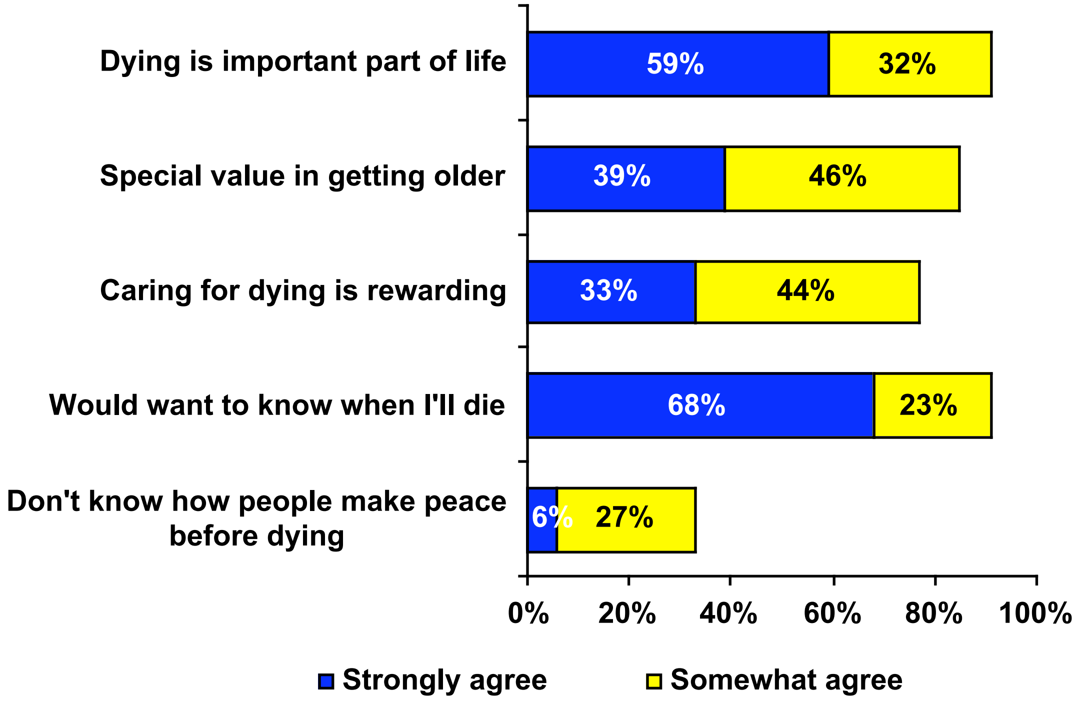
Most respondents report that during their childhood their families rarely (35 percent) or never (11 percent) talked about death and dying. About one-third says their families had such discussions occasionally (46 percent), while only eight percent had them often.

Nonetheless, most Nebraskans say they are at least somewhat comfortable talking about death (40 percent very comfortable and 50 percent somewhat comfortable), and most are at least somewhat likely to speak freely to loved ones about death and dying (34 percent very likely and 49 percent somewhat likely). Half are very comfortable thinking about life after death; 40 percent are somewhat comfortable.

At least 85 percent of Nebraskans agree that dying is an important part of life and that there is special value in getting old. Seventy-seven percent agree that caring for people who are dying is a rewarding experience, and 67 percent disagree with the statement that "I don't know how people make peace with themselves before dying."

Ninety-one percent of Nebraskans would want to know if they were likely to have six months or less to live.

Opinions on Dying

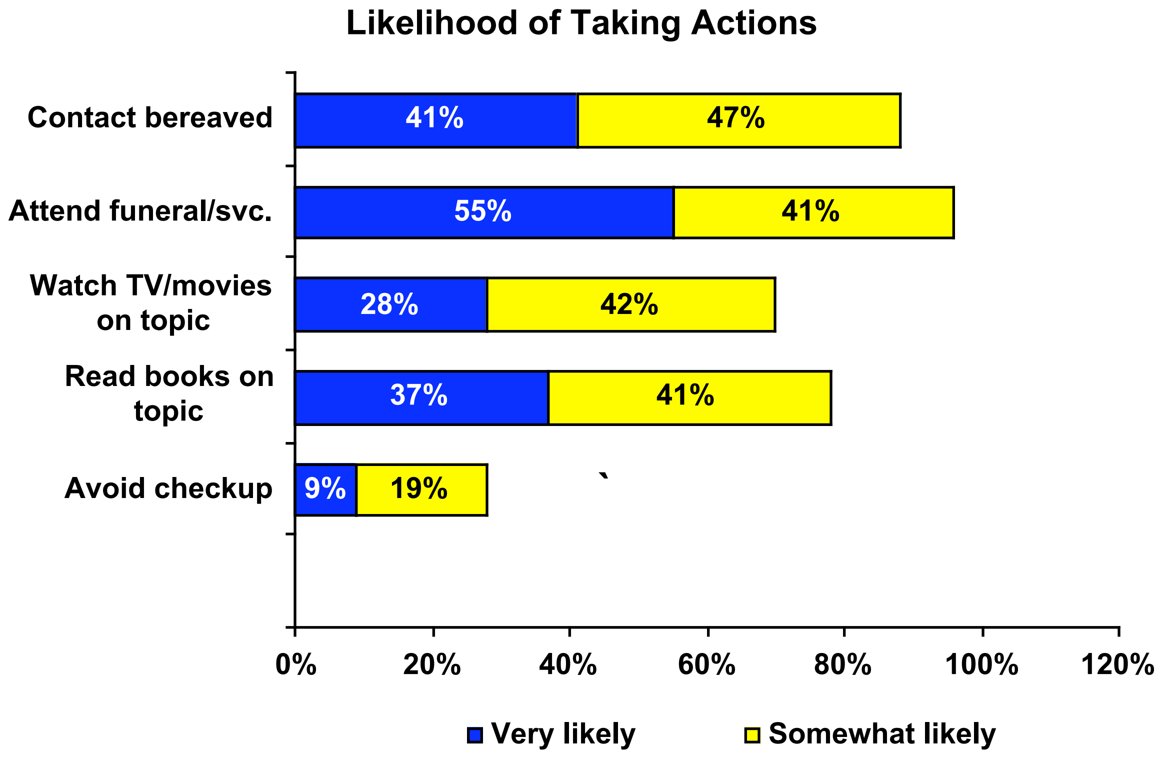


The survey explored the likelihood that Nebraskans would engage in a wide range of actions related to death and dying.

- When a death occurs, about nine out of ten Nebraskans say they are likely to attend funerals or memorial services (91 percent) or to visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing (88 percent).

- About three quarters are at least somewhat likely to watch a television program or movie dealing with the subject of death and dying (70 percent) or to read a book or article on the subject (78 percent).

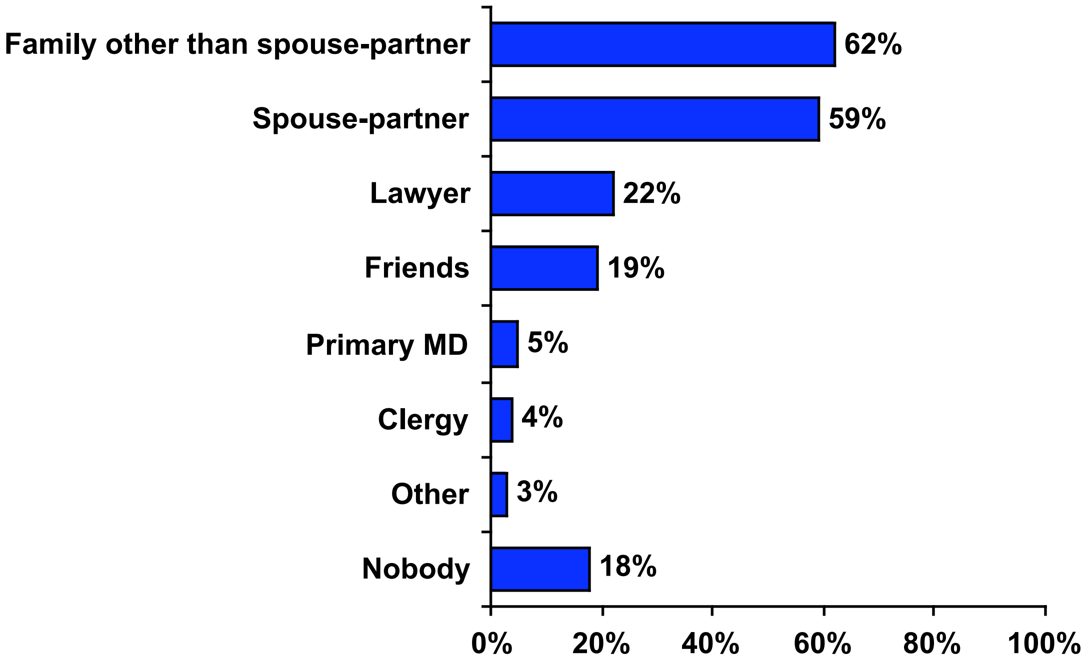
- Over a quarter say they are likely to avoid medical checkups because of fear that the doctor will find something serious (9 percent very likely and 19 percent somewhat likely).



Although 90 percent report being comfortable talking about death and dying, family members are the only people with whom many Nebraskans have spoken about their own end of life wishes.

Analysis of the responses shows that 40 percent have talked about end of life issues with someone outside of their family while another 43 percent have discussed such issues only with a spouse or other family member.

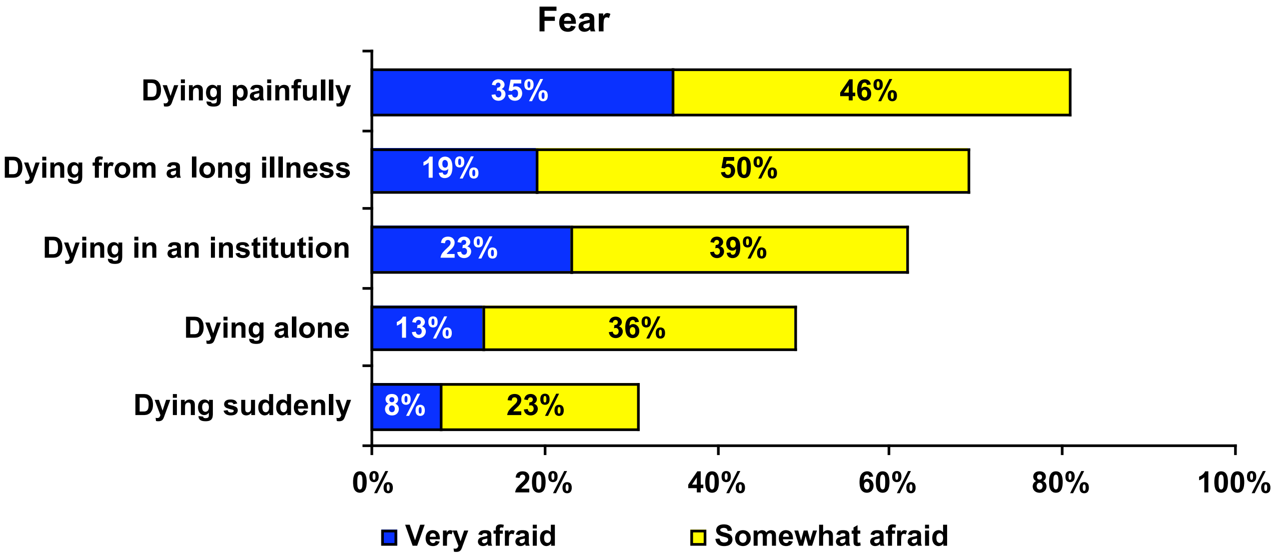
People Talked to about End of Life Wishes (multiple answers allowed)



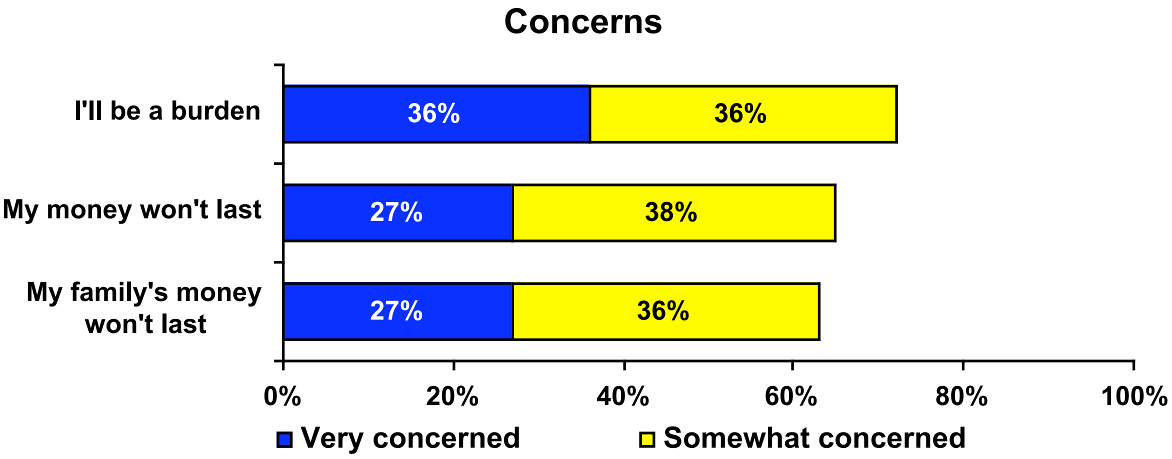
2. End of Life Concerns

Nebraskans were asked whether three potential health problems were worse than death itself. Eighty-four percent say total physical dependency on others, such as being in a coma, is worse than death, 72 percent indicate that not being able to communicate their wishes to family and friends is worse than death, and 66 percent say that living with great pain is worse. Only 7 percent said none of those problems was worse than death.

Indeed, when asked about fears related to death, a similar picture emerges. Eighty-one percent of Nebraskans fear dying painfully, 69 percent fear dying from a long-term illness, and 62 percent fear dying in an institution. In contrast, only 31 percent fear dying suddenly.



Nebraskans' concerns about the end of life are not limited to concerns about the process of dying. Nearly three quarters of Nebraskans are concerned about being a burden to family and friends and nearly two thirds are concerned about financial issues.



3. Pain Management

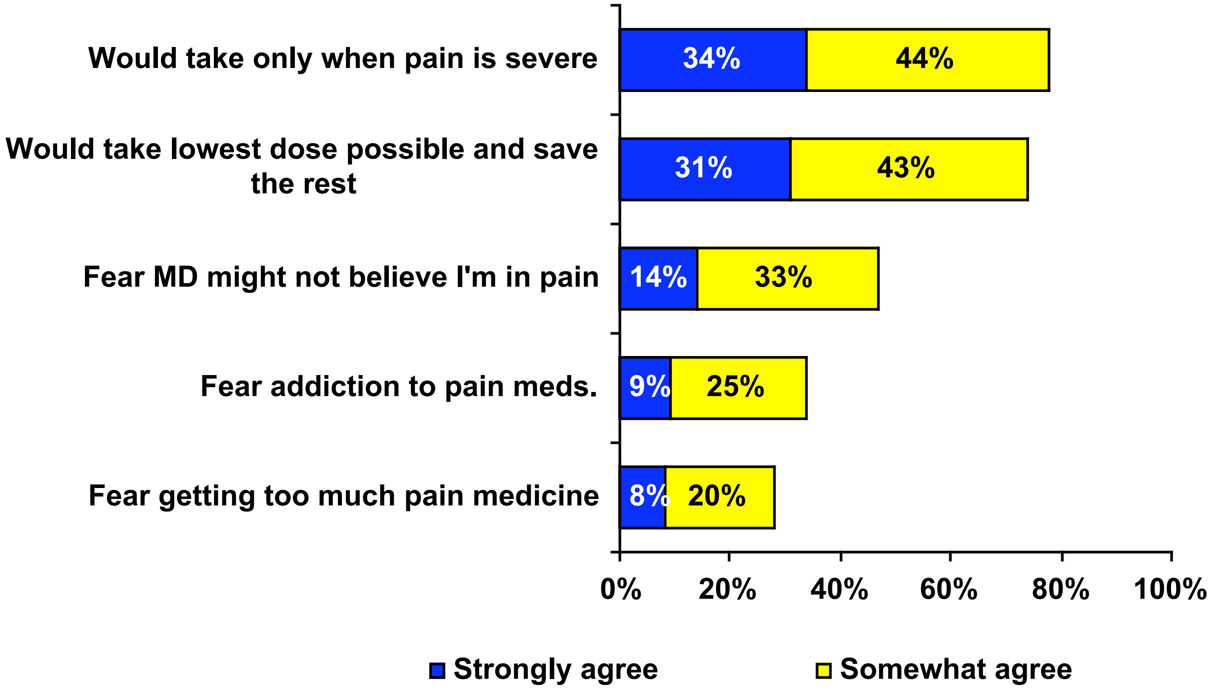
If they could choose how and where they would die, a majority of Nebraskans say they would prefer to die while sleeping (67 percent) and at home (59 percent). (To the related question of how important would "being able to stay in your own home" "when dealing with your own dying," 67 percent said very important and 29 percent said somewhat important.) The second most often selected option of "how" would be a sudden death (17 percent), and the second most often selected option for "where" would be a hospital (8 percent). Relatively few Nebraskans say they have no preference (12 percent as to how, and 18 percent as to where).

One of Nebraskans' biggest fears, as already noted, is that of dying painfully. However, many indicate that they might restrict their pain medications.

- Three in four say they would only take pain medication when the pain is severe. A similar number say they would take the least amount possible, saving larger doses for when pain worsens.

- Thirty-four percent of Nebraskans fears becoming addicted to pain medications.

Opinions on Pain Management



4. End of Life Needs

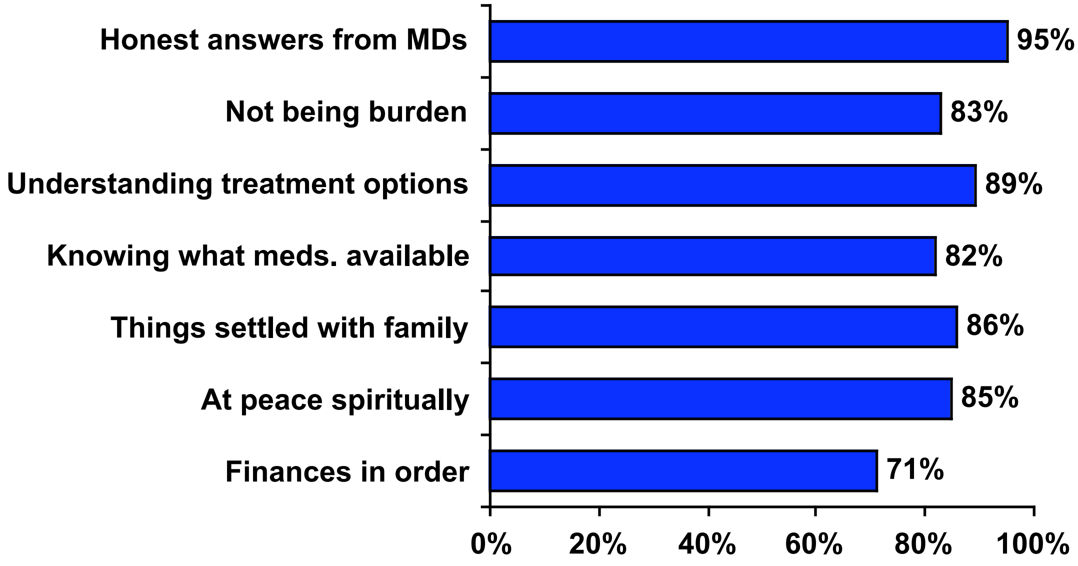
The survey asked Nebraskans to rate the importance of various aspects of their own dying.

- Several of the most important issues raised relate to the medical aspects of death, such as getting honest answers from their doctors, understanding options for treatment, and knowing about the available medicines.

- Also among key issues are family and finances: not being a burden, having things settled with the family, and getting finances in order.

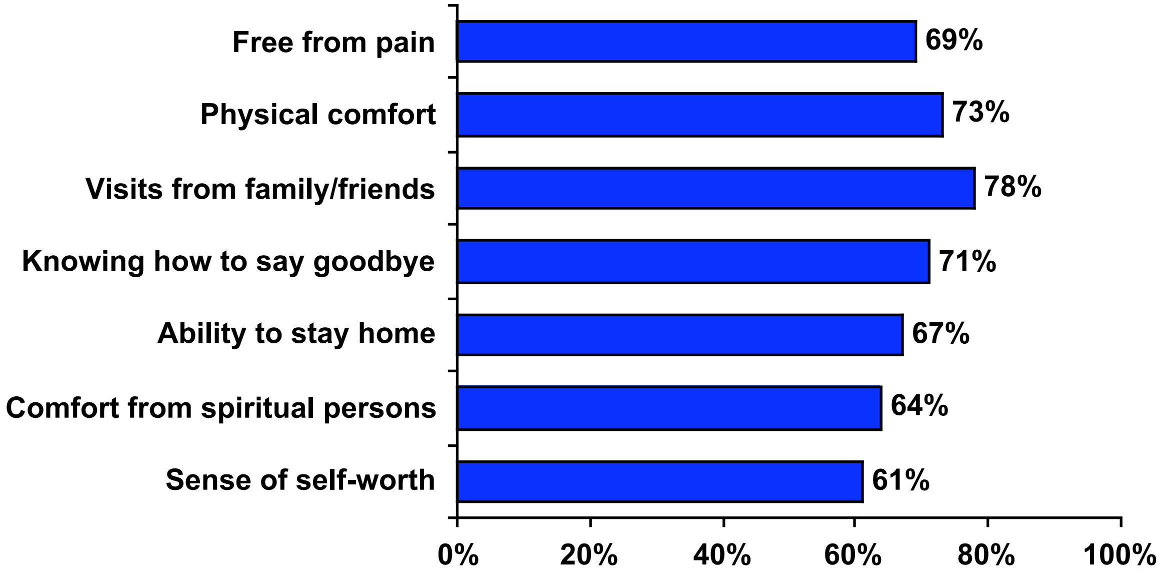
- Spiritual peace also is very important to a large majority of Nebraskans.

Very Important Aspects of Dealing With or Thinking about Dying



A second set of issues is also rated very important by a strong majority of Nebraskans. These include:

- Being free from pain and being physically comfortable.
- Having family and friends visit and knowing how to say goodbye.
- Being able to stay at home, getting comfort from religious/spiritual persons, and having a sense of self-worth.



Very Important Aspects of Dealing With or Thinking about Dying

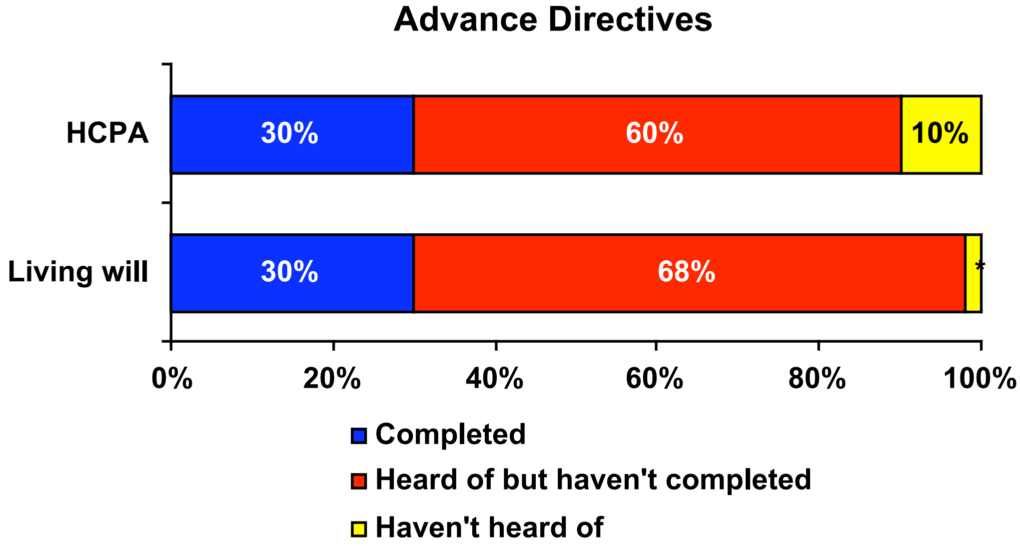
Other aspects of the end of life are at least somewhat important to a majority of Nebraskans; however, they are not rated 'very important' as frequently as the aspects just mentioned.

- Ninety-one percent indicate that it is at least somewhat important to give to others in time, gifts, or wisdom – 61 percent rate this very important.
- Eighty-seven percent say that having in-home visits from healthcare professionals would be important; 47 percent say very important.
- Eighty-two want to be able to fulfill personal goals and pleasures; almost half (48 percent) say this would be very important.
- The ability to review their life history with their family is important to 71 percent, with just over one-third (36 percent) rating it very important.

5. Advance Care Planning

As noted earlier, many Nebraskans have clear end of life wishes. For example, 72 percent say it is very important to be off machines that extend life, such as life support. But, many have not translated end of life wishes into action through advance directives.

- Thirty percent say they have completed a living will and the same proportion has completed a health care power of attorney (HCPA). Most who have completed one have completed both, but 66 percent of Nebraskans have completed neither.



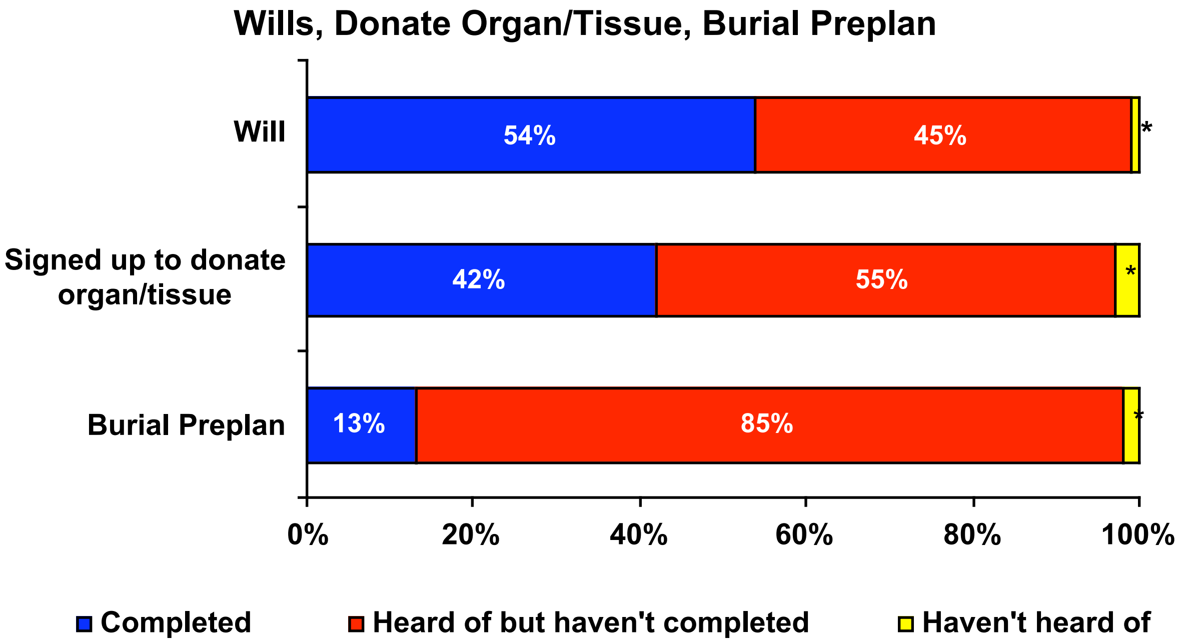
*** Less than 5 percent**

The survey also included other aspects of advance planning, such as having a will, registering to donate organs and tissue, and preplanning of funerals and purchasing of burial plans.

- Seventy-one percent of Nebraskans say wills are very important, yet only 54 percent say they have completed one.

- Forty-two percent of Nebraskans say they have signed up to donate organs/tissue for use by others in need of transplants.

- Seventy-nine percent say it will be very important to plan their own funeral, yet only 13 percent report having a funeral or burial preplan in which they plan or purchase in advance any goods or services.



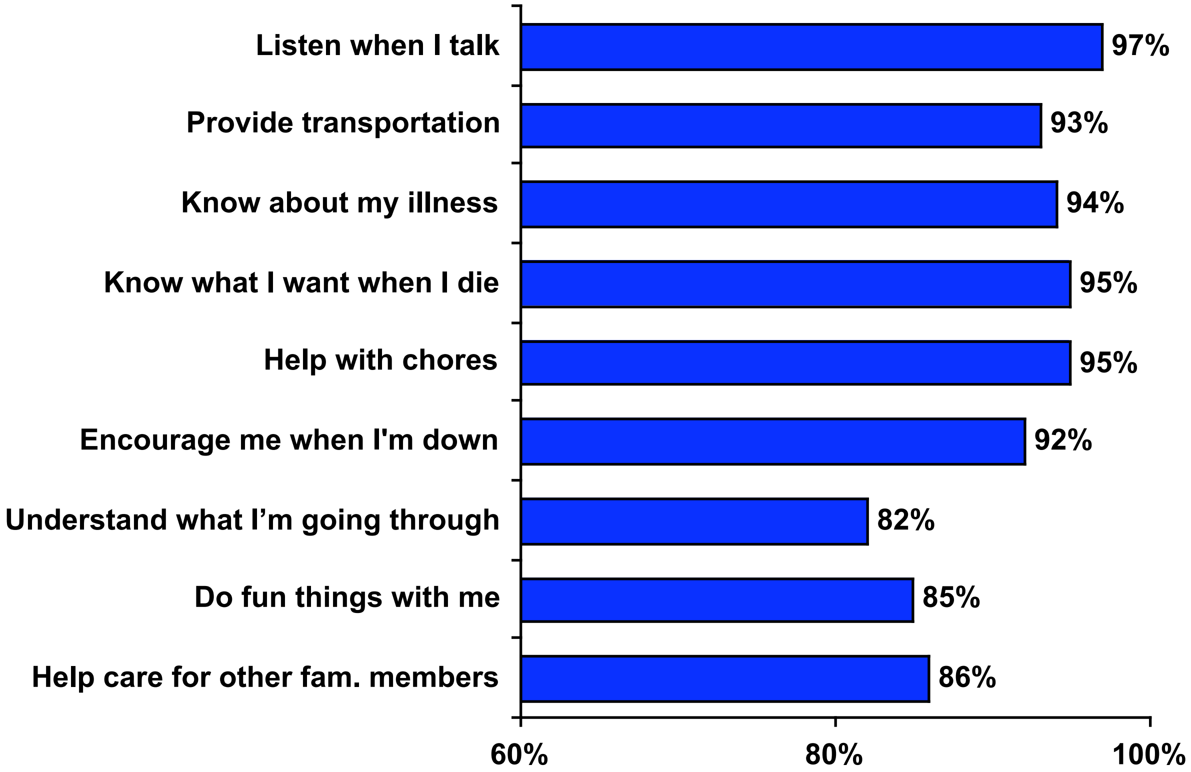
***Less than 5 percent**

6. Support from Others

The survey asked respondents which of nine types of support they expected to need near the end of their lives, ranging from helping with chores to encouragement to listening when they talk. Then, for each type of support, we asked Nebraskans who should be the "provider." The provider list included eight possibilities, again with a wide range, from family to community to faith organizations.

At least eight in ten Nebraskans expect to need each particular type of support: ranging from a "low" of 82 percent who expect to need someone to understand what they are going through to a "high" of 97 percent who expect to need someone to listen to them.

Support That Nebraskans Expect to Need Near End of Life



Some of the sources of support are seen as playing many different roles, while others are seen as more specialized:

- As expected, the vast majority of Nebraskans expect each type of support from their **immediate family**.
- Beyond this, Nebraskans typically expect most types of help from **friends/ neighbors** and **other family members**. Knowing what they want when they die and caring for other family members are more family-based than non-family-

based. Conversely, doing fun things with the dying person is expected somewhat more from friends and neighbors than from other family members.

- About one third say the **faith community** should support them through listening, “knowing about my illness,” understanding, and helping care for family; nearly half expect encouragement from their faith community.
- Approximately half of Nebraskans say that **health providers**’ roles are listening, understanding what the person is going through, and knowing about the illness.
- About 20 percent say **community organizations** should support them through transportation services and help with chores.
- Few expect any of these support activities from **work associates**.

Who Should Provide Various Types of Support

	Children	Spouse-partner	Other family	Friends/ neighbors	Faith cmty.	Health providers	Community orgs.	Work assoc.
Listen when I talk	78	77	55	44	36	49	5	9
Transportation	66	74	46	43	20	16	22	4
Know my illness	75	75	60	48	32	51	11	10
Know my desires when I die	78	76	50	24	23	18	3	4
Help with chores	68	71	47	42	16	16	19	2
Encourage me	76	72	64	61	47	34	9	11
Understand what I’m going through	70	69	54	45	34	47	10	8
Do fun things with me	82	76	60	65	20	5	8	7
Help care for my family	65	63	66	41	34	18	14	4

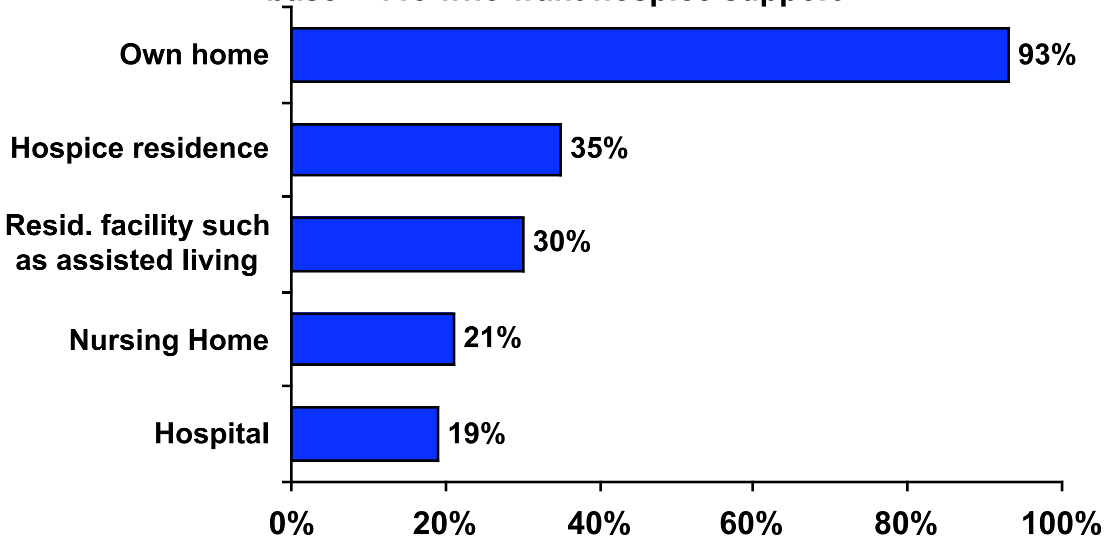
Note: The numbers for children and spouse/partner reflect nearly 100 percent of those respondents who indicated that they have children or have spouse/partners.

7. Hospice Services

Reported awareness of hospice services is mixed, with 51 percent indicating that they have heard a lot about hospice and 49 percent saying they have heard little or nothing about hospice.

- Only 17 percent are aware that Medicare pays for hospice services.
- Nebraskans who heard about hospice typically say they learned about it from someone who used hospice services (75 percent). Just over one third report that they heard about it from others (38 percent), heard about it from the media or literature (37 percent), or heard about it from a health care professional (35 percent); fewer mention other sources such as using hospice themselves (9 percent), or being hospice volunteers (5 percent). (Multiple responses were allowed.)
- Eighty-three percent of Nebraskans who have heard of hospice report that they would want hospice support if they were dying. When asked where they would want to receive the hospice support, 93 indicate that they would want it in their own home.
- Fifty-four percent say they would be interested in hearing more about hospice services, and an additional 13 percent say they are not sure if they would. Thirty-two percent express a lack of interest in more information.

Where They Would Want Hospice Support
(multiple answers allowed)
base = 113 who want hospice support

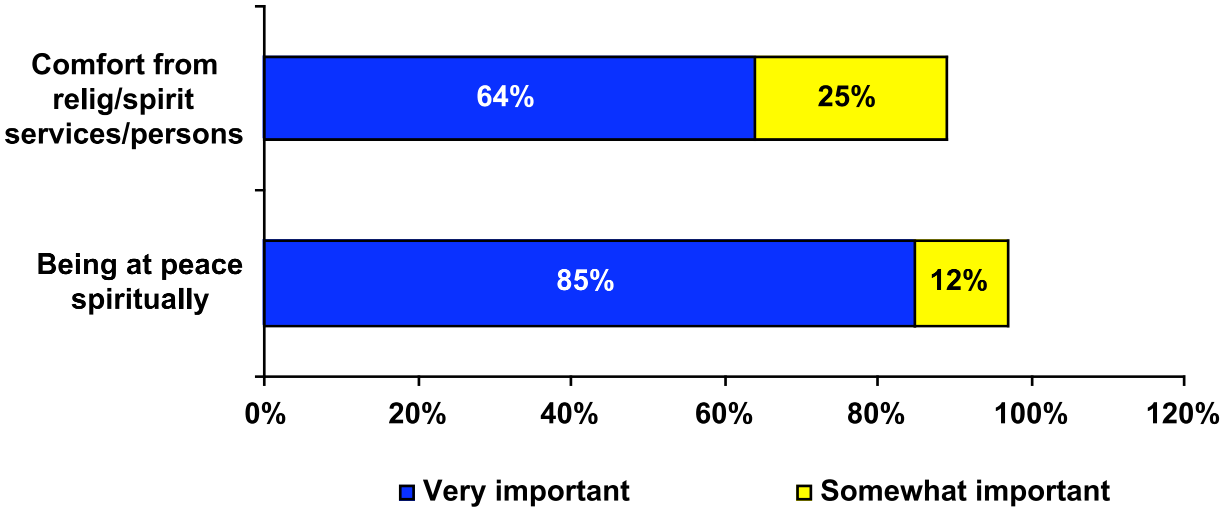


8. Spirituality/Religiosity

Nebraskans report a high degree of spirituality/religiosity. One in three rate themselves as very religious/spiritual, and another 55 percent say they are somewhat religious/spiritual.

It is not surprising then that 85 percent say it is very important to be at peace spiritually when you think about dying. Furthermore, 62 percent think that comfort from religious/spiritual services or persons would be very important when dealing with their own dying.

Importance of Spiritual/Religious Peace and Comfort



Nevertheless, only six percent of Nebraskans have talked with clergy about their wishes for care at the end of their life.

Appendix A: Methodology

This survey is based on a similar survey conducted among North Carolina AARP members in 2002 and on an earlier survey developed by the Missoula Demonstration Project (now the Life's End Institute (LEI)) and conducted in Missoula as part of LEI's community profile of end-of-life experience and care (www.lifes-end.org). The Nebraska End of Life Survey is the first such survey conducted with a random sample of adults across an entire state. Responses to each question asked are included in bar graph form for reference as an appendix in this report.

A random sample of 3,002 Nebraska households in which at least one adult was twenty-five years or older was obtained from ACUDATA America, a company that has access to all of the most credible lists and data for mail, telephone sales, permission-based email and Web marketing campaigns. Rural, urban, and Hall County, households were sampled separately to obtain enough participants in each geographic location to conduct sub-group analyses. From the original sample (3,002), 2,402 contacts were randomly selected and mailed surveys. Extra contacts were obtained for the purpose of further mailings if necessary. Three-hundred-four residents responded. However, four surveys were incomplete and not analyzed, resulting in an N of 300, and a response rate of 13 percent.

Nebraska Sample Description

	Contacts Obtained	Contacts Sent Surveys	Respondents	Non-Respondents	Response Rate
Rural	1351	1076	147	929	14%
Urban	1351	1076	128	948	12%
Hall Cnty.	300	250	29	221	12%
Total	3002	2402	304	2098	13%

The survey sampling error is plus or minus 6 percent. This means that in 95 out of 100 samples of this size, the results obtained in the sample would fall in a range of ± 6 percentage points of what would have been obtained if every Nebraska household had been surveyed.

All contacts were considered to be the head of the household. Race, age ranges of household members, gender, income, and phone numbers of those who had them were included in the sample data. This data was used to compare the respondents to non-respondents on these characteristics for the purpose of examining potential biases due to response rate.

In July 2003, all contacts received a survey with a return postage paid envelope and a letter asking them, or another adult in the household, to complete the survey and return it within two weeks. As an incentive, participants were offered the opportunity to take part in a raffle if they returned a completed survey. Four eligible participants received $50. Follow-up procedures consisted of one post-card reminder to non-respondents mailed in August.

To determine if the sample of respondents differed from the group that did not respond analyses were conducted to examine potential differences between the two groups on various demographic items. The significance level was set at $p < .05$. Using this criterion it was determined there were no differences in the *rate of response* between the rural communities, urban communities, and Hall County. A statistically equal percentage of individuals responded from all three locations, χ^2 (2) = 1.799, p = .407. Analysis of the responses themselves did not indicate any significant urban/rural differences. Additionally, there were no differences between respondents and non-respondents on three other variables: *household income*, χ^2 (8) = 11.98, p = .152; *race*, χ^2 (10) = 12.14, p = .276; and *marital status*, χ^2 (3) = 3.777, p = .287. Thus, we can conclude that the respondents were representative of the entire sample on these variables.

The *gender* of the respondents and non-respondents was also examined. The contact list was based on head of household. In most cases, a male was listed as head of household and the survey was addressed to him. Typically women are more likely to complete surveys than are men. That was the case with survey, as well (see table below). Additionally, a significantly higher percentage of female heads of household completed the survey compared to the female contacts who did not, (40% female respondents vs. 31% female non-respondents), χ^2 (1) = 9.155, p = .002. Except as noted in the report itself, response difference between woman and men were not great.

Gender Response Rate

	Contacts Sent Surveys		**Respondents**		**Non-Respondents**	
Contacts	**Females**	**Males**	**Females**	**Males**	**Females**	**Males**
Rural	36% (328)	70% (748)	33% (48)	67% (99)	30% (280)	70% (649)
Urban	35% (379)	65% (697)	49% (63)	51% (65)	33% (316)	67% (632)
Hall Cnty	27% (67)	73.2% (183)	35% (10)	66% (19)	26% (57)	74% (164)
Total	32% (774)	67.8% (1628)	40% (121)	60% (183)	31% (653)	70% (1445)

Individual ages were not available, but information on the age range, and gender of each household member was provided. Each classification grouping (e.g., females ages 25 to 34, males ages 25 to 34, etc.) was examined comparing respondents and non-respondents. Only one group was different, females age 35 to 44. There were fewer females in the household age 35 to 44 in the respondent group (15%) compared to the non-respondent group (23%), χ^2 (1) = 9.626, P = .002, indicating that this age group of women respondents were not representative of all the women sampled in this age group. One could interpret this difference in response as indicating that women in Nebraska falling in this age range are less inclined to complete a survey of end-of-life issues than other female age groups. It might be surmised that, in general, women in this age group may be focused on raising young children, may not yet face the decline of their parents, and/or may be too busy to complete a long survey.

The scant differences between the demographic variables of the respondents and non-respondents suggest that the Nebraska survey results are representative of the entire sample.

Nebraska Coalition for Compassionate Care

www.nebrccc.org

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