

South Dakota's **Dying to Know**

A Survey of Attitudes and Knowledge about Dying and End-of-Life Care in South Dakota

This is a summary of preliminary findings from statewide research conducted in the fall of 2005 to provide a profile of knowledge, attitudes and preferences about end-of-life care among South Dakotans. It replicates previous research conducted by the Life's End Institute in Missoula, Montana and by groups in Nebraska, Michigan, and North Carolina. From surveys sent to 10,204 randomly selected South Dakota households, 2,533 people responded (24.8% return rate). Please share this information with colleagues in your organization and community members who are interested in quality of life at end-of-life. Thank you.

Sample Profile (N = 2,533)

Age	Average (mean & median)	54	Self-Rating of Health	Excellent	17%
	Range	18-95		Very good	35%
Sex	Male	46%	Insurance coverage	Good	33%
	Female	54%		Fair or poor	15%
Race	White	96%	Household member with chronic illness	yes	90%
	Native American	3%		yes	23%
	Other	2%	Experienced death of someone close in last 5 years	yes	76%
Geographic Location*	East River	72%		Residence	Ranch/farm
	West River	28%	City <2500 pop.		22%
	Sioux Falls	18%	City 2500-9,999		12%
	[*3-4% of every county]		City 10,000-49,999		19%
			City 50,000 or more		27%

[Note: Percentages may not total to 100%, given rounding error.]

Thoughts about death and dying:

- 44% of respondents are "very comfortable" talking about death, 10% are not comfortable
- 74% fear dying in pain
- 75% would **not** want artificial nutrition if they were terminally ill
- 64% would **not** want artificial hydration
- 23% **would want** suicide assistance if they were terminally ill

Advance planning and preparation

- 35% of respondents have completed an advance directive (living will or health care power of attorney)
- 74% said that completing a will is "very important", **but only 53% have done so**
- 49% report having designated themselves as organ donors
- Talking with someone about "your wishes for care at end of life":
 - 6% have talked with their physician about their wishes for care at end of life; **but 39% would like the primary physician to initiate such a conversation**
 - 4% have talked with a member of the clergy; **but 36% would like a clergy member to initiate such a conversation**
 - **15% have talked with no one** about their wishes at end of life
 - Respondents trust their primary physician most to provide information on end-of-life issues (76%), a clergy member second (54%) and the local hospice third (35%).

Dealing with dying

- 62% would prefer to die at home in their sleep, but national statistics suggest that **only 25% of Americans die at home**
- 71% consider it "very important" to be off machines that extend life
- 80% consider it "very important" to know that medication is available for pain relief, and 65% say being free from pain would be "very important"; **but 77% would take medication only if they were in severe pain**
- 95% said it was "very important" to have honest answers from their physician; and 84% would trust their physician to provide this information

Hospice care (defined as care provided by a team of professionals either in a home or institutional setting and focused on comfort and quality of life for the dying person and his/her family)

- 67% of respondents would want hospice care at end of life
- Only 24% know that hospice care is paid for by Medicare

Statistically significant differences in responses by age

Older South Dakotans are more likely to trust physicians to provide honest answers, to have an advance directive, and to want hospice support if dying

Younger respondents are more likely to have talked to no one about end-of-life wishes and more likely to want artificial nutrition

Statistically significant differences by race

Native Americans are less likely to report that they have health insurance, are less familiar with hospice care, less likely to want hospice support, and less likely to trust their doctors to provide information on end-of-life issues

Native Americans are more likely to believe that good patients don't talk about pain and that health care providers will not believe and treat their pain

When thinking of their own dying, Native Americans are more likely to believe that reviewing life history with family is important and less likely to want outside help for their families

Statistically significant differences by sex

Males are more likely to have talked with no one about end-of-life wishes and to want assistance with suicide if diagnosed with a terminal illness

Females are more likely to want honest answers from their physician, to want hospice care, and to want artificial nutrition and hydration if terminally ill

Statistically significant differences by marital status

Married respondents are more likely to want artificial nutrition if terminally ill

Unmarried respondents are less likely to have talked with someone about their end-of-life wishes but more likely to have an advance directive

Statistically significant differences by geographic location

East River respondents are more likely to have talked with no one about their end-of-life wishes, to trust their physician for honest answers, to want artificial nutrition and hydration, and to have health insurance

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**The mission of LifeCircle South Dakota (formerly the Partnership for Improving End-of-Life Care in South Dakota) is to assure that the people of South Dakota receive the care needed to complete their lives and die peacefully, that their loved ones receive support, and that health care providers are skilled in palliative care. LifeCircle South Dakota is interdisciplinary (medicine, nursing, social work, pharmacy, and chaplaincy) and inter-institutional (Augustana College, North American Baptist Seminary, SDSU, USD, and USF) with a wide array of clinical sites committed to education (Avera McKennan Hospice, Sioux Valley Hospice, assisted living centers, and long-term care facilities). See our website: <http://www.LifeCircleSD.org>
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More details about the study will be forthcoming in a final report. For more information, contact Jolaine Kempema at the Sanford School of Medicine, University of South Dakota (phone: 605-357-1331, email: jolaine.kempema@usd.edu) or visit <http://www.LifeCircleSD.org>.

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