



In 1999, the Sanford School of Medicine at The University of South Dakota invited professionals and community members to engage in dialogue about end-of-life care in South Dakota. The Partnership for Improving End-of-Life Care in South Dakota evolved from that initial meeting with three distinct work groups: Public Policy, Academics, and Community Education. Financial support from the Wellmark Foundation has allowed the Partnership to be renamed LifeCircle South Dakota and to strengthen its statewide network.

LifeCircle South Dakota's mission 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, South Dakota State University, The University of South Dakota and the University of Sioux Falls), and utilizes clinical education sites in Sioux Falls, Yankton, and Rapid City.

### **SOUTH DAKOTA'S DYING TO KNOW: A SURVEY OF ATTITUDES, KNOWLEDGE AND PREFERENCES 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. Some 2,533 people responded to surveys sent to 10,204 randomly selected South Dakota households (24.8% return rate).

#### **Thoughts about death and dying:**

- 44% of the 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

*(The survey defined artificial nutrition and hydration as being fed or given fluids through a tube into one's stomach or through intravenous or IV methods.)*

#### **Advance planning and preparation**

- 35% have completed an advance directive (living will or healthcare 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
- 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, are less likely to want hospice support, and are 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

**Sample Profile (N=2,533)**  
(Note: Percentages may not total 100% given rounding)

<b>Age In years</b>	Average (mean & median) 54	<b>Geographic Location</b>	East River 72% West River 28%	<b>Household member with chronic illness</b>	yes 23%
	Range 18-95		Sioux Falls 18%		
<b>Sex</b>	Male 46% Female 54%	<b>Insurance coverage</b>	yes 90%	<b>Experienced death of someone close in last 5 years</b>	yes 76%
<b>Race</b>	White 96% Native American 3% Other 2%	<b>Self-Rating of Health</b>	Excellent 17% Very good 35% Good 33% Fair or poor 15%	<b>Residence</b>	Ranch/farm 21% City <2500 pop. 22% City 2500-9,999 12% City 10,000-49,999 9% City 50,000 or more 27%

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More details about the study will be forthcoming in a final report funded by the Wellmark Foundation. For more information, contact Jolaine Kempema at the Sanford School of Medicine, University of South Dakota  
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