

**University of New Mexico  
When Cure is No Longer Possible - A Palliative Care System  
of Excellence for Rural New Mexico**

**End-of-Life Care Survey**

- a. This is an unpublished instrument.
- b. The purpose of this survey is to identify concerns and issues, needs, and community actions/activities related to care when cure is no longer possible, and to identify local strengths and barriers to improving care when cure is no longer possible in the community.
- c. This survey was administered to representatives from community organizations identified by the local Chambers of Commerce. Organizations whose members consisted of individuals who would not likely have much concern about end-of-life care, such as the Boy Scouts, were excluded.

## End-of-Life Care Survey

We appreciate your willingness to fill out this survey. Your responses are not anonymous, but they will be kept confidential. Nothing you share with us on this survey will be reported in such a way that you could be identified.

|                               |
|-------------------------------|
| Name:                         |
| Organization/community group: |
| Address:                      |

**Please answer the following questions about hospice and palliative care. If you need additional space, please continue on the back of the survey.**

What does the word "hospice" mean to you?

What does the term "Palliative care" mean to you?

What would make it likely for you, a member of your family, or an individual you work with to **choose** hospice care?

What would make it likely for you to **discuss** hospice as a choice for a family member or an individual with whom you work?

What would prevent you, a member of your family, or an individual you work with from **choosing** hospice care?

What would prevent you from **discussing** hospice as a choice for a family member or an individual with whom you work?

As far as you know, are there discussions or activities in your community about care when cure is no longer possible?

What is the content of those discussions and who is responsible for them?

Please circle the number that indicates the degree to which you are concerned about the following issues surrounding end-of-life care in your community:

|  | <b>Very<br/>Concerned</b> |   | <b>Not at all<br/>Concerned</b> |   |   |
|--|---------------------------|---|---------------------------------|---|---|
|  | 1                         | 2 | 3                               | 4 | 5 |
| Information about available programs                                       | 1                         | 2 | 3                               | 4 | 5 |
| Alleviation of pain  | 1                         | 2 | 3                               | 4 | 5 |
| Symptom management<br>(other than pain control)                            | 1                         | 2 | 3                               | 4 | 5 |
| Perception about and understanding<br>of the quality of available programs | 1                         | 2 | 3                               | 4 | 5 |
| Financial support for<br>individuals in need                               | 1                         | 2 | 3                               | 4 | 5 |
| Involvement of clergy/spiritual leaders from<br>your community             | 1                         | 2 | 3                               | 4 | 5 |
| Conflicting beliefs about care when cure is no<br>longer possible          | 1                         | 2 | 3                               | 4 | 5 |

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| Issues about geographic distance                        | 1 | 2 | 3 | 4 | 5 |
| Language concerns                                       | 1 | 2 | 3 | 4 | 5 |
| Religious concerns                                      | 1 | 2 | 3 | 4 | 5 |
| Cultural concerns<br>(other than religion and language) | 1 | 2 | 3 | 4 | 5 |

Comments:

**Thank you for your responses.**

If you have any questions, please contact [*Name*], [*Institution*] [*Phone #*].

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**One-on-One or Small Group Interviews - Community Members**

- a. This instrument is unpublished.
- b. The purpose of these interviews is to identify concerns and issues, needs, and community actions/activities related to care when cure is no longer possible, and to identify local strengths and barriers to improving care when cure is no longer possible in the community.
- c. We conduct one and a half-hour interviews with spiritual leaders and other community leaders, as well as health care professionals who were unavailable to attend the health care professional focus group.

## Inquiry Process: (One-on-One or Small Group) Interviews - Community Members

- What does the word hospice mean to you?  
Probe: Are there other terms that you use to describe hospice care?
- What does the term "palliative care" mean to you?
- What would make it likely for you, a member of your family, or an individual you work with to choose hospice care?
- What would make it likely for you to discuss hospice as a choice for a family member or an individual with whom you work?
- What would prevent you, a member of your family, or an individual you work with from choosing hospice care?
- What would prevent you from discussing hospice as a choice for a family member or an individual with whom you work?
- What suggestions do you have about improving care when cure is no longer possible in your community?

Regarding:

Information about available programs

Alleviation of pain and other symptom management

Perception about and understanding of the quality of available programs

Financial support for individuals in need

Involvement of clergy/spiritual leaders from your community

Conflicting beliefs about care when cure is no longer possible

Issues about distance

Language, religious and cultural concerns

- As far as you know, are there discussions or activities in your community about care when cure is no longer possible?  
Probe: What is the content of those discussions and who is responsible for them?