Compassionate care for dying people involves taking care of the whole person – body, mind, spirit, heart, and soul. Sometimes called “palliative care,” it improves the quality of life people and their families experience when facing problems associated with life-threatening illness and the end of life. Having adequate information and decisions honored is important for survey respondents as they shared thoughts about the role of social supports and medical treatment at the end of life.

A key part of the social supports for people in Idaho are strong family ties. Many people said they would rely primarily on family, friends and their faith community to provide various types of end-of-life support.

- Family (“spouse/partner” and “children and other family) was consistently the highest response in all categories of support
- People expect encouragement when they are down; 76% from spouse or partner, 86% from children or other family, 57% from friends or neighbors and 41% from their faith community
- 74% believe not being able to communicate their wishes and/or needs to family or friends would be worse than death
- 40% are afraid of dying alone and 56% said they are afraid of dying in an institution
- People in Idaho also want their spouse or partner (78%) and children and other family members (89%) to know what they want when they die

Much of what people want when they die can be provided by hospice. People in Idaho reported that they know about hospice care and would consider using this type of service at the end of life...

- 96% are aware of hospice services and 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

Hospice care

- is most often provided in the 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

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 healthcare professional
Next Steps

The survey project clearly documents that many people are aware of various issues surrounding the end of life. There has been an increase in availability of services such as hospice and palliative care but this necessary growth is not yet sufficient to ensure improvements in outcomes the survey tells us are most important to the people of Idaho.

Specific activities suggested by survey outcomes provide an outline for the organization of future efforts to promote advance care planning and better care at the end of life in Idaho.

1. The medical community, faith leaders, and others recognize the importance of good end-of-life care and respond with compassion to dying people.
2. Effective pain management policies are created, approved and implemented and pain at the end of life is significantly reduced.
3. Palliative care is available and considered at the time of diagnosis of a life threatening illness.

"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."

4. Dying people are provided the information they desire, are included in decision making providing for autonomy and self determination.
5. Support is provided to family and friends so that people wishing to die at home or in another non-institutional setting are able to do so.
6. Hospice services are discussed and physicians make referrals earlier in the allowable 6-month time frame (expanding beyond the median of 22 days).
7. Hospice educational material is distributed through informal networks such as faith communities, community centers, libraries, etc.
8. Services for care at the end of life are designed for people without family or other support systems so that no one has to die alone.
9. The information in advanced directive documents 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.

Reference