



## In Their Own Words: What Direct Care Workers Say About Providing Spiritual Care Through End-of-Life

Direct Care Workers<sup>1</sup> are often the ones closest to a person at the end of their life. Because of this closeness, Direct Care Workers have the opportunity to be a “confidential sounding board” for a dying person they are caring for. Direct Care Workers can be present with the dying person as they sort through their thoughts, beliefs, feelings, memories, concerns, joys, and fears. Direct Care Workers can also offer needed support to family members.

The following recommendations on how to improve spiritual and physical care through end-of-life come from focus group interviews and surveys with Direct Care Workers<sup>2</sup> as part of a grant project on end-of-life care.<sup>3</sup>

### Direct Care Workers Make Five Key Recommendations for Improving End-of-Life Care

- 1. Offer More Educational and Training Opportunities on End-of-Life Care** — Direct Care Workers want to learn more about both the spiritual aspects and the physical process of dying. They want to be better able to support both the person they are caring for and the person’s family.
- 2. Provide Direct Care Workers With Tools to Address Language and Communication Barriers** — Individuals whose primary language is not English or who have conditions such as dementia can be challenging for Direct Care Workers to care for through end-of-life. Direct Care Workers suggest that ways to address language and communication problems be found and put into practice. This might include translator services, language resources, and special Direct Care Worker education on how to communicate with people with dementia and other conditions that affect communication abilities.
- 3. Allow Direct Care Workers to Spend Time with Families Following a Person’s Death and Allow Time for Direct Care Workers to Experience Their Own Grief** — Many Direct Care Workers express a need for more time to spend just being with the family immediately following a person’s death so the Direct Care Worker can begin to grieve the loss. This would require more adequate staffing levels.
- 4. Create Privacy Settings for Dying People and Their Families** — Most Direct Care Workers say that changes are needed in the settings where they work so that both the dying person and their family can have privacy, quiet, and other needed services during the dying process.
- 5. Include Direct Care Workers’ Input in Care Plans** — Direct Care Workers are often the staff who work most closely with the dying person and their family. Direct Care Workers have valuable information about both physical and spiritual concerns that need to be shared with and addressed by other staff. Direct Care Workers suggest that care will be improved if their input is included and valued as care plans are developed and put into practice.

## What Direct Care Workers Say About Their Role in End-of-Life Care

- It's important to do more listening than talking.
- Adapt yourself to the person, and let them lead the conversation about their spiritual beliefs.
- It's ok to pray with a person if that's what they want.

## What Direct Care Workers Say They Would Like to Learn More About

- What do you say when the person you are caring for ...
  - Says, "I just want to die"? Does the person really mean it? Are they miserable about something else, lonely, or in need of attention?
  - Asks you if you believe the same things they do?
  - Tries to convert you to her or his own religious beliefs?
- How do you care for people of other faith traditions?
- What is the difference between being spiritual and being religious and what does this mean for Direct Care Workers offering spiritual care through end-of-life?
- How do you support the dying person's family?
- What are the stages of physical dying? Are the stages different in different illnesses?

## Direct Care Workers Say Communication Difficulties are an Issue

- Direct Care Workers say that caring for someone who speaks a different language can be even more difficult than caring for someone of a different faith. That's because if the person speaks a different language, the Direct Care Worker can't ask them how they would like to be cared for or find out what is important to them.
- Caring for someone who can't express themselves is difficult. Direct Care Workers say it is very important for them to have information in advance that tells them the person's preferences rather than going in "cold" to take care of the person.

## References

<sup>1</sup>Direct Care Workers provide hands-on, personal care in nursing homes, homes, hospitals, hospices, adult day centers, and other settings.

<sup>2</sup>Source of Direct Care Worker Recommendations on End-of-Life Care

- In September 2008, five Direct Care Workers from a variety of settings (nursing home, home care, in-home hospice, and adult day center) took part in a focus group discussion about spiritual care through end-of-life.
- Three educational sessions for Direct Care Workers on spiritual care at end-of-life were held in October and November 2008 in Des Moines, Indianola, and Adel. Participants filled out surveys before and after the workshop to measure what they had learned and also filled out an evaluation. They were then interviewed by phone in March 2009 to get follow up information about what they had learned in the sessions.
- A survey on end-of-life care was completed by 162 Direct Care Workers from across the state who attended the Iowa CareGivers Association's annual conference in October 2009.

<sup>3</sup>Funding for this project was made possible through a grant from the Mid-Iowa Health Foundation. Project partners are the Iowa CareGivers Association, Des Moines University, and Hospice of Central Iowa.

The Iowa CareGivers Association (ICA), an independent, non-profit organization founded in 1992, has as its mission, "Enhancing the quality of care by providing education, recognition, advocacy, and research in support of Direct Care Workers." For more information about Direct Care Worker issues and how you can become involved, please visit the Iowa CareGivers Association website, [www.iowacaregivers.org](http://www.iowacaregivers.org) or call 515-223-2805 or 888-710-2762 (toll free).

