

***Community Action, Research, and Education (CARE) Fellowship Program:  
Cultivating Communities of Compassionate Caregivers***



### **Program Overview**

The Community Action, Research, and Education (CARE) program is an experiential learning program that trains undergraduate students to serve as surrogate family members to hospice patients in community-run residential homes for the dying. The CARE program includes a curriculum that challenges students to examine the cultural, social, ethical, political, and economic barriers to hospice care while encouraging them to develop skills to become agents of change. The curriculum includes learning modules on biological, psychosocial, emotional, and spiritual aspects of dying conveyed through communication exercises and exercises targeting specific dimensions of end-of-life care. The modules include self-assessments, educational videos, case studies, and journal prompts for reflective writing. Students working at different homes communicate with one another online so that they may learn collectively about the societal factors that make it difficult for vulnerable and marginalized members of the community to experience a dignified, meaningful death. In addition, CARE fellows conduct an agency-driven research project supervised by faculty from their home institution. When conducting the program during the summer, CARE fellows may be eligible to receive research/internship funding to assist with living expenses.

### **Learning Outcomes**

- Recognize the importance of psychosocial support in end-of-life care;
- Identify symptom management approaches for conditions common at the end of life including pain, dementia, anxiety, nausea, edema, and dyspnea;
- Identify and develop skills for managing the unique challenges caregivers face when providing end of life care;
- Demonstrate compassionate, non-judgmental, empathetic care that preserves a resident's dignity at the end-of-life;
- Serve as a member of an interdisciplinary care team under hospice's medical management;
- Have an increased comfort communicating with terminally ill residents and their family members;
- Conduct research that is of benefit to the home's mission of helping terminally ill members of the community have access to a safe, caring place to die.

### **Key Service Components**

- Serve as a surrogate family member responsible for resident care needs (toileting, feeding, taking medications etc...);
- Observe hospice care team members and resident care staff including volunteers from the community;
- Offer emotional support to family members and visitors to the home;
- Provide resident care narratives and document care decisions;
- Complete self-reflection activities/assignments;
- Maintain a reflective journal based on field notes from each shift;
- Complete learning modules and reflection exercises through an online curriculum;
- Participate in regular discussions about caregiving experiences with other CARE fellows, faculty mentors, and palliative care specialists.

## Assessments

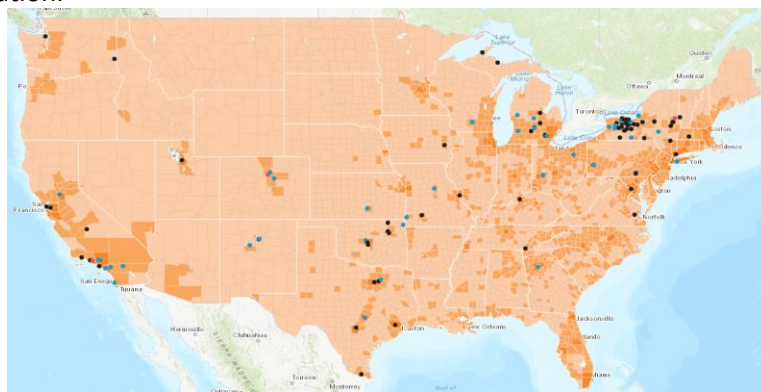
- **Empathy:** Jefferson Scale of Empathy-Health Professions Version (JSE-HPS; Hojat, 2016); Qualitative analyses of narratives from reflective journals.
- **Comfort providing end of life care:** Palliative Care Skills Assessment (PCSA), a 20-question instrument based on a Palliative Care Self-Efficacy scale developed by Phillips, Salamonson, & Davidson (2011). *International Journal of Nursing Studies*, 48(9), 1096-1100.
- **Communication, working as a member of a team, understanding of the complexities and challenges of end of life care:** Qualitative analyses of narratives from reflective journals.

## Results

To date, the CARE program has enrolled 50 students from eight different institutions (Colgate University, Connecticut College, Hobart, William and Smith Colleges, Siena College, Skidmore College, St. Lawrence University, Union College, and Wells College) who have trained in six different homes in Upstate New York. Assessment data from the first 2 years reveal that CARE fellows exhibited significant increases in empathy and in perceived self-efficacy to provide palliative care following completion of the program (Weisse, Melekis, and Hutchins, 2018). In addition, participants reported a greater sense of meaning in their own lives after completing the program. Research projects have engaged students and faculty in collaborative research projects addressing topics such as changes in nutrition at end of life, existential angst, fall prevention, and cultural practices in end of life care. [Academic Minute summary <https://academicminute.org/2019/08/carol-weisse-union-college-lessons-learned-at-the-bedside-of-the-dying/>]

## Summary/Implications

The CARE program is an immersive experience enabling undergraduate students to provide care to hospice patients over the course of their dying process. The program offers emerging adults an opportunity to serve their communities while developing empathy and confidence providing end of life care, skills that will be invaluable to them not only as future healthcare providers but as caring, compassionate members of society. The opportunity to journey alongside terminally ill patients and family members in a home setting offers a special lens to the dying experience in a holistic, patient- and family- centered way. Upon completion of the program, students gain a deeper understanding of the cultural and societal factors that make it difficult for members of the community to experience a dignified, meaningful death. With this knowledge and expertise, CARE fellows are uniquely poised to become agents of change in healthcare delivery. The map below identifies nearly 70 homes across the U.S. (black) with 40 more homes (blue) in development where the CARE program could expand training of the next generation of leaders as they set out to improve the care of the nation's most vulnerable population.



Weisse, C. S., Melekis, K., & Hutchins, B. (2018). Providing End-of-Life Care: Increased Empathy and Self-efficacy Among Student Caregivers in Residential Homes for the Dying. *American Journal of Hospice and Palliative Medicine*, 36(6), 538-545. <https://doi.org/10.1177/1049909118820844>

**Contact:** Dr. Carol Weisse, Director of Health Professions, Union College, Schenectady, NY [weissec@union.edu](mailto:weissec@union.edu)