

Resources and Tools

A. ORIGINAL TOOLS FROM HOSPICE & PALLIATIVE CARECENTER:

CHF Self Care Calendar

© 2003 Hospice & Palliative CareCenter. Published here with permission.

COPD Self Care Calendar

© 2003 Hospice & Palliative CareCenter. Published here with permission.

To obtain a copy of the CHF or COPD workbook for patients and family caregivers, contact Betsy Clark, RN, CHPN or Terrie Spease, LPN via telephone at (336)768-3972, or email at betsy.clark@hospicecarecenter.org or terrie.spease@hospicecarecenter.org. The cost is \$11 plus shipping.

B. WEBSITES RELATED TO THIS ISSUE'S CONTRIBUTORS:

American Hospital Association (AHA)

www.hospitalconnect.com/aha/awards-events/circle_of_life/index.html

AHA is a key sponsor of the 2003 Circle of Life Award. Visit this site for more information about this year's award and/or to apply for next year's award. Applications for the 2004 award are due on August 15, 2003.

Hospice & Palliative CareCenter (HPCC)

www.hospicecarecenter.org

HPCC is guided by the principles of raising public expectations and improving the quality of end-of-life care as it seeks new and creative ways to increase understanding and improve the delivery of care near the end of life. To achieve these goals, HPCC has developed close relationships with a wide range of health care providers in medical centers, long-term care facilities, and community organizations in order to improve professional and public education about end-of-life and palliative care and deliver home and hospice care to diverse populations, including people with chronic, life-threatening conditions, and nursing home residents.

Institute for Healthcare Improvement (IHI)

www.ihl.org

IHI is a Boston-based, independent, nonprofit organization working since 1991 to accelerate improvement in health care systems in the United States, Canada, and Europe by fostering collaboration, rather than competition, among health care organizations. IHI was a sponsor, with Rand Center to Improve Care of the Dying (presently known as the Washington Home Center for Palliative Care Studies), and the Department of Veterans Affairs, of the Breakthrough Series Collaborative to improve end-of-life care.

**Providence Health System
End-of-Life Care Program**

www.providence.org

End-of-life care is one of the five clinical priorities at Providence Health System. The philosophy behind this program is to be proactive, and span the entire continuum of care—from addressing advance care planning to supporting families through bereavement—while carrying out its healing ministry, with special concern for the poor and vulnerable.

Supportive Care of the Dying: A Coalition for Compassionate Care

www.careofdying.org

The three priorities of the coalition are research, developing models of comprehensive, community-based, supportive care for dying people, and creating a professional development program. The site has a variety of tools and resources and back issues of *Supportive Voice*, a quarterly newsletter that allows readers to share in the experiences and challenges of members and professional colleagues in order to help improve end-of-life care. Providence Health System is a founding member of this coalition.

**University of California Davis Health System
West Coast Center for Palliative Education and Research (WCCPER)**

www.ucdmc.ucdavis.edu

WCCPER strives to raise the standards of end-of-life care by enhancing the quality, appropriateness, and effectiveness of palliative care services, and access to such services, particularly for underserved populations, from those participating in aggressive cancer clinical trials to patients living in isolated rural areas or correctional settings. The center is one of the first in the country to promote independent, innovative research, training, and care modules in all aspects of palliative care.

C. OTHER RELATED WEBSITES:

Promoting Excellence in End-of-Life Care

www.promotingexcellence.org

A national program office of The Robert Wood Johnson Foundation with direction and technical assistance provided by the Practical Ethics Center at the University of Montana, Promoting Excellence has funded more than 20 projects to improve palliative care in different parts of the United States.

The website includes Program Evaluation Tools developed or used by its grantees and a resource of validated, published Key Clinical Assessment and Research Tools used in the field of palliative care. Relevant to this issue are the following tools:

www.promotingexcellence.org/instruments/index.html

[Note: search Key Clinical Assessment and Research Tools and scroll down to view the alphabetical list of tools]

The FACT-G was developed by David Cella, PhD, Professor of Psychiatry and Behavioral Science at Northwestern University Medical School and is used to measure quality of life for patients with advanced disease.

www.promotingexcellence.org/hov

PhoenixCare is a program that cares for patients diagnosed with metastatic cancer, chronic obstructive pulmonary disease and congestive heart failure. Its tools include an Initial Clinical Assessment, After Death Surrogate Interview and more than 70 fact sheets for patients and families.

The Washington Home Center for Palliative Care Studies

www.medicaring.org

Formerly the Rand Center to Improve Care of the Dying, CPCS offers expert support to hospitals, nursing homes, health systems, hospices, and other organizations that serve individuals nearing the end of life. CPCS has worked with nearly one hundred health care organizations to implement effective quality improvement projects in end-of-life care. With the Institute for Healthcare Improvement (IHI), the Center has directed two successful Breakthrough Series Collaboratives on improving end-of-life care and published the results of these efforts in its authoritative book, *Improving Care at the End of Life: A Sourcebook for Clinicians and Managers*. Teams from Hospice & Palliative CareCenter and Providence Health System that participated in the Collaborative on CHF and COPD are featured in this issue of *Innovations*.

CPCS has also published two guides for family caregivers of patients with CHF or COPD, which grew out of the 1999 Collaborative focused on palliative care for patients with CHF and COPD. *Living with Advanced Lung Disease: A Guide for Family Caregivers* and *Living with Advanced Congestive Heart Failure: A Guide for Family Members*, authored by Anne Wilkinson, MD, are both available for download from www.medicaring.org.

Two earlier issues of *Innovations in End-of-Life Care* relate closely to two of this issue's Featured Innovations:

"Building Bridges for Better Continuity of Care." *Innovations in End-of-Life Care*. 2000;2(5): www2.edc.org/lastacts/archives/archivesSept00/default.asp. This issue spotlights AHA Circle of Life Award winner Franciscan Health System West's bridge program, after which the Providence program was modeled.

"Reinterpreting Comprehensive Cancer Care." *Innovations in End-of-Life Care*. 2002;4(4): www2.edc.org/lastacts/archives/archivesJuly02/default.asp

This issue highlights the work of fellow Promoting Excellence grantee Project Safe Conduct, winner of one of the 2002 AHA Circle of Life Awards. Project Safe Conduct represents another effort to bring palliative care to patients with cancer even as they may be pursuing curative treatments.