

## 2010 Marked a Year for Caring, Community & Collaboration

*Mark M Murray, President & CEO*

Thanks to your continued support, 2010 was a great year for your local not for-profit hospice and palliative care agency. Center for Hospice Care (CHC) served 1,774 patients and their families, the most of any calendar year. CHC continues to care for more patients than any other program in Indiana.

The greater medical community continues to play a fundamental role in our success. We are grateful to receive support from hundreds of physicians, group practices, hospitals and other healthcare facilities and educational institutions. Currently, CHC has educational internships and teaching affiliations with Memorial Hospital, Saint Joseph Regional Medical Center, Southwestern Michigan College, Indiana University South Bend, Valparaiso University, Ivy Tech State College South Bend, St. Mary's College, Bethel College, Indiana Wesleyan University, and the University of Notre Dame.

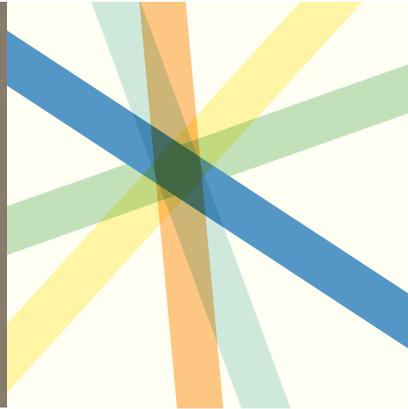
Additional partnership opportunities include agreements to provide hospice services with more than 80 different extended care facilities throughout northern Indiana. These include licensed skilled nursing homes, as well as group homes and assisted living facilities. We have additional patient care partnership agreements with Memorial Hospital, Saint Joseph Regional Medical Center in Mishawaka and Plymouth, Elkhart General Hospital, and the Community Hospital of Bremen. These partnerships exemplify what is important to us: Caring, Community, and Collaboration.

The high numbers of patients choosing CHC also means an increased number of survivors taking part in our many grief counseling and bereavement services. Because these services are open and available to anyone in the community, regardless of having a prior experience with CHC, we now estimate on any given day over 2,300 people participate in CHC bereavement services through individual counseling, our many support groups, telephone support, specialty programming, and mailings.

In 2010, CHC opened the area's first Palliative Care Center. This new space allows for palliative care consultations where our board certified hospice and palliative medicine physicians collaborate with attending physicians to address the goals and concerns of individuals with life-limiting illnesses. The consultation offers the patient and family an opportunity to talk about priorities regarding care and is intended for people who are actively seeking curative treatment. CHC palliative care consultations provide options and choices for appropriate palliative treatment plans. Consultations are by physician referral and by appointment only.

With 2011 in full swing, your continued support is appreciated. We look forward to another year of collaboration as we care for the patients and families in our community.

hospice & physician  
**team**  
newsletter



newsletter



*Mark M Murray  
President & CEO*

“CHC continues to care for more patients than any other program in Indiana.”



choices to make the most of life

# Center for Hospice Care to Participate in Johns Hopkins Dementia Caregivers Research Study

by Dr. Gregory Gifford, MD JD & Gail Wind, RN



Gregory Gifford, MD JD,  
AMBS Board Certified  
in Palliative Medicine,  
Chief Medical Officer



Gail Wind, RN, Assistant  
Director of Nursing

Recently, Gail Wind, RN, Assistant Director of Nursing, Center for Hospice Care (CHC) attended the Indiana Healthcare Leadership Conference focusing on Alzheimer's disease and Dementia. Presenting was Dr. Peter Rabins of Johns Hopkins Medical Institutions. After the presentation, Gail spoke with Dr. Rabins about our concern for advanced dementia patients' caregivers as well as patients, and about our new hospice Dementia Support Program which kicked off in January 2011.

Advanced dementia itself prevents patients from being able to tell their caregivers their subjective symptoms - what they feel or need - from moment-to-moment. These symptoms are then often expressed in adverse behaviors, resulting in more caregiver frustration and stress. This, in turn, diminishes both the patient's and caregiver's quality of life. However, subjective symptoms of advanced dementia cannot be measured – only the behavior of these patients can be studied and measured.

The Johns Hopkins study instead measures the caregiver's interpretations of the patients' behaviors. It is hoped that changes in these measurements can be used to determine, through the prism of the caregiver, whether or not specific interventions benefit the patient. CHC is excited about being able to participate, learn more, and be of more value to both patients and caregivers.

The details of the study are as follows. The Alzheimer Disease Related Quality of Life (ADRQL) was developed by Peter V. Rabins, M.D., Judith D. Kasper, Ph.D., and Betty S. Black, Ph.D. at Johns Hopkins University to assess the health-related quality of life of people with Alzheimer's disease. ADRQL is a multidimensional 40-item behavior-based assessment instrument that is interviewer administered. Each ADRQL item falls into one of five domains: social interaction, awareness of self, feelings and mood, enjoyment of activities, and response to surroundings. It is valid across the entire spectrum of the disease including those people who are unable to participate in a self-assessment. In that scenario, which is consistent with late-stage Alzheimer's disease, ADRQL is administered to the patient's formal or informal caregiver who is considered to be knowledgeable of the day-to-day activities and behaviors of the individual with Alzheimer's diseases. ADRQL is also reliable across the various settings people with Alzheimer's disease reside, including the nursing home, assisted living and home setting.

CHC has been granted the licensure to utilize ADRQL in an 18-month research project for the purpose of assessing the efficacy of our Dementia Support Program interdisciplinary interventions and ultimately the broader context of meeting our mission of improving the quality of life for those we compassionately serve at end-of-life.

# While Nearly All Hospices Now Serve Patients with Dementia, Family and Provider Awareness May Be Lacking



In 1995, only 1% of all hospice patients entered with a primary diagnosis of dementia, and only 21% of hospices served these patients, according to the authors of a recent study published in the *Journal of the American Geriatrics Society*. During the past year, 11.2% of hospice patients enrolled with a diagnosis of dementia, and 94% of hospices and 72% of

nonhospice palliative care programs had cared for a dementia patient.

“Almost all hospices and a majority of nonhospice palliative care programs serve patients with dementia,” write the authors. “This finding is encouraging news, in that more patients with dementia and their families may be getting needed help in managing the disease.”

The investigators analyzed survey responses from executive directors of 426 programs providing the following services: hospice care only; both hospice care as well as non-hospice palliative care outside of the traditional hospice insurance benefit; or non-hospice palliative care only.

Ninety-six percent of respondents agreed or strongly agreed that dementia is a terminal illness, and 98% agreed or strongly agreed that palliative care is effective for these patients.

## BARRIERS TO PALLIATIVE CARE

The most frequently cited barriers to palliative care included:

- Lack of awareness about palliative care for patients with dementia by families (54%) and referring clinicians (50%)
- Policies making reimbursement for care of dementia patients more difficult than for those without dementia (58%)
- The need for formal respite services for caregivers (46%)

Lack of awareness of palliative care programs for dementia patients by providers and families can lead to infrequent referrals and extremely late referrals, according to many administrators. “We may not get referrals on these patients until they are in the dying process,” one respondent commented.

Palliative care needs and services most often rated as “extremely important” in the care of patients with dementia included:

- Family information regarding disease progression (83%)
- Management of behavioral symptoms (83%)
- Assistance with caregiver burden or guilt (78%)

“Most of my time is spent with emotional support, teaching and reassuring the family caregivers,” commented one respondent, while another noted, “many dementia patients live at the edge for long periods of time. Families and caregivers are overwhelmed.”

## SUCCESSFUL STRATEGIES

Strategies considered critical for success in caring for dementia patients included the following:

- An interdisciplinary team structure
- Collaboration with community organizations, such as nursing homes or local support groups
- Alternatives to aggressive end-of-life care

“Education and policy efforts should focus on education for families and providers, support for caregivers, and reforming reimbursement structures to provide coverage for interdisciplinary palliative care earlier in the disease, when patients have high needs but are not hospice eligible,” the authors conclude.

Reprinted with permission from Quality of Life Matters®, copyright 2011.

# palliativecarecenter

4220 Edison Lakes Parkway, Suite 200  
Mishawaka, IN 46545

Hours: Tuesday and Thursday 2 - 4 p.m.  
Phone: 574.243.3712

Physician referral only.

For an inservice on Palliative Care, call 574.243.3712 or email [info@centerforhospice.org](mailto:info@centerforhospice.org)

# Staff Updates



Deb A. Nygren, FNP-BC

## Deb Nygren

Center for Hospice Care is pleased to welcome Deb Nygren, MSN, FNP-BC, to its staff. Serving as CHC's Nurse Practitioner, she will work in tandem with the medical directors. Nygren was a career nurse for more than 20 years, and obtained her Bachelor of Science in Nursing from Ball State University in 1991. She earned her Master of Science in Nursing with emphasis as Family Nurse Practitioner from Ball State University in 2001.

Nygren has practiced in both hospital and community settings. After nursing school, she spent her first six years devoted to Pediatrics. During her next 20 years, she specialized in working in and managing different types of critical care facilities (PACU, CCU, NICU, MICU, SICU, CCU, Neuro CCU, Trauma Unit). These were in several Indianapolis-area hospitals, including St. Vincent, Methodist, Riley, Wishard, and Indiana University Hospital. This field of nursing gave her considerable acute-care experience with terminally ill patients and their families.

In 2001, she began working as a Nurse Practitioner in family practice and psychiatric care in both predominantly indigent areas and in suburban freestanding walk-in clinics, primarily in Indianapolis.

In addition to her Indiana Nurse Practitioner Authorization license, she holds ANCC-FNP Certification, as well as RN licenses in Indiana and Illinois. Her professional organization membership includes the American Academy of Nurse Practitioners, American College of Nurse Practitioners, Coalition of Advanced Practice Nurses of Indiana, National Association of Nurse Practitioners in Women's Health, and the National Nursing Honor Society.

---

## Admissions Department Grows

Lisa Zollinger, a third community liaison was recently hired to serve Elkhart, LaGrange and Kosciusko counties. Zollinger is a Goshen resident and most recently worked as Admissions Director at the Maples at Waterford Crossing in Goshen since 2006. From 2000 - 2003, Zollinger was the Community Liaison for Elkhart General Health System/Hospice/Home Care. To request Lisa to speak to your organization about hospice care, please call 574.309.6763 or email [zollingerl@centerforhospice.org](mailto:zollingerl@centerforhospice.org).

Sarah Lambert joins Center for Hospice Care as an Admissions Representative. She will perform pre-assessments for patients interested in either home health care, hospice, or Hospice House. Since 2007, Sarah served as the branch manager for Help at Home in Bloomington, IN, providing services to more than 200 seniors and disabled clients.

© 2011 Center for Hospice Care