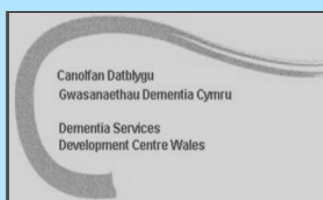


Volume 22, Number 2, Winter 2016-17

SIGNPOST

Journal of Dementia and Mental Health Care of Older People



Signpost is the specialist, tri-annual, not for profit journal produced by the Practice Development Unit (MHSOP) of Cardiff and Vale University Health Board in association with Dementia Services Development Centre Wales
www.bangor.ac.uk



Defining the Mission

For years Levine and many of his colleagues were affiliated with the National Alzheimer's Association. But they made a decision to return to their roots as an independent organization in 2015. Their approach features three key components:

Looking beyond the disease and acknowledging the whole person, as well as the emotional and psychological impact of what that person and their caregiver are going through. Developing a culture of creativity, compassion, and a personalized approach to services

Reaching out to diverse communities and targeting services to their needs

Creating a Culture of Compassion and Caring
Anna is worried that her stepfather is emotionally and financially abusing her mother, who is living with dementia. Her mom is thousands of miles away. Anna wants to go to her and get her into a safe place, but she can barely afford to feed her children. When Anna finally spills her fears to a social worker at CaringKind, she receives guidance, access to special assistance funds, and help with long term planning. "Building relationships and having a direct personal connection has a profound impact on the way we deliver our services," Levine says. "So many families are living on the edge. If people have to give up work to care for a parent with dementia, they can put themselves in real jeopardy."

Reaching Diverse Cultures

CaringKind is also moving to a more localized approach, with plans to have a social worker in every borough. That means they can connect people who live in Brooklyn or Queens with special services and providers in their neighborhoods.

"Every person has his or her own pathway through dementia," Levine says. "Our goal is that everybody receives the support within the context of their own culture when they need it."

Filling Gaps and Changing Healthcare Systems

Debra L. Cherry, PhD

Executive Vice President
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Alejandra worked a full-time job, took care of her two children and also cared for her mother, who had a diagnosis of dementia. Her mother could no longer eat solid food. She desperately needed dentures, which Alejandra could not afford. Her mother was becoming increasingly frail and malnourished and Alejandra did not know where to turn. Fortunately, she approached the Alzheimer's Greater Los Angeles, an independent non-profit organization dedicated to supporting people with dementia and their families. Their Caregiver Emergency Fund helped pay for the dentures. Once she was able to eat regular foods, her mother's health improved.

Alzheimer's Greater Los Angeles has served the family of a President and they've served undocumented immigrant workers. "We tailor our work and offer person-centered care to our ethnically and socioeconomically diverse population," says Debra L. Cherry, PhD. "We also strive to change big healthcare systems so we can increase access for the underserved and improve quality of care."

"We look at the family's culture, language, socio-economic resources, and legal status,"

Dr. Cherry says. “Then our care counselors create care plans and connect them to appropriate resources.” The organization provides 24/7 support in English and Spanish through their helpline and website. A translation service helps with calls in other languages. Their educational programs are far-reaching and offered in a variety of languages and locations. In addition, they have “plain language” pamphlets for those who have literacy challenges or who speak English as a second language.

Collaborating for more Complete Care

Dr. Cherry and her team have won national awards for building coalitions among community partners in targeted ethnic communities. “During a period of three years, we learn about their community, they learn about dementia and caregiving, and we work together to bring in resources and build services,” Dr. Cherry says.

These coalitions have created legal clinics, started support groups, and founded adult day care centers. “We learn to better serve the community and they learn to better care for people with dementia,” Dr. Cherry says. “The communities then continue the care counseling and support groups on their own.”

Alzheimer’s Greater Los Angeles also steps in to assist groups that need services. They started an LGBTQ community support group and another group for people diagnosed with young onset. They then provided consulting assistance as people in the communities gradually took over. “That work highlights our individualized and collaborative approach,” Dr. Cherry says.

Changing Systems, One Diagnosis at a Time
Dr. Cherry works with large healthcare systems, such as Kaiser Permanente, helping to improve recognition and diagnosis of dementia.

“Only 50% of people with dementia get a diagnosis, and only half of those get the disease documented in their charts,” she says. “Some people are never even told.”

Part of the organization’s focus is keeping people out of hospitals and nursing homes by teaching health care systems to identify family caregivers and evaluate them to assess their stress and needs for services.

In the ideal world, people would be diagnosed in the early stage and given good disease education and support from the beginning to the end of life. Family caregivers would receive respite delivered by reliable, high quality caregivers and other services as needed. This would allow people to stay in their homes and out of hospitals and nursing homes longer. “System change is about educating people and it’s about partnerships with those who can make the change happen,” Dr. Cherry says.

Deborah Shouse

DementiaJourney.org

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