

# CARING

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Honoring  
Home Care &  
Hospice Nurses:  
Fifty Nurses who are  
Tops in Home Health

*Congressman Walter Jones  
Visits a Special Home Care Patient  
in North Carolina*

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By Val J. Halamandaris  
Editor and Publisher

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Congressman Walter Jones was stirred by the close bond he witnessed between patients and nurses when he spent a day with Lisa Angel, RN. As a home care nurse for WellCare, she provides lifesaving, acute care for tiny, premature babies and helps parents deal with the stress of having their baby come into the world too soon. Seeing the gifts of caring that Lisa provides strengthened the congressman's resolve to preserve funding for home care and keep the industry strong.

### 8 Breaking down Barriers for Nurses By Elaine D. Stephens

What is the state of nursing? How do changes in health care delivery affect the profession's needs? Many of the answers appear in *The Future of Nursing*, a joint study by the Institute of Medicine and the Robert Wood Johnson Foundation. Based on their findings, IOM and RWJF have offered a blueprint to develop the nursing workforce and give nurses a say in decisions about the nation's health. Learn how NAHC and the Home Healthcare Nurses Association have partnered with other key nursing groups to help nurses meet our nation's growing demands for care.

### 10 Caring for the Sickest 1%: Nurses at the Center of Home and Community-Based Long-Term Care By Mary Wehrberger and Florence Marc-Charles

Long-term care patients often do better at home. That's the mantra behind PACE, a growing model for giving all-inclusive care to the aged. CenterLight in New York operates the largest and one of the oldest PACE programs in the nation. CenterLight's approach is based on a number of key ingredients: home care nurses, respect for cultural diversity, telehealth, and coordinated care. Combined, they help seniors with chronic conditions to avoid hospital stays and remain independent at home.

### 14 Hands Down, There's No Place Like Home By Nicole Fedeli-Turiano and Bill McManus

Judy Weaver promised her aging parents that she would honor their wish to stay in the home they loved. The single, working mom has kept her word with help from Home Nursing Agency Healthcare. The Pennsylvania agency provides Judy's parents with services ranging from wound care to blood draws, rides to adult day care, and help preparing meals. In addition, Home Nursing Agency Healthcare has joined efforts to reform the state's Medicaid system by bring more long-term care to the home.

### 20 In Search of the Top Home Care & Hospice Nurses in the Nation Read real-life stories from the top 50 nurses nationwide. Learn how they help patients meet their goals whether they live in the crowded streets of New York or the open spaces of North Dakota. See how they help seniors cope with chronic conditions and aid disabled children in surmounting the challenges they face. Find out about the small but important things they do to make their patients smile. Read on as our nation's top nurses remember patients who touched their hearts and whose hearts they touched in turn.



*CARING* is published to address the critical issues and needs of those millions of Americans who, in the words of Vice President Hubert H. Humphrey, are on the fringes of life. He spoke of the millions of children facing problems in the dawn of life, he added the elderly, experiencing compound burdens in the twilight of life, and the handicapped and disabled, whom he said were in the shadows of life. *CARING* is dedicated to the belief that there is no problem experienced by humanity that cannot be solved. Moreover, it posits that the solution to most human problems lies in the love, understanding, and caring of one human being for another. As one of its major themes, *CARING* is committed to advancing the proposition that as much as is humanly possible, health care and supportive services should be delivered in the home. Home health care and hospice both serve to keep families together, and *CARING* is wholeheartedly committed to advancing this most important social value.

# *Hands Down, There's No Place Like Home*



*By Nicole Fedeli-Turiano and Bill McManus*

The care giving dynamic in the Chesney family from Altoona, Pennsylvania is becoming more prevalent as an increasing number of family members must balance the long-term living preferences of their aging parents or loved ones with their own demanding careers and family obligations.

Judy Weaver, daughter of Altoona natives Bob and Shirley Chesney, is embarking on her eighth year as her parents' primary caregiver, helping to preserve their independence and unwavering desire to remain at home even as they require daily medical and personal assistance.

With an array of home and community-based services offered by Home Nursing Agency Healthcare, Weaver has maintained the balance fairly well. She's quick to cite how the quality, cost-effectiveness, and value-added benefits of private duty home care and adult day services should be the centerpiece of long-term care discussions when families weigh their options. "I want people to know the possibilities," Weaver claimed.

"I love my life here, and I want to die here with my wife, Shirley," said Bob Chesney, 79, gesturing to his surroundings in the modest homestead built by his father-in-law over 50 years ago in this historic railroad town.

Weaver promised her parents, both living with chronic health conditions including congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD), that no matter what the circumstances, she'd abide by their wishes. Upholding her pledge thus far, Weaver has undoubtedly experienced trials and tribulations along the way. The good times have exceedingly outweighed the bad, according to the upbeat 47-year-old single, working mother as she greets her parents' spirited long-haired dachshund, Brownie.

"Coming into this house and seeing both of them here is such a joy and provides such a sense of inner peace and satisfaction that's hard to describe," she said. "Married for 56 years, I know they are where they want to be and are surrounded by what — and whom — they love most."

Just as current and ongoing research from MetLife and AARP<sup>1</sup> indicates "home" as the overwhelming preference of the elderly, the founders of Home Nursing Agency had an unequivocal belief almost 50 years ago that "aging in place" would also be the preference for many families like the Chesneys.

As a result, John Sheedy, M.D. and Mary B. Kraft, both of whom died within weeks of each other last year, cultivated seed monies and formed stealthy alliances — many still intact today — to launch what is now known as Home Nursing Agency Healthcare. Built on the premise of *whole person orientation* and care for *all stages of life*, the agency provides post-acute and chronic disease management, preventive services, and palliative/hospice care.<sup>2</sup> Currently headquartered in Altoona, the agency serves over 30,000 residents throughout 13 rural counties in central Pennsylvania.

### *A Visionary Approach to Care*

In the 1960s, the notion of sending skilled health professionals out to meet the needs of the community was not commonplace throughout the Allegheny Mountain region. Fortunately, Sheedy, Kraft, and several health care pioneers were innovative and courageous enough to move the frontier to develop one of the first home and community-based care providers in the state, capturing the attention of national caregiver advocates like former First Lady Rosalynn Carter and former U.S. Assistant Secretary of Aging Josephina Carbonell, both of whom have visited the agency.

What the agency's founders could not have foretold was how the rural region, decades later, would be in dire need of such services as it grapples with one of the nation's fastest-growing populations of rural elders, 65 and older.

The state is now ranked fourth nationwide in the number of rural elders with 15 percent of the population in the 65 years old and older age group. This is projected to increase to 51 percent by 2030 at which time 25 percent of the state's rural population will be 65 years old and older.<sup>3</sup> Moreover, could they have predicted that 7.8 million Pennsylvanians would now suffer from chronic conditions, representing over 60 percent of the Commonwealth's population?<sup>4</sup>

Teaming up with numerous civic groups, community action agencies like United Way, and Area Agencies on Aging (AAA) to provide services, the agency is also grateful for its partnerships with fellow NAHC members like Delta Health Technologies, also based in Altoona. "Delta was very fortunate to have partnered with Home Nursing Agency in the early 1970s. The agency's broad offering of services introduced our development team to the broadest possible view of care in the



home and community setting,” said Keith Crowover, President/CEO of Delta Health Technologies.

“We have worked with hundreds of home care agencies, of all types, during our decades in home care but have never encountered an organization with the depth and breadth of services offered by Home Nursing Agency,” added Crowover.

### *Home Care & Adult Day Go Hand-in-Hand*

“A seamless network of services including private duty home care, adult day service, and home health care have not only helped to alleviate the stress and ongoing demands of care giving, but they’ve also fostered my parents’ independence for many years,” said Weaver, whose parents also have a personal emergency response system.

According to Georgetown University’s Health Policy Center, the quality of life for people with long-term needs depends on their ability to obtain care in an environment and manner they prefer. With increased availability of community options such as assisted living and home care, there’s growing awareness of how important it is to give people control over their care, which helps to improve their quality of life. Seventy percent of adult day centers are affiliated with larger organizations such as home care, skilled nursing facilities, medical centers, or multi-purpose senior organizations.<sup>5</sup>

With the Chesneys’ medication, medical devices, private duty home care and adult day services covered by private insurance and the state’s aging waiver, Weaver is striving to be excluded from an AARP national statistic which purports that 69 percent of working caregivers have to rearrange their work schedule, decrease their hours, or take unpaid leave in order to meet their care

giving responsibilities.<sup>6</sup>

“You don’t know what it means for me to be able to go to work with regularity and to perform my duties well. Working in health care, there’s always pressure. Can you imagine the amount of stress and added pressures I would have to endure without the agency’s services?” Weaver quipped. Over the last few years, her father has suffered a stroke and heart attack, along with enduring coronary artery surgery at which time his atrial fibrillation was also discovered. Weaver’s mother just recently completed a 10-day IV-antibiotic regimen for an infection which prompted a brief hospitalization.

“My other sister lives in Texas and provides a great deal of support to our family, but without home care and adult day all of the day-to-day caregiver tasks, challenges, or upsets are in my hands,” said Weaver.

Like many middle-aged caregivers, her hands are already in myriad areas every day – raising her teenage son, working as a secretary for the agency’s pediatric home connection program, tending to her home just blocks from her parents, keeping tabs on her own well-being and when the rare opportunity presents itself – journeying to yard sales.

Weaver’s hands are also inextricably linked to program assistant Judy Aigner at the adult day center and to Sue Jarrett, the Chesneys’ soft-spoken blue-eyed private duty caregiver whose extraordinary capacity to serve the Chesneys has earned her significant praise and admiration from her supervisors, colleagues, and most notably from agency clients. “She is number one!” Mr. Chesney said emphatically.

Nearly every day for four years and counting, Jarrett, 41, crosses their threshold for two two-hour stints. Beginning at 7:30 a.m. and again 12 hours later, she delves into routine personal care, meal/snack preparation, an overview of any upcoming appointments, and some good-ole chit-chat on the news of the day. Jarrett also makes certain Mrs. Chesney completed her telehealth regimen, administered her insulin injection, and checked her blood sugar, especially since she’s showing early signs of Alzheimer’s as is Mr. Chesney.

In the morning, she prepares some breakfast for Mr. Chesney, a dapper gentleman who worked at Conrail and

retired from the manufacturing sector. She keeps an eye on him, too, as he enters the Blair Senior Services van. A 30-minute ride takes him to the agency's adult day care program where he's been going most every weekday since 2006 for socialization, exercise, and meals, as well as symptom management and oversight as a result of his CHF diagnosis. "But he gets so much more," Weaver claims. "The staff has adopted him as their dad and the camaraderie with the other clients is just priceless. They just love him and the feeling is mutual."

Initially, Jarrett's caregiver role may sound pretty rudimentary until one realizes the complexities like cellulitis, incontinence, and edema she has encountered as a result of Mrs. Chesney's CHF, COPD, and diabetes.

What is not so apparent is the detail — and Jarrett's thoughtful consideration — needed to ensure her comfort not only during routine personal care, but for the remainder of the day when Mrs. Chesney is self-sufficient and home alone. "Empowering clients to care for themselves is such an important aspect of my role. I know their surroundings and teach them how to arrange, or rearrange, their setting to be safe and comfortable," said Jarrett. "Knowing I am helping them to live an easier life at home the way they want to makes me happy and makes them happy."

Working around her diabetic foot wounds, catheter, nebulizer treatments and need for continuous oxygen requires Jarrett's constant attention as well as the greatest of all virtues and rarest of commodities — patience.

"Shirley's safety and comfort are of utmost concern to Sue," said home health nurse/case manager Julie Kling, who oversees the Chesneys' medication management and dispensing. "She goes above and beyond with every aspect of their care," added Kling. She also reviews Mrs. Chesney's telehealth readings and makes periodic blood draws and potassium checks for Mr. Chesney.

"Telehealth is also an eye in there every day and has helped to prevent several hospitalizations and emergent care visits for Shirley. We know any fluctuations in her pulse ox or blood pressure may warrant a

## **1. Equalize Access to Medicaid Eligibility – Eliminate substantive and procedural barriers to accessing home-based care and support. PA General Assembly should enact legislation to:**

- a) Establish a funding priority or preference for the less expensive home-based care over nursing home care.

### **The Administration should:**

- a) Employ both expedited clinical and presumptive financial eligibility for seniors and individuals with disabilities.
- b) Submit a Medicaid State Plan Amendment to create a "spend down" (technically adopting a "medically needy only" option) so that individuals whose incomes are in excess of current waiver program income limits can pay a portion of their monthly cost of care and become eligible for Medicaid for the rest. This spend-down option is now offered to nursing home residents.

## **2. Improve Access to Home and Community-Based Services through Medicaid**

### **The Administration should:**

- a) Submit a state Medicaid Plan amendment to add the Community First Choice Option, which would make the full menu of waiver services available through the state plan instead of a waiver slot for individuals who are nursing facility clinically eligible (NFCE) and
- b) Elect to make this available to those on Medicaid with incomes up to 300 percent of FBR.



visit from us and if needed Sue is always ready and willing to take her for follow-up care,” added Kling.

### *A First-Hand Account of Savings & Value*

Home health professionals such as Kling can help patients like the Chesneys manage multiple medications and physicians in a very cost-effective manner and in the environment they overwhelmingly desire most, according to Vicki Hoak, Executive Director of the Pennsylvania Homecare Association (PHA).

“Their ability to forge strong relationships with their patients allows them to assist people in self-management of their condition and provide necessary follow-up to ensure they remain on track with their therapy,” Hoak added.

In addition to a host of state legislative and regulatory priorities, the agency works alongside PHA as they continue leading advocacy efforts with federal lawmakers. Agency staff joined more than 30 PHA members who convened on Capitol Hill in March to meet with members of the Pennsylvania Congressional Delegation and explain the value and importance of home care.

One of PHA’s successes occurred last year when the Pennsylvania General Assembly amended the Family Caregiver Act, increasing the monthly reimbursement limit from \$200 to \$600 and the home modification cap from \$2,000 to \$6,000. With no additional state appropriation needed from the Commonwealth, the act merely provides local AAAs the flexibility they need to effectively target the state funding to caregivers so more seniors can remain in their homes. This marked the first adjustment since the program began in 1990.

### *Advocating Reform of Long-Term Care Services and Supports*

Although the Chesneys receive home care and adult day services via the state’s aging waiver since they meet

income eligibility guidelines, there’s also a concerted effort by PHA and its 400-plus member agencies to ignite broader reforms to the state’s obsolete Medicaid long-term services and supports (LTSS) statutes. They are pushing for further balance of the long-term care system where costs for 35 percent of the Medicaid population (elderly/adults with disabilities) represent 69 percent of Medicaid’s total budget. These disproportionate, high costs are mostly attributed to nursing home care — the most expensive type of care and the least desired.<sup>7</sup>

While Pennsylvania has seen a marked rise in Medicaid dollars being spent on home and community-based care for our seniors and those with disabilities, the state still lags behind the national 55 – 45 percent balance nursing home to home-based care.

An equal-access, comprehensive and balanced LTSS system will never exist without a comprehensive program transformation. PHA continues its efforts to educate state lawmakers and officials with its comprehensive plan unveiled last year for transforming the state’s LTSS system. It’s a plan that will bring Pennsylvania into the forefront of states having a LTSS system that is designed to respond swiftly to consumers and is based on quality and cost efficiency. On the previous page are the first two of the five proposed system changes to *Bring Long-Term Care Home*, which PHA members are strongly endorsing.<sup>7</sup>

### *Remarkable Care, Hand-Delivered*

“And in the end it’s not the years in your life that count. It’s the life in your years.” The meaning behind the words of Abraham Lincoln emphasizes that the quality of one’s life is by far the most important aspect. The Chesney family represents just one of thousands of families impacted by the mission-driven service of NAHC and its affiliates/membership to ensure that the highest quality of care is delivered where people want to be most — at home. *CARING* editor Lisa Yarkony said it best in her editorial last month in terms of advancing the home and community-based service spectrum as the silver tsunami ensues: “Make a stand. Let’s march ahead for the long-term future of health care in the United States.”

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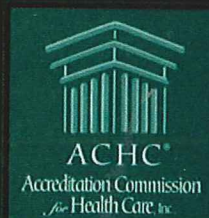
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