



Extending The Caregiver's Reach



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As the Founding Executive Director of the University of the Sciences in Philadelphia's Health Policy Institute, Dr. Stefanacci is building on his recent tenure as a Centers for Medicare and Medicaid Services (CMS) Health Policy Scholar. In that role, he spent a year working on policy development and implementation of the Medicare Part D Pharmacy Benefit, particularly regarding access issues for frail elders.

Dr. Stefanacci has a long and passionate history in long-term care (LTC). Having served as medical director for several nursing facilities and continuing care retirement communities, he is well versed in the needs of LTC facility residents. Additionally, Dr. Stefanacci's geriatric experience includes over a decade as a medical director of a large primary care private practice, a full risk provider group, a Medicare + Choice (M+C) HMO, and a Program for All-inclusive Care for the Elderly (PACE) initiative in Philadelphia.

A graduate of A.T. Still University, Dr. Stefanacci completed his clinical training at the University of Medicine and Dentistry of New Jersey in Internal Medicine and a fellowship in Geriatrics at the same institution.

Dr. Stefanacci serves on the board of trustees at A.T. Still and previously served on the National PACE Association board. He also is an active member of the American Medical Directors Association (AMDA), American Society of Consultant Pharmacists (ASCP), and the American Geriatrics Society (AGS). Recently, he was recognized as an American Geriatrics Society Fellow (AGSF). In addition to writing and lecturing extensively, Dr. Stefanacci serves on the editorial boards of *Caring for the Ages*, *LTC Interface*, *Jefferson's Health Policy Newsletter*, *The Journal of Quality Healthcare*, and *Medicare Patient Management*.

Individual residents can achieve much more when they and their caregivers are actively involved in the care plan. Providing assistance in living is based on that simple belief that involvement of the caregivers with the care team is needed to fill in the gaps or deficiency in care needs.

"When patients and their families are educated and understand why and how they need to actively participate in their care, and when they feel empowered to do so, their involvement can help to prevent medical errors and enhance safety."¹

This was the start of an editorial by Drs. Kevin Bowman and David Nash in a recent issue of the *Jefferson Health Policy Newsletter*.² This quote encompasses the central theme of two important new books, *Patients as Partners: How to Involve Patients and Families in Their Own Care*, by Meghan McGreevey, and *You: The Smart Patient, An Insider's Handbook for Getting the Best Treatment*, by Michael Roizen, MD, and Mehmet Oz, MD.³

Recently I learned firsthand the power of team work among healthcare providers, patients, and family. Such teamwork has very definite applications to assisted living (AL), especially timely as we get ready to celebrate National Assisted Living Week, starting September 9th. During my oldest son's Richard's battle with Ewing's sarcoma, we needed a tremendous amount of assistance despite our own health care-related abilities. Much of this assistance was provided by family and friends, as is also common with senior care. But despite a fairly wide support network, we required supplemental assistance from healthcare professions and facilities that went well beyond our own abilities at home.

Enabling us to extend our reach beyond our normal grasp was

technology. For example, through Richard's Web site, we stayed in touch with friends and family throughout his therapy. Technology can be used to pull patients' families into the healthcare process and to allow them to keep in touch with their loved ones. In this issue, our *Experts' Roundtable* (see p. 40) touches on the role of technology in health care, which too many facilities fail to take full advantage of despite the extremely high return on investment for all involved.

Caregiver Burden

Any discussion regarding extending caregiving beyond the power of one obviously starts with caregivers. Just a few weeks ago the American Association of Retired Persons (AARP) released a study examining the role of caregivers. Their press release headline stated, "Family Caregiving Valued at \$350 Billion," a headline that surely gained reader attention.

The mentality of dropping off grandma at the nursing home and forgetting about her so that someone else can do all the work is wrong on so many levels that each of us can recite. But family pressures and demographics seem to increase this trend. More and more adult children are becoming less reliable sources of custodial care for their parents. People have fewer children, more women have children after age 35, and adult children live greater distances from their parents—all of which factors reduce the availability of adult children to provide long-term care (LTC) services for their elder family members in the home. The result is increased use of LTC services such as home care, adult day care, and AL.

This is, of course, a major issue for many reasons, not the least of which is that the trend leads to

poor quality of life for residents and increased responsibilities for administrators and staff of LTC facilities.

Ideally, family members need to be active members of the care team.

Family caregivers have the opportunity to improve the quality of life for residents of LTC facilities by being involved at 3 levels:

1. Providing guidance in the care planning process
2. Providing additional personal hands-on assistance within the facility where a family member resides
3. Taking the family member outside the LTC facility to visit community facilities and attend social functions

Involvement in the Care Plan

From the beginning, the care team must be on the same page. Leadership must come from the patients themselves or a single responsible party. Healthcare professionals can lend support by helping to move the plan in a specific direction, but they must be aware of the desires of the individual. Although we healthcare providers talk about patient-centered care, still too often we base care on a standardized approach developed by us for us. Instead we need to bring each individual into the development of his or her care plan.

We need to include a discussion of trade-offs that exist for various therapeutic options. With each therapy or diagnostic test there are costs and benefits that must be weighed. These assessments of costs and benefits can only be made by the individual patient. Even simple tests

Richard Glew Stefanacci

September 27th 1992 – June 12th 2007

Richard Glew Stefanacci, of Merchantville, NJ, spirited soul of his parents Beth and Richard; loving brother to Christopher, Morgan, and Nicholas; and friend to many—especially at Camden Catholic High School, St. Peters School and parish, and Camp Wood-



ward—passed away at the young age of 14 after a year-plus battle with Ewing's sarcoma. His challenging year with cancer is detailed at: www.Go4theGoal.com.

In thinking of Richard, words that come to mind are Happy, Spirited, Soulful, Extreme, Friend, Teacher, Surfer, Inliner, Snowboarder, Rock 'n Roller, Traveler, Philly, and Smile.

Richard has always given his all to friends, family, and strangers and continues to do so in dying. He still leads us as he donates his corneas. Unfortunately, because of Richard's disease, these were all that he could give.

In lieu of any gifts, please consider a donation to Go4theGoal Foundation at: www.Go4theGoal.org. This foundation will continue to be guided by Richard's spirit—in a way that only Richard could lead us in caring for children affected by cancer.

such as blood glucose testing may in fact be incredibly difficult for some patients with limited benefits, causing them to forgo this diagnostic study. Only by including patients in the development of their care plans can these limitations be known. Such treatments as pain management, palliative care, hospice, living wills,

feeding tubes, and ventilators require individualized decisions.

Discussions with patients need to include end-of-life care and organ donation. Even in dying everyone can provide some level of assistance to others. Organ donation is available to all individuals who indicate their intent to donate. (Persons

“ Do not resent growing old.
Many are denied the privilege. ”

– Anonymous

younger than 18 years must have a parent's or guardian's consent.) Medical suitability for donation is determined at the time of death.

All too often seniors don't even consider this opportunity, or worst yet, healthcare providers wrongly believe that seniors are not candidates to donate. This is oftentimes a wrong assumption. In our son Richard's case, he had undergone a year of therapy including surgeries, chemotherapy, and radiation, but he was still able to donate his corneas to provide vision for someone else. Knowledgeable involvement in the complete care plan including end-of-life care and beyond is critical, especially given the tremendous need (see *Candidates for Transplant*).

Hands-on Assistance

This article on advanced technology devices (see *Beam Me Inside, Scotty!* on page 24) discusses the ability of robotic devices to provide a helping hand for onsite and offsite caregivers, residents, families, and other

Candidates for Transplant

Waiting List Candidates	96,965	as of 07/09/2007 7:19pm
Transplants January to February 2007	6,799	as of 06/29/2007
Donors January to February 2007	3,478	as of 06/29/2007

Based on Organ Procurement and Transplantation Network (OPTN) data. Available at: www.organdonor.gov

staff members. Still, "live" family caregivers who can provide hands-on feeding or bathing assistance to residents are irreplaceable.

Of course family caregivers cannot be present at all times. So families and residents depend on onsite healthcare teams working at their best, as is discussed in *Facility-based Physicians in LTC: A Win-Win Model* (page 28) and *The Role of the Clinical Pharmacist in AL Facilities* (page 37).

Take-Out

Entry into a LTC facility should not

be the end of relations with the outside world. With the support of the facility, residents can continue relationships with people and places "on the outside" and even explore new ones. Family are invaluable in planning resident trips outside the residence and staff can help facilitate these outings.

Providing assistance in living is what we are all about and this issue with its focus on caregiving and technology is no exception.

You'll note a new *ALC* feature we're introducing that underscores quality of life issues for elders. Contemplate our "age quotes" that appear on the bottoms of some pages within this issue, like the one on page 7 of this editorial—just another way that we are working to add to everyone's quality of life. ALC



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Reference

1. McGreevey M. *Patients as Partners: How to Involve Patients and Families in Their Own Care*. Oakbrook Terrace, IL: Joint Commission on Accreditation of Healthcare Organizations; 2006.
2. Bowman K, Nash DB. Activating patient involvement. *Jefferson Health Policy Newsletter*. June 2007;20(2):1-2.
3. Roizen MF, Oz MC. *You: The Smart Patient—An Insider's Handbook for Getting the Best Treatment*. New York: Free Press; 2006.

Letter to the Editor

In reference to the May/June issue of *Assisted Living Consult's* "Case study: Optional Transition to the ED," by Barbara Resnick, one of the things we consider in the feasibility of treatment in the nursing home are the goals of acute care/goals of long-term care (LTC). I think that should be added to the guidelines.

With regard to information to be sent to the ED, we strongly advise:

- Baseline vital signs, not just the most recent set
- Same with labs, weights, etc.
- Baseline self-care or care/support needs (ADLs).
- Optimum pain management (especially medications/interventions tried but ineffective)
- Prosthetics (teeth, glasses,

hearing aid)

- Advance directives or verbal statements of treatment wishes
- Sleep and bowel movement patterns
- Normal appetite

In reference to Red Flags—absent the baseline info, it would be very difficult/impossible to assess changes.

I know this is more writing, but it gives the ED a better picture of how far the resident is off his or her normal.

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