

Continuing the Conversation

End-of-Life Issues—Navigating the Maze

Lou Horvath

At a roundtable session of the PEPC on January 26, 2010, John "Jack" Lombard, Esq., Special Counsel at McCarter & English, LLP, and Lou Horvath, Executive Director of Intervention Associates, discussed "End-of-Life Issues — Navigating the Maze of Legal and Care Issues." The topic generated significant interest among attendees. Many expressed a desire to continue the conversation. We asked Lou Horvath to share additional insights on the subject.

Why didn't I call you earlier?

At Intervention Associates, we so often hear this question when a client contacts us in response to an immediate need for a family member. More often than not, that family member is in a hospital or a rehabilitation center, ready for discharge the next day, and unable to care for himself. Suddenly, the family faces a very real dilemma.

Concern for the safety of an elderly parent (or parents) living independently is another all too common scenario. Mom or dad has grown forgetful and disorganized, isn't navigating in the home well, and continues to drive, even though she or he really shouldn't. Often, by the time we receive this kind of call, families are operating reactively. Emotions are running high and family members frequently disagree about what to do. They want realistic options and potential solutions fast.

As we face issues of aging and end of life with our clients, our loved ones (or even ourselves!) preparing for a change in health should be top on our list of priorities. Too often, it never makes the list at all. I'm convinced that the drama and enormous strain these emotionally charged care-related situations place on families can be improved vastly if professionals proactively engage in health care planning, just as we do in estate and financial planning. It can be as simple as knowing in advance who to call and when.

What should I do?

When faced with the (often sudden) development of a family emergency, care management is usually the answer. Care management should be an integral part of any well-planned health care delivery system.

What is Care Management?

Though some people have heard the term, few seem sure of its meaning. Care management encompasses a variety of activities and steps required to properly plan for and deliver care to a person whose limitations prevent him from caring for himself. It often includes the coordination of client access to various community-based services.

The main components of care management include ...

- Patient assessment/reassessment
- Development of an individualized care plan
- Arrangement and coordination of services (usually multiple)
- Continuous monitoring of services and client needs
- Patient advocacy

The care management function takes the burden of determining what's best for mom or dad, for example, and the onerous task of finding and arranging appropriate services, off the family's shoulders. Ideally, it transfers that responsibility into the hands of a degreed, highly credentialed professional care manager. Understandably, families find this an immense relief.

Who is the Professional Care Manager?

The professional care manager ("PCM") is a health and human services specialist who formally assesses the needs of the individual and then creates, coordinates and monitors his care plan. The care plan might include transportation to doctors' visits, arrangement for home health aides to assist with activities of daily living, and any number of other nonmedical services. Most care managers are trained and experienced in fields such as social work, nursing, geriatrics, psychology, or other disciplines related to health care or mental health.

continued on page 2

Some care managers work specifically with older adults to help them attain and maintain their maximum functional potential. These geriatric care managers serve as specialized resources for families of older adults and others with chronic illness, including people suffering from Alzheimer's or Parkinson's disease, or those exhibiting symptoms of dementia. It's best to look for geriatric care managers who are members of the National Association of Professional Geriatric Care Managers (NAPGCM). As members, they commit to a prescribed code of ethics and standard of practice.

What a Good Professional Care Manager does

The PCM works closely with families, the community, physicians, attorneys, estate planners and financial advisors to arrange for and provide a range of services for people of all ages and also provides assistance in over diverse geographic areas.

The best of these service providers have the ability and willingness to handle difficult, challenging and complex situations. Their clients include elderly adults, children and adults with special needs, people with multiple disabilities or chronic ailments, and patients with psychiatric issues and other mental health conditions.

Professional Care Managers range from solo practitioners to group practice arrangements to organizations.

This is a detailed description of services provided by PCMs:

Care management services

- A professional needs assessment followed by an effective care plan to help the individual maintain independence, function and quality of life (we believe home care does not mean homebound!)
- Identifying the most appropriate links to the community and private resources, including home-delivered meals, transportation and other services such as home care
- Complete care coordination, monitoring and oversight
- Patient advocacy, from inpatient admission through discharge
- Referrals to additional care providers, such as physicians, adult daycare programs, rehabilitation centers or nursing homes
- Assistance in selecting assisted living or other senior facilities, if needed, plus help with the actual move and

- monitoring the care and services received there
- Power of Attorney and Guardianship services

Complementary Services

Some Professional Care Management Organizations, like Intervention Associates, provide care from a holistic approach and offer additional services like home care and concierge services. This includes:

Home health care services

- Best practices include the availability of trained certified nursing assistants/home health aides to help with activities of daily living—such as eating, bathing, dressing, grooming, using the bathroom, and getting in and out of bed—available on an hourly, overnight or live-in basis
- Supplemental care within institutions like nursing homes or assisted living facilities
- Homemaking companions to help with meal preparation and light housekeeping

Home care concierge services

- Bill paying and home office services
- Grocery shopping, transportation to doctors and other appointments
- Social companionship
- The ability to accommodate just about any request

The primary challenges

Lack of awareness

Few people are aware that care management services even exist, let alone understand the role of a PCM. In other words, families of individuals who need support (and sometimes even their professional advisors) don't know what they don't know, until they are thrust into a situation where they are trying to find and coordinate services on their own. Education is one of the greatest hurdles. PCMs report that, once their clients get the concept and experience the service, they find it indispensable.

Cost concerns

The economy has had a dramatic impact on service organizations and their clients. PCMs must strive always to develop a cost-effective, comprehensive care plan that meets a client's needs and budget. At first, clients may question the expenditure; they may not initially realize that having a care manager is an investment that

will pay significant personal dividends in quality of care and peace of mind.

Choosing a trusted resource

The health care system is an incredibly complicated maze to navigate, even for an experienced professional. Clients caught in a family predicament feel predictably overwhelmed. This is where a highly credentialed, experienced care manager proves invaluable. Well qualified PCMs have extensive knowledge about the cost, quality and availability of health care and long-term-care services in the communities they serve. Their skills and compassion are unsurpassed. They have access to programs that families and their professional advisors may never know about otherwise. They manage every detail with the goal of restoring their clients' independence wherever possible.

Not all PCMs are created equal, of course. You need a resource you can trust and Intervention Associates can help. Besides providing PCM services in the geographic area that corresponds with that of PEPC, as an active member of The National Association of Geriatric Care Managers, we have the ability to offer referrals to well qualified PCMs in other geographic locations.

Louis D. Horvath has been Executive Director of Intervention Associates since 2007. He serves as an adjunct faculty member at St. Joseph's University in Philadelphia and at the University of St. Francis in Joliet, Illinois. Lou is a Fellow of the American College of Health Care Executives, a certified member of the National Association of Geriatric Care Managers and a certified member of the Association of Behavioral Health Care Executives. Intervention Associations is a nonprofit, Quaker-based care management and home care organization serving the greater five-county Philadelphia area. It is a subsidiary of the Friends Life Care System (www.friendslifecare.org).

A note about moving forward:

How do we keep navigating legal and care issues at the end of life?

The dialogue on end-of-life legal and care issues must continue. We can all contribute to greater understanding. A few suggestions:

- PEPC can identify this client need as one of the priorities in the work of its members.
- A dedicated task force of medical, legal and financial professionals is needed, along with care providers and ethicists, to develop guidelines that will assist PEPC members with their clients' end-of-life issues.
- Another need is an alliance with care managers to implement a collaborative model for holistic planning that includes health-related concerns and care.

It has been my pleasure to meet many PEPC members during the past few years. You are part of a remarkable array of professionals helping people with a variety of needs. I hope you will regard Intervention Associates as a resource on this important topic.