

## VNA: CARING FOR A LOVED ONE AT HOME WITH SERIOUS ILLNESS

News that a loved one is facing a serious illness can be difficult to understand and cope with at first. This happens very frequently to families with perhaps no formal medical background who may not be prepared to take on a new role as caregiver.

According to a 2004 study by AARP and the National Alliance for Caregiving (NAC) "44,000,000 Americans are providing unpaid care to an adult relative or friend." Nearly 60% of those caring for an older adult are working, with almost half, full time employees. (MetLife/ NAC 2006) US businesses lose \$17.1-33.6 billion per year in productivity for full time employees with caregiving responsibilities. The annual cost of grief in the workplace is also estimated to be \$75.1 billion. (Caringinfo.org) Some employers have recognized that providing formal support for working caregivers can help the employee, the workforce in general and the business. If available, it is worthwhile to take advantage of this type of assistance. There are other forms of help in each community as well.

A caregiving example: Mary's mother has just been diagnosed with end stage kidney disease and will be requiring ongoing dialysis. Normally, Mary's parents function as a team, though they both have their own medical conditions. But, Mary's father is now considered legally blind and has been diagnosed with cancer with a poor prognosis. Though Mary works full time, she is now the primary caregiver for her parents medical, physical, transportation, financial, legal and emotional needs. She has many questions and is not sure of where to get help to supplement the care that she so willingly provides.



*Hospice Life Care's management and staff would like to thank all of the wonderful volunteers, employees and community customers who contributed to the success of this season's Hospice Life Care gift wrapping fundraiser. In addition, special thanks are extended to the management of Holyoke Mall at Ingleside for their support and the Hampden Papers and Hazen Paper Company who so kindly provided all of the wrapping paper for the event.*

This is just one example of the scope and commitment of becoming a caregiver while also balancing a job and ones own family. Statistics show that this is a frequent occurrence.

An evidence brief, Palliative Care and Advanced Illness Management, by the Visiting Nurse Services of New York Center for Home Care Policy Research, found "caregivers are looking for support." Families are often plunged into the role of unpaid caregiver. Responsibilities may include managing medications, understanding side effects, dressing changes, assisting with walking, transferring, dressing, bathing, meals, transportation for appointments, conferring with physicians and other medical personnel and supervision for safety.

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Additionally, "caregivers have many questions that should be addressed with ongoing education, discussion and family contact." The study also noted that "caregivers should learn to recognize when their loved one is showing signs of decline and be able to rely on healthcare providers to communicate and explain the active dying process."

Along with the physician, home health care, palliative care and hospice programs have the expertise to provide this kind of ongoing care and teaching at home when there is a medical need. Home care professionals, such as nurses, social workers, physical therapists, occupational therapists, speech therapists and home health aides are all part of the team that can assist.

The team's communication should be simply stated and specific to the unique needs of the family and caregivers. The VNSNY research shows, "caregivers prefer to receive information in small chunks with trusted health-care professionals who can balance honesty with hope."

The services of the Aging Service Access Point network and private pay services to assist with many types of care can also be accessed in the community.

Below is a listing of websites and resources that can help along the journey of caregiving, which can be rewarding, though impact a physical and emotional toll when caring for a loved one with serious illness. These resources can help a family establish a volunteer or paid support system and help to take care of the caregiver too.

Orientation to Caregiving: A Handbook for Family Caregivers of Patients with Serious Illness.

[http://cancer.ucsf.edu/\\_docs/crc/Caregiver\\_Gen.pdf](http://cancer.ucsf.edu/_docs/crc/Caregiver_Gen.pdf)

[www.caregiver.org](http://www.caregiver.org)

[nac@caregiving.org](mailto:nac@caregiving.org)  
National Alliance for Caregiving

[www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)

The Holyoke VNA and its Palliative Care and Hospice Life Care program are trusted names for patients and families facing serious illness who live in Holyoke or the eighteen surrounding cities which we have served since 1905.

Visit our website [www.holyokevna.org](http://www.holyokevna.org) or call 413-534-5691 for information. □