

Boomers, Elders, and More E-Newsletter

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Nashville, TN 37212

<http://vanderbilt.edu/child-family-center/>

Message from the Coordinator

Vanderbilt Child and Family Center's 6th Annual Elder Care Fair is right around the corner. The Elder Care Fair is designed as an opportunity for the employees of Vanderbilt to obtain helpful information about the resources and services in the community that are offered to seniors and their adult caregivers.

More than 15 vendors are expected to fill Light Hall. Display tables will be occupied by organizations and businesses specializing in the health, comfort and general well-being of the elderly and their caregivers. Examples include assisted living facilities, in-home care agencies, adult day programs, future planning consultants, and much more.

The 2015 Elder Care Fair will be held Friday, October 9, 2015 from 11:30 a.m. until 2 p.m. in Light Hall, North Lobby.

For questions about this event, please contact Stacey Bonner, Family Services, Coordinator, at stacey.l.bonner@vanderbilt.edu or 936-1990.



News Highlight

Dementia Patients, Caregivers Prefer Better Care, Support Over Research for Alzheimer's Cure

Study finds dementia spending priorities chosen by those living with the disease differ from those in national Alzheimer's plan

More than \$100 million in federal funding was spent last year toward searching for a cure for Alzheimer's disease. However, if given the choice, most people with dementia and those caring for them would like to see the money go elsewhere, according to a recent study led by Davina Porock, PhD, RN, a professor in the University of Buffalo School of Nursing.

The study surveyed people with dementia and their care providers on how funding from the National Alzheimer's Project Act (NAPA), a federal plan to overcome the disease, should be spent.

It revealed that the majority of respondents ranked caregiving support and resources for long term care ahead of research for a cure.

The findings are in contrast to current NAPA spending to support those with Alzheimer's disease, which dedicated only \$10 million to care services and education, according to the Department of Health and Human Services.

With more than 5 million people in the United States living with dementia, each person receives less than \$2 for care support, Porock says.

"Sure, most people in our surveys would love for there to be a cure, but in the meantime they all have this disease and they need help," Porock says.

"We have 10 times more money going toward research instead of supporting the people who are living with dementia. Research is still high on the agenda, but they think that support is more important."

The study, "National Priorities for Dementia Care: Perspectives of Individuals Living with Dementia and Their Care Partners," was published in the **Journal of Gerontological Nursing**.

The nationwide survey recorded nearly 700 responses, drawing participants from more than 25 Alzheimer's disease advocacy and patient-support groups. Participants were asked to rank funding priorities based on 11 themes that included care setting, quality of life, and advocacy, and awareness.

Of the responses, the top five priorities were the following:

1. Financial resources for respite care and short-term caregiving support—care that typically lasts less than a

week and is used to relieve family and daily care providers.

2. Financial resources for long term care support and aging in place, which includes assistance with nursing home and assisted living expenses;
3. Research for a cure and medication;
4. Education and training for families, health professionals, and volunteers;
5. Advocacy and awareness to reduce the stigma of dementia.

Respondents also preferred that not all research funding be allocated by finding a cure. Other areas of focus included workforce issues, education and training, impact on quality of life and the family, and alternative therapies and treatments.

Person-centered approaches to care were a clear theme in many of the responses. Most participants desired the person and family living with dementia, and not the disease, to be the center of care, policy, and research.

Dementia is an irreversible condition that slowly impairs memory and cognitive skills, and eventually a person's ability to carry out daily activities. People with dementia often need assistance eating, bathing, and dressing, and sometimes have difficulties communicating.

Alzheimer's disease make up nearly one-half of all dementia cases, and symptoms typically first appear after age 65.

"It's a taxing job to take care of someone with dementia," Porock says. "Families, as much as they love each other, can find these tasks physically and emotionally difficult to do. And when the caregiver is a spouse who is close in age, it's not unheard of for them to die first."

Another common issue involves caregivers putting their careers on hold to support an ailing family member and having difficulty returning to the workforce, Porock says.

Increased funding for families with dementia could improve their ability to afford nursing support in their home or at an assisted living home.

"Dementia is a major—and increasing— issue in the world because we have more and more people living longer.



Source: http://www.todaygeriatricmedicine.com/news/081915_news.shtml

Caregiving: A New Job on a Silver Platter

By: Aileen Ruess (a fourth generation caregiver)

Most new jobs don't come without work or effort or on a silver platter! New employment usually begins with a phone call after interviews and negotiations. We may even remember where we were and what we were doing when we got the call.

Likewise, I will always remember the call that began the most worthwhile job of my life. I got the call "Your mother had a stroke." I was in the bathroom I remember I collapsed on the vanity. I thought of my favorite place on earth. I had always wanted to take her, but had not.

When a family member has a stroke or heart attack, is diagnosed with dementia, cancer or has a life threatening event, our lives change. We also don't realize that it is the beginning of a brand new job. A job for which there was no application or interview and in most cases it is full-time with vary long hours.

We certainly did not negotiate or prepare for this new endeavor. It arrived like a tidal wave, totally engulfing us physically and emotionally. There is no tour or orientation that will help us navigate this new job. A new job with life threatening consequences and real goals. The goal to get our loved one the quickest best possible care and treatment.

In our panic, we have a brief moment of relief: They are ALIVE!

Oh yes, so thankful, they are alive. We realized that we can live with this. The tidal wave is receding.

So round one begins with a maze of hospitals, doctor's appointments and seeking specialists. This results in round two of rehab, chemo, radiation, therapy, medications, etc. We juggle our time between our job, family and our loved one, always neglecting one or the other.

We have the diagnosis and the prognosis and we are searching for the best care. We soon learn that health care has become a game: the Medicare game. Care is dispensed by what Medicare will pay for, so many days in the hospital, so many days in rehab, and so many days for therapy.

Our new job, the one that was handed to us on a silver platter, starts encroaching on our real job - - and it is getting harder and harder to manage. Navigating the medical issues and finding the best care and treatments are all very time consuming. We are thankful for the tasks at work that we can do with our eyes closed but how long can that last.

So we move into the next phase in the back of our mind hoping that life can somehow get back to normal. We would like to get our work caught up and back on track and spend time with our husband and children.

But danger is lurking - - we are blindsided by unexpected complications.

Once our feet are wet with our new job, we start to experience the complications that are inevitable; misdiagnosis, side effects of medications, access to specialists, infections, access to care, treatment and applying for experimental treatments.

At some point along the way, we may realize that our new job has a title: caregiver. It is taking care of someone who is unable to take care of themselves. It takes time and dedication. Caregiving is done in many ways from near or far. Sometimes it can be managed from a far but it is not easy. Caregiving is different for everyone. There is no right or wrong way.

Decisions have to be made for care. The care that you need may not be available or be too expensive. You may choose to care for your loved one. Teachers are retiring early, civil servants are getting their hardship requests turned down and opting out, practices are being turned over, all in favor of the new job handed over on a silver platter.

Caregiving is a worthy endeavor. There is no greater joy than to serve another. Even if it involves taking care of one from a not-so-great past relationship. All families have issues. This is an opportunity to forgive and make it right.

It is not necessary that you do the one-on-one care, but make sure that those that are unable to care for themselves are properly cared for. Your caregiving journey will enrich your life as well as those that need the care.

Since I received that phone call, my mom and I have traveled the 500-mile trip to my favorite place on Earth - - twice! Embrace your journey as a new adventure handed to you on a silver platter. Get the resources and help that you need. Put one foot in front of the other every day and do the best you can.

source: http://www.huffingtonpost.com/aileen-clancy-ruess/becoming-a-caregiver_b_6130876.html

10 Tips for Family Caregivers

1. Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.
2. Watch out for signs of depression, and don't delay in getting professional help when you need it.
3. When people offer to help, accept the offer and suggest specific things that they can do.
4. Educate yourself about your loved one's condition and how to communicate effectively with doctors.
5. There's a difference between caring and doing. Be open to technology and ideas that promote your loved one's independence.
6. Trust your instincts. Most of the time they'll lead you in the right direction.
7. Caregivers often do a lot of lifting, pushing, and pulling. Be good to your back.
8. Grieve for your losses, and then allow yourself to dream new dreams.
9. Seek support from other caregivers. There is great strength in knowing you are not alone.
10. Stand up for your rights as a caregiver and a citizen.

Source: *Pinterest*

Upcoming Events

Vanderbilt Child and Family Center will be hosting its 6th Annual Elder Care Fair on Friday, October 9, 2015. This event will take place in Light Hall, North Lobby from 11:30 a.m. to 2 p.m. Representatives from area agencies who provide resources and services to those who are caregivers for a parent or spouse will be available. This will be your opportunity to ask questions and receive valuable information.

Vanderbilt Family Resource Center's Caregiver Support group will be held on October 14, 2015 from 12:00 p.m. to 1:00 p.m. in Medical Center East Room 8380A. The caregiver support group is a time to share information and openly discuss your problems without judgment, to process your feelings, and to hear others talk about their experiences.

If you need information or resources to assist you in your caregiving journey, contact Stacey Bonner, Family Services Coordinator, at stacey.l.bonner@vanderbilt.edu or 936-1990.