

North Star News

NOVEMBER / DECEMBER 2011



For the Health Of It

November is **NATIONAL FAMILY CAREGIVERS MONTH!**

Family caregivers provide the support that millions of Americans rely on to stay healthy and live independently. In fact, AARP estimates that nearly 44 million Americans provide care to a family member today.

Caregivers can be family members, partners, or close friends, and are there to provide care and support for a loved one, many of whom are older adults with multiple chronic conditions. Family caregivers provide assistance with day-to-day tasks like bathing and dressing; they help pay bills and provide transportation; and they monitor medication and navigate a fragmented health care system. It is estimated that an individual over the age of 65 with multiple chronic conditions will have an average of **37** doctor visits, see **14** different doctors, and get **50** separate prescriptions in ONE YEAR alone (nationalpartnership.org). Family caregivers play a critical role, but often do not have the support they need.

Many caregivers struggle to balance day-to-day responsibilities and often lack the assistance they need to meet the demands of caring for a loved one. In 2000, the National Family Caregiver Support Program was established to provide critical assistance to caregivers, but implementation of the program in Pennsylvania failed to adequately meet the needs of many family caregivers. Read more about the FAMILY CAREGIVER SUPPORT PROGRAM in the following pages, and what steps are being taken to improve supportive services for Pennsylvania families.

→ Are you providing care for a loved one? Check out these valuable tools from the Pittsburgh Caregiver Support Network:
[Caregiving Toolkit](#) and [blog](#)

→ Read powerful stories from Community Catalyst about family caregivers like you and [ADD YOUR VOICE](#) to the wall.



PA Campaign for Better Care

THERE IS A BETTER WAY!

We all deserve comprehensive, coordinated health care. We get it. There is a better way. And we invite you to join a campaign like no other— the Campaign for Better Care.

The PA Campaign for Better Care (PA CBC) is a statewide campaign to secure quality, coordinated, and patient-centered care in PA. CHC is the driving force behind the Campaign here in PA, which was selected as one of six state-based campaigns along with Maine, Massachusetts, North Carolina, New Jersey, and Ohio. A partnership with Community Catalyst, a national healthcare advocacy organization, provides valuable oversight and guidance.

READ MORE about PA CBC at www.consumerhealthcoalition.org

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Raising Health



The National Family Caregiver Support Program was passed in 2000 to provide financial, emotional, and physical assistance to family caregivers. Under the program, families have access to care management, respite care, and financial reimbursements for home modifications. The national policy was based on the **PENNSYLVANIA FAMILY CAREGIVER SUPPORT ACT** of 1990, though the national program contains key components not included in the Pennsylvania model. Unlike the Pennsylvania model, the national Support Program allows non-relative caregivers to access assistance and does not require that caregivers live with the care recipient.

In Pennsylvania, legislation has been proposed to update the Family Caregiver Support Program. **HOUSE BILL 210** and **SENATE BILL 639** would provide these key updates:

- ★ Raise the monthly reimbursement rates
- ★ Raise the lifetime home modification allowance, which is currently set at \$2,000
- ★ Expand the definition of *primary caregiver* to include non-traditional caregivers

How can you get involved?

The Family Caregiver Support Act passed the House and is currently in the Appropriations Committee of the Senate. CONTACT YOUR SENATOR and ask them to support SB 639. Remind your elected official that the bill does not require any new sources of revenue, and that the proposed updates are critical to caregivers across the state who provide care to a loved one.

Keep up to date on the local AARP [here](#)

Advocacy Toolbox

Did you know that the Editorials are the most-read section of the newspaper? A Letter to the Editor is a great place to start when you are passionate about an issue, have a point of view to share, or need to spread the word about advocacy and action.

Join in National Family Caregivers Month with a letter of your own! Family caregivers play a crucial role in our families and communities. This month, say thank you, but don't forget that these caregivers also need our support. We know that there is a better way to provide care, and that family caregivers should not have to navigate a fragmented, poorly coordinated health care system.

With 250 words or less, you can make your voice heard and raise awareness about the need for better care. Here are a few tips to help you get started:

- About what? Make your point quickly.
- Accurate information. Make sure facts are correct and current.
- Awareness. What do you want readers to know?
- Action. What do you want readers to do?
- Always follow-up. The day after you send the letter, call to make sure it was received.



Advocates Speak Out

In 2007, Barbara became a full-time caregiver for her husband. This is Barbara's story, as told by Joyce Schlag, LCSW.

In 2007, I became a full time caregiver for my husband of 30 years. He suffered a series of strokes. There was no one to help with his daily care needs. I left my full time job to be his caregiver and thus lost my own health insurance. My husband needs assistance with all of his personal care, help with his medications and mobility. He depends on me to take him to his doctors' appointments, to give the doctor information about changes in his condition, and to ask questions when further information is needed.

Two years ago, I took my husband to a stroke support group. We met with other stroke survivors and their caregivers. At first, I only noticed the survivors and not the people providing their care. At a certain point, I looked across the table and realized that caregivers are separate people who have their own needs, some which are similar to mine and other needs specific to their situation. I realized that some of the caregivers could be going through even more than I. Until then, I didn't even identify myself as a caregiver. After that, I was able to tell myself and others, including my husband's doctors, "I am his wife and his caregiver." This was my starting point for forming a caregivers group.

As I focused more on what caregivers need, I decided that we need some time to break away from the survivors, to share time together, and to figure out how we can take care of ourselves. As caregivers we need to recognize our own individual needs. This is especially important when our day to day experience is filled with thinking about and anticipating our loved ones needs. The group gives us the opportunity to share our ideas and get encouragement to pursue our own goals. It's not selfish to do the things we like to do or to share our thoughts and feelings with others. Barbara advises caregivers, "You can be a caregiver and still be the person who you are. In the end, both you and person you are providing care for will benefit."

A special thanks to Joyce Schlag, LCSW, who worked with Barbara to compile her story.

News You Can Use

- Check out an [op-ed](#) from the Milwaukee Sentinel Journal. The op-ed was written by Community Catalyst and talks about how to reduce health care spending without cuts to Medicare eligibility or benefits.
- Read an [article](#) published in the American Society on Aging journal about how the Affordable Care Act could impact the supportive services available to family caregivers.
- Bookmark the Caregiver Champions blog to keep up to date on important caregiving information and resources.
(Available [here](#) or at www.caregiverchampions.org/blog)
- Are you a family caregiver? Get answers to common questions and read tips on how to manage the care of a loved one with the Family Caregiving 101 website.
(Available [here](#) or at www.familycaregiving101.org)



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Consumer Health Coalition was founded in 1996. We are a non-profit health care advocacy organization with a mission to "inspire a consumer movement to advance health and enhance access to quality, affordable health care."

We believe that access to quality, affordable health care, and ultimately good health and wellness, are critical to a person's ability to reach his or her potential. We also know that people experience disparate "starting points" or access to resources that are unfortunately correlated with socioeconomic status, racial or ethnic background, and disability status. CHC is dedicated to the eradication of disparities in health access and outcomes, and will continue pushing until every person has the health coverage and care they need.

Mark your calendar for these important dates!

November 2011

TUESDAY NOVEMBER 22

The Facts About Social Security and Medicare
PCN Forum with Eric Kingson
1:00 pm
Location:
Sheraton Station Square Hotel
300 West Station Square Drive
Pittsburgh, PA 15219

TUESDAY NOVEMBER 29

Community Catalyst Webinar
Beyond 'Just Say No':
Strengthening Medicaid Defense Work
1:00 pm to 2:00 pm

December 2011

MONDAY DECEMBER 5

Healthy Hospitals Workgroup
6:00 pm to 7:30 pm
Location:
Consumer Health Coalition
415 E Ohio St Suite 300
Pittsburgh, PA 15212

THURSDAY DECEMBER 8

PA CBC Conference Call
10:00 am to 11:00 am
Call-in: (712) 432-1630
Access code: 411307#