Is it dementia or normal aging? How to recognize the difference

By Alicia M. Colombo

Are you getting forgetful? Have you misplaced your keys lately? You might be concerned that it’s something serious, like Alzheimer’s. Almost 6 million Americans have Alzheimer’s disease, according to the Alzheimer’s Association. It is estimated that one out of every nine people older than 65 has Alzheimer’s or another dementia and that one in three seniors will die from a form of dementia.

“The incidence of Alzheimer’s and other dementias is only expected to increase over time, as the baby boomers continue to age,” said Krista McKay, director of programs and services for the Alzheimer’s Association Delaware Valley Chapter. “Beyond 65, every five-year age group has an increased risk for Alzheimer’s.”

Because Alzheimer’s and other dementias are so prevalent in older adults, it’s important to know the difference between normal aging and signs of a problem — and when it may be time to seek help.

The aging process

It is normal for people in their 50s or 60s to have trouble with word retrieval or multi-tasking. “Older people, compared to younger people, may struggle to learn multiple things at one time,” said Jason Karlawish, M.D., co-director of the Penn Memory Center. “But what they do learn, they retain over time.” Retaining knowledge over time is known as fluid intelligence, and remembering the information is called crystallized intelligence. With aging, crystallized intelligence is stable or even increases as we learn new things. In contrast,
Health Brief

Practicing self-care is essential for a caregiver’s overall health, well-being

Practicing self-care is integral to leading a healthy lifestyle. However, people often place the needs of others above their own, putting their physical and mental health at risk in the process. This is especially true of caregivers. Caring for the needs of others often comes at the expense of meeting one’s own needs. The self-care checklist below was put together by Iona, a senior services program based in Washington, D.C. It can serve as a reminder for seniors to keep their individual needs at the forefront every day, even if they are caring for another.

**Physical needs**
- I’m seeing my doctor(s) regularly and keeping up with recommended appointments.
- I’m exercising daily.
- I’m maintaining a balanced diet.
- I’m getting the recommended seven to eight hours of sleep each night.
- I’m taking my medications on schedule (if applicable).
- I’m not misusing alcohol or drugs.

**Social needs**
- I’m seeing family and friends on a regular basis and keeping up with the lives of people in my social circle(s).
- I’m participating regularly in at least one activity I enjoy.
- I have fun at least once a week.

**Emotional needs**
- I engage regularly in at least one healthy outlet for stress. (This can include enjoying a hobby, confiding in someone, writing, reading, exercising, meditating or otherwise relaxing.)
- When I feel I cannot handle difficult emotions on my own, I reach out to those I rely on for emotional support.

**Spiritual needs**
- I take time to engage in the faith-based practice that helps to sustain me (if applicable).

**Caregiving-specific needs**
- I understand the diagnosis and prognosis for my loved one’s condition, so I am prepared for the challenges of caregiving.
- I understand the financial and legal situations surrounding my caregiving responsibilities.
- I have a plan for the future as my loved one’s needs change, or I know where to get help making a plan.
- I’m not tolerating abuse from the person I am caring for.
- I’m asking for, and accepting, help from family, friends, neighbors and professionals.

While being aware of one’s own needs is an important first step to ensuring a healthy lifestyle, caregivers may need additional support. For caregivers who are struggling, PCA’s Caregiver Support Program offers education and training, information and referrals, and financial benefits for those who qualify. Visit pcaCares.org/caregivers or see article on page 16 for more information.

Checklist source: Iona.org
PA Health & Wellness is focused on whole health care, reflecting on a person’s total well-being and meeting each person’s unique needs. Providing whole health care and long term supports and services requires us to broaden our services and provide solutions to address all of life’s changes.

Our full continuum of health, support, and services options provides diverse solutions to improve outcomes. We understand and address barriers to health and provide access to the best care for each and every person to live his or her best life.

PAHealthWellness.com
1-844-626-6813
More millennials caring for elders

By Marcia Z. Siegal

While most people think of family caregivers as middle-aged or older, one-quarter of those caring for family members are considerably younger. These millennial caregivers (born between 1980 and 1996) play a critical role in families by providing unpaid care to their chronically ill, disabled and aging parents, grandparents or other relatives. The number of millennial caregivers continues to expand as the baby boomer generation ages. Many are studying in college or beginning their careers, building their professional networks, and starting families. Elder caregiving is not something that people in their early 20s to late 30s typically anticipate.

Conlan Crosley attests to the shock of suddenly becoming a caregiver. He was 32 when his mother, Dorothy Roberts, was diagnosed with Alzheimer's disease in 2013, and he became her caregiver. The next five years proved to be a harrowing journey for both of them.

A 2017 study by researchers at the University of Southern California reported that one in six millennial caregivers is providing care to a dementia patient. Around 40 percent of those millennials are the sole caregiver for their loved one, as was Crosley.

When symptoms of his mother's illness first became apparent, Crosley was an undergraduate at Temple University. He had previously supported himself as a union carpenter, but that work had dried up in 2008 during and following the Great Recession. To make ends meet, he was living at home with his mother. He remembers his shock when one day he came home to find her sitting alone in the basement. The house was totally dark. None of the lights were working. "I called up the electric company to find out what was going on, and it turned out that she had not paid her bills in months," Crosley said. "I started looking into all the bills. It was a mess." Soon after, a neurologist diagnosed Roberts with Alzheimer's disease. At that time, she was on disability leave from her job as a Pennsylvania Turnpike toll collector due to knee surgery. After years of often desperate financial struggles, she had recently reached the point where was finally able to buy a car and move from her tiny apartment to a house. She was so proud of this, her son remembers: "She had worked for 25 years to get out of destitution and have some dignity." Roberts, then 66, had a plan for her future and was looking forward to a secure retirement at the time of her choosing.

That plan changed, and Roberts retired when her Alzheimer's worsened. Crosley's plans also changed as he focused on his mother's increasing medical and personal care needs.

While Alzheimer's progresses differently for each individual, in Roberts' case, significant points of decline occurred roughly every six months for a while and then precipitously. "The first six months after her diagnosis, she was about 93 percent," Crosley said. "She was still driving to do errands. Six months later, she was about 85 percent. Each time she got worse, I would get used to it and say, 'It's not so bad. I can deal with it.' Eventually, things got a lot worse. She became really incontinent. She was up at all hours of the night. After these incontinence incidents, I would have to dress her and shower her. She hated being in the shower. Sometimes she would escape out of the house."
As winter looms, PCA Emergency Fund is in a major financial crisis

Alma Baron*, 82, is a volunteer in her community and a dedicated member of her church. She lives alone and often worries about how she can afford to heat her two-story home due to her limited income. Last December, she was out of home heating oil and in desperate need of help. A counselor at her neighborhood senior center made a referral to Philadelphia Corporation for Aging’s (PCA’s) Emergency Fund for Older Philadelphians on her behalf. As a result of help from the fund, Baron received a delivery of 100 gallons of oil to keep her warm during the cold months.

This vital crisis assistance program for low-income Philadelphia seniors is now itself in crisis. The Emergency Fund, which provides cash assistance to help low-income Philadelphia seniors purchase food, fuel, medications and other necessities, may have to shut down soon. As of late October, the fund had half the amount as at the same time last year, according to Chris Gallagher, director of PCA’s Helpline; who oversees fund distribution. This decrease is especially troubling going into the cold season, when demand for assistance is highest.

"You have no idea how much this helps," Baron said. "I often have to choose which bills I am going to pay, so the assistance from the Emergency Fund was a huge relief. This program is truly a blessing."

To compound the funding crisis, requests for help are increasing. "We saw the amount disbursed jump by 18 percent this last year over the previous year," Gallagher said. A total of $184,023 in emergency assistance was disbursed between July 1, 2017 and June 30, 2018 – an increase of nearly $28,000 from the previous year. This increase included a 26 percent rise in referrals for home heating oil assistance and a 51 percent increase in the total dollars spent on oil.

"PCA has always placed the highest priority on caring for the most vulnerable older Philadelphians," said Holly Lange, PCA’s president and CEO. "The Emergency Fund does just that – helping impoverished seniors in crisis pay for critical needs when they have nowhere else to turn." Lange also pointed out that Philadelphia has the second-highest percentage of people 65 and older of the nation’s 10 largest cities. Our city’s elderly experience poverty at nearly double the rate of the elderly in the rest of the nation. "It is vital to ensure that the fund remains open," Lange said.

Since the Emergency Fund was created in 1979, it has only had to close down once due to lack of funds, from April to December of 2005. During that period, oil prices spiked from an average of $1 to $2.16 per gallon, driven partially by the impact of Hurricane Katrina. However, Gallagher said PCA is planning for the worst this year, as predictions indicate there will be an extremely cold winter, increased demand for home heating assistance, and a rise in oil and other fuel costs.

PCA does not receive regular government funding to support the Emergency Fund and undertakes fundraising initiatives to address the need. The fund relies on corporate and foundation giving, donations from individuals, and funds raised by the agencies that are members of the Emergency Fund Coalition, an alliance of more than 20 community-based social service organizations and service providers that coordinate fundraising efforts for the Emergency Fund. Fundraising goes on year-round.

For information on corporate and foundation giving, call Joan Zaremba, PCA’s director of marketing and development, at 215-765-9000, ext. 5051, or email Joan.Zaremba@pcaCares.org.

About the Emergency Fund

The Emergency Fund provides emergency support for eligible low-income older Philadelphians who have exhausted all other resources. Referrals are accepted only from recognized social service agencies and the clergy, and payments are made directly to the vendor. PCA administers the fund at no cost on behalf of the Emergency Fund Coalition for Older Philadelphians.

To learn how to donate to the Emergency Fund or for more information, call the PCA Helpline at 215-765-9040; or visit pcaCares.org/emergencyfund.

*Name changed to protect confidentiality
Caregiving

Tips to help care for a cancer patient

By Constance Garcia-Barrio

Among life’s storms, a cancer diagnosis hits like a hurricane. It can send shock waves not only through patients’ emotions, finances and relationships, but also through those of caregivers. Some of us have faced or will face the dilemma of caring for someone with cancer – and cancer incidence increases with advancing age.

Medical breakthroughs offer the promise of long-term recovery. Cancer now has a 69 percent five-year survival rate, according to AARP’s "Helping to Care for a Loved One with Cancer," a free online guide for caregivers available at aarp.org/caregiving/caregivers/cancer. But during treatment, much rests on a caregiver’s shoulders.

"Caregivers may find themselves helping to make decisions about insurance, money, transportation and day-to-day issues," said Matthew Stevenson, a licensed clinical social worker at Penn Medicine’s Abramson Cancer Center. Caregivers can keep some things in mind to help manage this difficult role.

Managing communication

Good communication assists the cancer caregiver and patient in navigating this difficult journey, Stevenson said. "It often helps if a patient and caregiver set up a weekly check-in time," he said. "That way, you avoid a situation where one person comes home from work exhausted, unable to have a quality discussion, but the patient feels eager to talk. If you have a pre-arranged time, both of you can feel rested and respected."

The stress of the illness can spotlight cracks in a relationship, Stevenson finds. "Seek professional help in that case," he said. "Anyone can benefit from therapy, especially in such a tough situation, but both people have to be open and willing. If things have gotten rocky but one person’s still reluctant, you could ask, ‘Do you think that what we’re doing now is working? If not, why don’t we try something different?’ The questions may provide a much-needed opening." He also encourages patients and caregivers to try journaling as a way to express feelings.

Fear is often part of the picture, Stevenson notes. "It’s OK to have anxiety," he said. "It doesn’t mean there’s something wrong with you. Cancer impacts everyone so differently.”

Radical changes in the caregiver’s activities and new limitations due to the loved one’s needs may let anger creep in, Stevenson added. "Instead of aiming your anger at your partner or becoming self-critical, put the anger on cancer," he said.

Seeking help

Caregivers can use the magic of "yes" to lighten their load, therapists say. Make a list of chores and errands so that when friends and family members ask if they can help, you can give them concrete answers. For example, you may need someone to pick up groceries or medications, make meals or rake the leaves.

In another spin on the strength-in-numbers theme, experts suggest joining a support group to benefit from others’ insights and to feel less alone. Hospitals and the American Cancer Society (ACS) can connect you with other cancer caregivers. The ACS can also help you arrange for meals and transportation and make suggestions about respite care that would give you a break.

The spiritual dimension may have a place not only in healing the patient but in strengthening the relationship as well, Stevenson advises. "Caregivers and patients may take comfort in prayer, meditation and other religious activities," he says.

Caregivers can play a role not only at home but during medical appointments. Caregivers who are attuned to the patient may sense when he or she feels overwhelmed with information and ask questions on his or her behalf. "Don’t be afraid to ask questions," Stevenson said. "You’re not a physician, and not understanding some medical terms may leave you uneasy. The caregiver could also request a summary of a visit to review it without pressure.”

Keep a bright outlook

Accentuate the positive, the ACS recommends. Caregivers can find satisfaction in helping the patient, deepening the relationship and meeting new friends through support groups.

It’s also essential for both the caregiver and the cancer patient to have something to look forward to. “Even things on the micro-level of day-to-day make a difference,” Stevenson said. “Are you anticipating your half-hour walk to unwind, a talk with a friend or an éclair for dessert? For a weekly treat you may want something more elaborate: a movie or a trip to your favorite restaurant. It refreshes caregivers so that they have more to offer the patient.”

The American Cancer Society’s helpline is available 24/7 at 800-227-2345 for information about many aspects of cancer caregiving. The website cancer.org offers information and resources for both cancer patients and caregivers, including the downloadable free booklets “If You’re about to Become a Cancer Caregiver” and “Listen with Your Heart: Talking with the Person who Has Cancer.”

Native Philadelphian Constance Garcia-Barrio writes about many topics, including black history.
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As reported previously in Milestones, a major shift in the way Medicaid-funded long-term services are provided in the home is coming to Southeast Pennsylvania – Bucks, Chester, Delaware, Montgomery and Philadelphia counties – in January.

Community HealthChoices (CHC) is Pennsylvania’s mandatory managed care program for individuals dually eligible for Medicare and Medicaid and people with physical disabilities. The program has already begun in the southwestern part of the state and will affect more than 100,000 seniors or adults with disabilities in the southeastern region.

Under CHC, both physical health care and long-term services and supports (LTSS) – meaning home-based or nursing-home care – will be coordinated through three state-selected managed-care organizations (MCOs): Keystone First CHC, Pennsylvania Health & Wellness, and UPMC Community HealthChoices. CHC participants will have to choose one of these MCOs to coordinate their care.

CHC has been developed to enhance access to and improve the coordination of medical care and to create a person-driven, LTSS system in which people have choice and control in and access to a full array of services to support their independence, health and quality of life. LTSS help people perform “activities of daily living” such as bathing, dressing, preparing meals and administering medications.

Eligibility

Individuals are eligible for CHC if they are 21-plus and meet one of the following requirements:

- Receive both Medicare and Medicaid (known as “dually eligible”);
- Receive LTSS in the attendant care, independence, COMM CARE or aging waivers (which will be phased out with the implementation of CHC);
- Receive LTSS in the OBRA waiver and are determined nursing-facility clinically eligible;
- Receive care in a nursing home paid for by Medicaid; or
- Participate in an Act 150 program, which provides attendant care services for people who are mentally alert but severely physically disabled, and are dually eligible.

Individuals cannot be enrolled in CHC if they receive services beyond supports coordination through the Office of Developmental Programs for an intellectual disability or autism.

Individuals who already participate in a Living Independently for Elders (LIFE) program can remain in their LIFE program and will not be moved into CHC unless they specifically ask to be. Anyone who is enrolled in CHC who would prefer to participate in a LIFE program and qualifies for LIFE will be free to do so.

Coverage

CHC covers the same physical health benefits that are part of the Medicaid Adult Benefit Package. The aging, attendant care, independence and COMM CARE waivers will be phased out with the implementation of CHC. The OBRA waiver will continue to cover people 18-20 who qualify for Medicaid LTSS and those who have a severe developmental physical disability and need an intermediate care facility or other related conditions level of care.

Behavioral health and drug and alcohol addiction treatment services are not a part of CHC and will be coordinated through a program called HealthChoices Behavioral Health. The CHC MCO must coordinate care with its members’ HealthChoices Behavioral Health MCOs and Medicare coverage.

For more information about Community HealthChoices, see the Q&A article on the next page, go to healthchoices.pa.gov or call 1-833-735-4416.
Community HealthChoices Q&A

Community HealthChoices (CHC) is Pennsylvania’s mandatory managed-care program that will coordinate physician’s care and community-based services for many seniors and people with disabilities. Anyone who is eligible for the program in Southeast Pennsylvania will transition into CHC on Jan. 1. Aging Well PA and Philadelphia Corporation for Aging (PCA) held community meetings throughout Philadelphia in recent months to educate those affected. Here are some of the most commonly asked questions about CHC. (For more information about CHC, see the article on page 8.)

Who is affected by CHC?

CHC is for “dual-eligibles” (people who are eligible for both Medicare and Medicaid, commonly known as “Medical Assistance”); anyone in aging, attendant care, independence, and COMMCARE waivers, which will be phased out; and people living in a nursing home that is paid for by Medicaid. Those eligible for CHC should have received an enrollment packet in the mail.

What is the purpose of CHC?

The program’s intent is to help keep seniors at home, in the community, for as long as possible and give them a better quality of life by centralizing health and community-based services, known as long-term services and supports (LTSS). These are the services they currently receive under the state’s Aging Waiver and other waiver programs.

What will change with CHC?

Anyone who is eligible for CHC will be required to choose one of three managed care organizations (MCOs) to coordinate their care: Keystone First CHC, Pennsylvania Health and Wellness, or UPMC Community HealthChoices. The chosen MCO will administer your Medical Assistance coverage, as well as oversee LTSS.

Will CHC affect my Medicare benefits?

Enrollment in CHC or the choice of an MCO will not affect your Medicare coverage or benefits. Dual-eligibles can keep their existing primary care physicians and will have all the same Medicare options, including Original Medicare and Medicare Advantage plans. Your Medicare plan will not change unless you decide to change it. The MCO will work directly with Medicare providers to coordinate your services. Questions about Medicare can be directed to the Apprise insurance counseling program at 800-783-7067.

How will CHC affect the in-home care services I receive through PCA?

During the first six months of 2019, known as the “continuity of care period,” you will automatically keep the same service coordination agency, which helps to manage a person’s care. PCA provides service coordination and will work with all three managed-care organizations. If you wish to remain with PCA as your service coordination provider, the MCO of your choice can help you stay with PCA.

How do I enroll in CHC?

First, consult the enrollment packet you should have received in the mail. The packet explains CHC, provides information on the three MCO health plans and benefits, and provides enrollment information.

For more information or to select a plan, you can call the CHC Enrollment Center at 844-824-3655 (or TTY: 833-254-0690), weekdays from 8 a.m. to 6 p.m., or go to the website enrollchc.com. You can enroll by phone, email or mail using the information and form included in your packet.

If you call the CHC Enrollment Center, a representative will ask you about your current providers and preferences. (It’s a good idea to make a list of your providers before calling.)

Upon enrollment with your selected MCO, you will receive materials from the MCO in the mail, including an MCO participant identification card.

What happens if I don’t select an MCO by the deadline?

Anyone eligible for CHC must select an MCO by the Nov. 15 deadline. If you do not enroll by the deadline, an MCO will be initially assigned to you through a process called auto-enrollment. You can change your MCO at any time, whether you selected it yourself or were auto-enrolled.

Questions about CHC, including about eligibility, can be directed to the toll-free CHC Participant Support Center at 1-833-735-4416.
November 2018

Lung and Pancreatic Cancer Awareness Month
National Family Caregivers Month

SUNDAY

DAYLIGHT SAVING TIME ENDS
(Fall Back)

4

Town Hall on Eradicating Marginalization: Violence Prevention & Economic Sustainability. 10 a.m. to 1 p.m. Juvenile Justice Center. 267-581-3963.

11

Great Poets & the Cultures that Shaped Them: Dante. 2 p.m. Parkway Central Library. 215-686-5322.

18

25th Philadelphia Marathon. Cheer on 30,000 runners at the start/finish line of this 26.2-mile race. 7 a.m. start. Benjamin Franklin Parkway. Philadelphiamarathon.com.

Milestones

Events that end with a “$” require an entrance fee or advance ticket purchase. Free events may request donations or sell items. Please call the number listed for pricing or other details.

Send your calendar items to:
ATTN: Milestones Editor
PCA, 642 N. Broad St.,
Philadelphia, PA 19130
Phone: 215-765-9000, ext. 5081
Fax: 215-765-9066
Email: milestonesnews@pcaCares.org

Event submission deadline: 25th of the month for publication in month after next.

MONDAY


Medical Marijuana 101. 6 p.m. Fumo Family Library. 215-685-1758.

12

Veterans Day (observed)

Veterans Day Family Festival. Veterans talks, letter writing stations, family-friendly activities. 9:30 a.m. to 5 p.m. National Constitution Center. 215-409-6600. $

19

Comforting Fall Side Dishes. Chef Dolores demonstrates how to create crowd-pleasing sides. 6 p.m. Fumo Family Library. 215-685-1758.

TUESDAY

ELECTION DAY

6

King Day of Service 2019 Planning Workshop: Center City. 4 p.m. Urban Affairs Coalition. 215-851-1806.

13


Workshop: Supercharge Your Caregiving. 10 a.m. to 2 p.m. PCA. Register: 215-765-9000, ext. 4391.

16

Town Hall Meeting: Bethel Burying Ground. Learn the history of this forgotten site & discuss its future. 6 p.m. Logan Library. 215-685-9156.

23


26


27

Rittenhouse Square Holiday Park Lighting. 5 p.m. Rittenhouse Square. 267-586-5675.
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<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<th>Contact Information</th>
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<tr>
<td>3</td>
<td>Lutheran Settlement House Open House &amp; Flea Market.</td>
<td>10 a.m.</td>
<td>to 2 p.m. Lutheran Settlement House Senior Center. 215-426-8610, ext. 1204.</td>
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<td>I am Here: Creative &amp; Therapeutic Support for the Dementia Caregiver.</td>
<td>9:30 a.m.</td>
<td>to 12:30 p.m. Drexel University. Center City Campus. Register: 800-666-7737. $</td>
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<td>7</td>
<td>Family Health Fair.</td>
<td>4 p.m.</td>
<td>South Phila. Library.</td>
<td>215-685-1866.</td>
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<td></td>
<td>Great Poets &amp; the Cultures that Shaped Them: Geoffrey Chaucer.</td>
<td>11 a.m.</td>
<td>Parkway Central Library.</td>
<td>215-686-5322.</td>
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<td></td>
<td>More Space in Your Place.</td>
<td>2 p.m.</td>
<td>Lovett Memorial Library.</td>
<td>Register: 215-386-2984.</td>
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<td>8</td>
<td>Healthy Aging Program. Keep your mind &amp; body fit as you age.</td>
<td>9:30 a.m.</td>
<td>Jefferson College of Pharmacy. Register: 800-533-3669.</td>
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<td>Veterans Breakfast.</td>
<td>9-11 a.m.</td>
<td>Center in the Park.</td>
<td>Register: 215-848-7722.</td>
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<td>14</td>
<td>WORLD DIABETES DAY</td>
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<td>Bake Sale</td>
<td>9-11 a.m.</td>
<td>Center in the Park.</td>
<td>215-848-7722.</td>
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<td></td>
<td>Chestnut Hill Hospital Presents ‘Healthy Bones for Life’</td>
<td>10 a.m.</td>
<td>Center in the Park.</td>
<td>215-848-7722.</td>
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<td>Preventing Falls: Assessment, Safety &amp; Management in Older Adults.</td>
<td>11 a.m.</td>
<td>Ralston Center. Register: 215-386-2984.</td>
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<td>16</td>
<td>2019 King Day of Service Planning Workshop: South Philadelphia.</td>
<td>2 p.m.</td>
<td>South Phila. Library.</td>
<td>215-851-1806.</td>
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<td>17</td>
<td>Food &amp; Fun Fair.</td>
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<td>Celebrate Phila.’s history &amp; vibrant food culture.</td>
<td>10 a.m. to 6 p.m. Historical Society of Pa. 215-732-6200. $</td>
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<td>21</td>
<td>Joint Replacement Class.</td>
<td>2 p.m.</td>
<td>Penn Medicine, University City.</td>
<td>215-662-8000.</td>
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<td>22</td>
<td>THANKSGIVING</td>
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<td>Thanksgiving Day Parade.</td>
<td>8:30 a.m.</td>
<td>to noon. Benjamin Franklin Parkway. Also televised. 6abc.com.</td>
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<td>23</td>
<td>Opening Day at Blue Cross River Rink Winterfest.</td>
<td>11 a.m.</td>
<td>to 1 a.m. Great Plaza at Penn’s Landing. 215-922-2386.215-763-8100. $</td>
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<td>Opening Day of Macy’s Light Show &amp; Wanamaker Organ Concert.</td>
<td>10 a.m.</td>
<td>Macy’s Center City.</td>
<td>215-241-9000.</td>
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<td>29</td>
<td>Know the 10 Signs of Alzheimer’s: Early Detection Matters.</td>
<td>11 a.m.</td>
<td>to 12:30 p.m. Ralston Center. Register: 215-386-2984.</td>
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<td>30</td>
<td>Final day to redeem 2018 Senior Farmers Market Nutrition Program produce vouchers. (Note: Vouchers are no longer available.) Redemption information: 215-765-9040.</td>
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Millenials
• continued from page 4

Crosley connected with Philadelphia Corporation for Aging (PCA) several years after Roberts’ diagnosis. PCA assessors evaluated his mother’s level of care needs and eligibility for services. A PCA service coordinator arranged for Roberts to have four hours of personal care weekday afternoons. Crosley also hired personal care aides privately to help with his mom’s morning and weekend care. Altogether, he was paying nearly $3,000 a month for his mother’s home care and medical costs that were not covered by insurance. He worked three part-time jobs to make ends meet. His fiancée, now wife, Seanna, worked out of town but helped whenever she could.

Financial burden
The burden of work and financial obligations often compound the stress of millennial caregivers. A recent AARP Public Policy Institute report, “Millenials: The Emerging Generation of Family Caregivers,” found that 73 percent of millennial caregivers are employed, more than any other generation of caregivers and ... they spend an average of 21 hours a week caring for loved ones – the equivalent of a part-time job. About one-fifth of millennial caregivers devote 40 hours a week or more to such service, which amounts to a full-time job.

Crosley’s jobs included working for the Philadelphia Department of Licenses and Inspections as a building inspector, and as a pizza delivery man. He also operated his own rug-cleaning business. Each job gave him the flexibility to check in on his mom and attend to the crises that frequently occurred. “I had to come home almost every day to ‘put out fires,’ like if she was fighting with her aide or wandered outside with the dog and was trying to give the dog away,” he said.

Typically, the caregiver’s relationship to the care recipient will determine how the caregiver responds to caregiving and the stress it brings, according to Fredericka E. Waugh, associate director of diversity and inclusion for the Alzheimer’s Association Delaware Valley Chapter. For Crosley, taking on the responsibility of caring for his mother was something he did lovingly. “She worked and sacrificed so much for me when I was growing up,” he said. “Becoming a caregiver at 32 was not how my life was supposed to go, but I did what it took. The experience taught me empathy; it taught me patience.”

Difficult choices
In January, after seven years of being an in-home caregiver, Crosley placed his mother in an assisted living facility that also provided dementia care. She had forgotten how to eat and had become increasingly resistant and belligerent to her caregivers. Her wandering had increased, despite the extensive physical barriers Crosley had put up at home and the fact that she was never alone there. At one point, after she had escaped and police had found her, she was dehydrated and had to be hospitalized. Crosley stayed in the hospital with her.

He outfitted Roberts’ room at the assisted living facility with furniture from home to ease her transition, but she did not adjust well, he said. She was temporarily placed in the psychiatric unit of another local hospital, where she was heavily medicated. Following that hospitalization, she returned to the assisted living facility. “But she no longer had that spark of my mom,” Crosley said. “She just shut down and died.”

Roberts passed away in March. “I wish things could have been different,” he said. “I wish she did not get sick. I did everything I possibly could and that was a heck of a lot, but I still wish I could have done more.”

Crosley is now in graduate school studying labor relations. He and Seanna, whom he married in 2017, have established the DMR Foundation in memory of his mother. The foundation’s goal is to raise enough money to fund eight hours of caregiving a week for one caregiver each year. A portion of the funds raised through a golf tournament and other endeavors also will help fund Alzheimer’s research.

As someone who has been there, Crosley hopes to provide advice and support to other Alzheimer’s caregivers through his local Alzheimer’s Association chapter. “I know what it is to walk down this path,” he said. “It is not for the faint of heart.”

Marcia Z. Siegal is public relations manager for Philadelphia Corporation for Aging (PCA).
The soothing powers of oatmeal

By Sally Friedman

I recently was given a recipe for a hearty meatloaf that included a half-cup of oatmeal among its ingredients. I realized that I hadn’t had oatmeal in the house for years, so off I went to get some.

The moment my hands reached for it on the supermarket shelf, a whole rush of feelings almost overcame me. That familiar carton of Quaker oats carried me right back to my mother’s apartment in a Philadelphia high-rise.

I’d almost forgotten oatmeal’s place in my life – and hers – until that moment. Suddenly, 12 years vanished, and I was back in Mom’s apartment, watching helplessly as a marauder called lymphoma changed everything. Mom had faced it a few years earlier, when she had seemed to conquer it. And then it was back.

She was an amazing little warrior. But this time, my tiny, 97-year-old mother was clearly losing the battle. Most of her hours were spent in her yellow and white bedroom, with occasional friends stopping by for short visits. My sister and I were the monitors who determined whether Mom could even handle those well-meaning visits.

Our caregiving was intense, painful and fraught with tension. But it also was supplemented by the “angels,” as we called them, of The Visiting Nurse Association of Greater Philadelphia’s hospice team. Could we have done that caring without them? Probably not.

These angels offered not just physical support, but emotional support as well. We became a caregiving team, a kind of support group for Mom – and in unexpected ways, for one another.

When you spend so much intense time with anyone, connections build. It’s easier felt than explained.

One of the problems, as the wonderful doctor who had cared for Mom had correctly predicted, was her total lack of appetite. Nothing appealed to her, including foods that she had once loved — soft-boiled eggs, chicken soup and Jell-O.

I remember how Mom once had gotten me through a childhood food rebellion during which I subsisted on saltines and strawberry jelly. She struggled to tempt me with other foods, but I stubbornly refused. One day, I’d tried to offer the Breyer’s vanilla ice cream, which she had loved all her life, then a small dish of mashed potatoes and even just a quarter-slice of bread – and she had refused them all. I went into her bathroom and cried.

And when I composed myself, and did one more search of Mom’s kitchen cabinets, I spotted it: that familiar carton of oatmeal that always had been in our home when I was a child. It was in my home when I had children and was kept in this very kitchen, perhaps, just in case a great-grandchild came to visit on a cold winter day.

Such hope resided in that simple box. This time, I didn’t ask. I just went to the stove and began making one of life’s simplest pleasures, ignoring the microwave option. No, it had to be oatmeal bubbling on the burner.

I looked for the nicest bowl I could find in this kitchen, where such niceties were no longer considered very important. I spotted a lovely, little white bowl with flowers around the rim, a relic from my old home.

I picked up that bowl and held it close to my heart. Fond memories surfaced of a steamy kitchen on a wintry day, and of Mom’s loving gesture: a sprinkle of cinnamon went into that oatmeal along with some sugar. It seemed centuries ago – and yesterday.

On that morning, this one with medicines lined up like sentries, I pulled up a chair close to the hospital bed my mother now occupied.

“How about some oatmeal?” I asked, trying so hard for nonchalance.

Those weary half-closed eyes opened wider, and a smile momentarily lit up my mother’s face. “Yes,” she said.

As the rest of the world outside this room turned, a daughter fed her dying mother spoonfuls of warm oatmeal — slowly, painstakingly and lovingly — until the bowl was almost empty.

“Delicious,” Mom said. It was the last word I ever heard my mother say, and the last food she ever ate.

Sally Friedman has written for the New York Times and other publications.
Dementia

fluid intelligence declines and this decline can get in the way with making decisions, but not with the kind of severity seen in a person with dementia.

Normal aging means being forgetful at times. “Everyone is forgetful,” said McKay. “Normal aging is forgetting to send an email but remembering it later or recalling it when it’s mentioned.” Factors such as stressors and diet can impact memory and mental sharpness, or acuity, which includes focus, concentration and understanding.

The terms “dementia” and “Alzheimer’s” are often used interchangeably, but they are not the same. Dementia is a term that describes a syndrome caused by any number of different diseases, most commonly Alzheimer’s disease.

Dementia indicates a decline in the ability to display cognitive behaviors, which can include memory, language, attention, concentration, multi-tasking, problem solving and visual function. “In someone with dementia, at least two of these cognitive abilities are impaired to the point that they are getting in the way of doing daily tasks,” he said. That’s a serious concern, well beyond walking into a room and forgetting why you came in, then remembering it a few minutes later.

“People misplace things, but they are usually able to trace their steps backwards to find them,” McKay said. “Someone with dementia would put things in unusual places, such as leaving their car keys in the refrigerator.”

Signs of a cognitive decline that might be indicative of dementia can include a senior asking repetitious questions or telling the same story over and over again in the same conversation without providing new information. Difficulty identifying the day of the week, managing money or medicines, or cooking are also signs of a cognitive decline. “Dementia is not being able to retain adequate short-term memory,” McKay said. “Dementia is like hearing the information anew each time.”

Dementia

Dementia is not just occasional forgetfulness or a “senior moment.” It is a disabling condition, according to Karlawish. “Mild memory loss that takes a person longer to get through daily activities is not dementia,” he said. “Someone with dementia will not perform well on memory tests but will also leave pots on the stove.”

It’s important to note that dementia is not a sudden change in memory or ability. “If someone has experienced noticeable cognitive changes that are interfering with daily life over the last several days or even a few weeks, that’s not dementia,” Karlawish said. “That’s a medical emergency.”

There are several medical conditions that may mimic dementia. Complaints about memory being a problem and lack of initiative are reported in people with both dementia and depression. Certain medications and urinary tract infections can also cause behavioral or cognitive changes that resemble dementia.

Someone with dementia has typically experienced at least six months of decline in cognitive ability to the point that it interferes with usual tasks, according to Karlawish. These tasks can include managing money, cooking a meal, finding their way around, or using a TV remote control, assuming the person used to perform these tasks without a problem. “Someone with dementia won’t bake anymore, or they tried to bake and it wasn’t as good as before,” Karlawish said. “They keep on having trouble using their computer, but they were fine before. They struggle to find their way around. These are signs that suggest dementia.”

Drastic changes in a person’s mood or personality over time may also signal dementia. “Your personality doesn’t really change over time,” McKay said. “It’s a tell-tale sign when someone has a favorite hobby, and they just regress from that. Your personality is set. When someone becomes aggressive, overly emotional or ‘just different,’ it’s probably time to see a doctor.”

Causes

Alzheimer’s disease is the most common cause of dementia. It is called a “neurodegenerative disease,” meaning that neurons, the cells in the brain, are dying. Other neurodegenerative diseases include Lewy body dementia and Parkinson’s disease; the latter starts out as a movement disorder but can develop into dementia. Vascular disease can cause vascular dementia, in which the brain is damaged from impaired blood flow.

Traumatic brain injury, which results from an impact to the head that disrupts normal brain function, also can lead to dementia. “It may be something that only happens once, then that person is really impacted by it for the rest of their life,” McKay said. Chronic traumatic encephalopathy (CTE), which results from continuous trauma to the brain, is another cause of dementia. “We’re seeing it more and more with former athletes, like football players, who have repeated concussions and damage to the brain,” McKay said of CTE.

Frontotemporal dementia (FTD) is a fairly uncommon form of dementia, according to Karlawish. In FTD, the frontal and temporal lobes of the brain — the areas associated with personality, behavior and language — shrink or atrophy, causing dramatic changes in behavior. This disease often occurs in people 40-45, much younger than Alzheimer’s is typically diagnosed, according to the Mayo Clinic.

There are a host of causes for dementia, beyond those mentioned here. According to Karlawish, a good clinician can sort it out. “If you are concerned about yourself or someone else, start with your general practitioner,” he said. “It may result in correction of a medical problem or referral to a specialist.” Karlawish recommends that people who have a memory problem go to the doctor with someone who knows them well, such as an adult child, close friend or partner. “This person can help to add information about how the person is doing,” he said.

Alzheimer’s disease

Alzheimer’s disease accounts for about 60 percent of dementia cases, according to the Alzheimer’s Association. Alzheimer’s is different from other types of dementia. “The disease progression is very subtle over stages,” McKay said. “It’s a very slow and steady decline over an eight- to 10-year life span of the disease. It’s characteristic to have memory loss as its primary and first-recognized symptom.”

There is no cure for Alzheimer’s. Fear of the disease and its effects may contribute to a delay in seeking diagnosis. “We have drugs that can treat the symptoms,” Karlawish said. “Putting a name on the problem is the first step towards making sense of it and dealing with it. An early diagnosis is important because the patient is suffering.” Someone with Alzheimer’s is at risk of having an automobile accident, getting lost in a familiar area, becoming dehydrated from forgetting to drink water, or becoming a victim of a scam or crime. “While there is no cure for Alzheimer’s, there are other causes of dementia that can be treated,” McKay said. “It’s important to not be afraid. I urge people not to be despondent. There is help out there.”

The Alzheimer’s Association Helpline is staffed by trained clinicians 24/7, 365 days a week, at alz.org or 800-272-3900. “We’re here to provide support,” McKay said. The helpline refers callers to clinicians, support groups and legal and financial experts. The helpline can also provide information and locations for memory cafés — organized gatherings where people with memory loss and their care companions come together to make new friendships and support one another. “It’s a one-stop-shop for up-to-date resources and information,” McKay said. “At the core of what we do is to help and support people within the community. We don’t want people hiding in the shadows. Life is not over with dementia.”

Alicia M. Colombo is editor of Milestones.
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“I can enjoy the luxury of living in the community with access to care whenever I need it.”
-Ricardo
Senior caregivers
• continued from page 1

Roberts, whose grandchildren and great-grandchildren call her “G” or “G-G.” “I’ve gotten a whole lot of satisfaction.”

She also is getting help through a Philadelphia Corporation for Aging (PCA) program that supports grandparents and other older relative caregivers. PCA’s Caregiver Support Program (CSP) provides assistance to people 55-plus who are caring for a relative under 18 who is not their biological child. The program helps older caregivers navigate educational, counseling, legal and other services to help them care for a child. In addition, it provides financial reimbursement for services such as day care or caregiver respite, tutoring, extracurricular activities, school supplies, counseling on benefits and entitlements for which caregivers and children may qualify, and caregiver education and training. (For more information see box above right.)

With funds from CSP, Roberts is able to access emotional support and help paying for child-rearing expenses. CSP pays for her to participate in a weekly telephone support group for older caregivers offered through SOWN.

Roberts has taken part in the support group for years and said it has been invaluable. “It’s so nice to get on the phone and talk and reach out this way,” she said. “We talk about the children, what the problems are… No matter what concerns people have, other people have ideas and suggestions.”

She also receives help through CSP to pay for Hydir’s school supplies and his weekly music lessons at Settlement Music School, where he studies percussion.

Roberts helps Hydir with his homework and attends parent-teacher conferences and other events at his school. Nonetheless, she said, “the main thing Hydir gets from me is love and attention.”

She encourages him to confide in her. “Every morning I tell him, ‘Have a good day,’ and every day when he comes home, I ask him ‘How was your day?’” Roberts said. “I tell Hydir there’s nothing that’s too bad or too good that we can’t talk about it.”

Hydir said that he and “G” have a strong, unbreakable bond. No matter what the issue, “she knows all the answers and is always cool-headed,” Hydir said.

Now that he’s a teen, Hydir is able to reciprocate Roberts’ care by helping his great-grandmother. “When he was a little boy, I took him to Sunday school,” Roberts said. “Now he takes me to church. I use a walker … He’ll walk with me, go to be with his friends at Sunday school, and then come get me to walk me home. He’ll make breakfast and bring it upstairs to me. Other times, he’ll say, ‘G, I’m going to the store; do you want anything?’ Or if he buys himself a water ice, he’ll bring one home for me too. He’s always looking out for me.”

Roberts has been the mainstay of her family since she was widowed at 33. She came to Philadelphia from Charleston, South Carolina, with five children to be near her sister and brother, who lived here. “I made a new life and did what I had to do,” she said. She worked for a time as a nursing assistant at a residential facility for people with disabilities.

After raising many of her grandchildren and great-grandchildren, Roberts has created a family that now serves as a strong support system for her. One or more of the adult children she raised check in each morning and evening on her and Hydir. They help provide meals, assist with shopping and take Hydir on outings with relatives his age. Granddaughter Kiki helps Hydir with his math homework and attends his school events when G is unable to.

All the family’s generations still seek Roberts’ advice on matters big and small. “I just love them all,” Roberts said of her 70 living descendants, including five children, 13 grandchildren, 50 great-grandchildren and two great-great-grandchildren.

She expected a large gathering at her North Philadelphia home for Thanksgiving. Many family members were slated to bring dishes they made according to family traditions she has passed on, like her potato salad and candied yams and the macaroni and cheese dish Roberts learned to make from her mother.

“I’ve raised so many kids,” Roberts said. She offers this perspective to a new grandparent, great-grandparent or other relative who is taking on raising a child: “If I can do it, you can do it. Every day is not going to be sunny, but together, all the good days far outweigh the hard ones. We’re all in this for the same reason — so we can help these children with what they need.”

Marcia Z. Siegal is public relations manager for Philadelphia Corporation for Aging (PCA).

Crossword puzzle solution
(See page 19 for clues.)
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Journey’s Way isn’t just part of the community; it is the community

By Michael Hanisco

Karen Rouse wants people to think a little differently about how they view senior community centers. After serving in various roles at centers across the city for three decades, she is now the director at Journey’s Way, a senior center serving adults 55-plus at the corner of Rector and Pechin streets in Roxborough.

“The senior center is the community; it’s not a separate part just for older people,” Rouse said.

It’s that attitude that has allowed her to develop partnerships with a wide array of community members during her time at Journey’s Way, something she sees as a point of pride for the center.

“We do a lot of intergenerational programming,” she said. “We’ve developed partnerships with nursing schools and with a high school in the neighborhood; we work with churches, the art center, and the weaving guild. I’m going to be developing some dance programs with Merge Studio. We do a lot of work bringing the community in and also offering our building so that they can use it.”

Rouse explained that Journey’s Way opens its doors to a number of organizations that are in need of meeting space. The local historical society, the Soroptomists — a women’s volunteer and empowerment group — and even the Philadelphia police have used the building for regular meetings.

Rouse credits the converted church that houses Journey’s Way as a major asset in courting community relationships. The spacious accommodations offer an advantage over the much smaller space five blocks away that housed the center until a move in 2009.

“Everything was clumped together in two or three little rooms,” Rouse said.

The newer center features two stories and contains rooms of various sizes, offering enough space for large gatherings and more intimate sessions to occur simultaneously.

“The building has really helped Journey’s Way develop into a center that can really provide something for everybody,” Rouse said. “It has enabled us to handle different kinds of programming. We’re able to accommodate a wide range of interests and activity levels.”

On a recent Monday, the center was a hub of activity, hosting a meditation class downstairs while a dozen seniors participated in a workout on the second level. Down the hall through a breezeway on the first floor, others...
Journey’s Way
• continued from page 18

Journey’s Way, located at 403 Rector Street in Northwest Philadelphia, is open weekdays from 8:30 a.m. to 5 p.m. For information, call 215-487-1750 or go to intercommunityaction.org/aging-services.

Michael Hanisco is multimedia communications specialist at Philadelphia Corporation for Aging (PCA).

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