



alzheimer's association

The End of Alzheimer's Starts With You



ALZHEIMER'S EDUCATION

Community collaboration the key

More than 6 million people in America are living with Alzheimer's disease, which includes more than 280,000 people over the age of 65 in Pennsylvania. Alzheimer's affects both men and women, knowing no bounds when it comes to gender. It affects people from all walks of life, and from every ethnic and socioeconomic group.

Simply put, it affects every community in Lancaster County.

The good news is that there is help available through the Alzheimer's Association Greater Pennsylvania Chapter. Through the efforts of its many supporters and volunteers, the Association is able to reach out to communities throughout the Lancaster area — including those that have been traditionally underserved — to provide information about the symptoms of Alzheimer's disease and other dementias, and the resources available for support, care and education.

"The goal of the Alzheimer's Association is to have a presence in all communities, because Alzheimer's does not discriminate," says Clay Jacobs, executive director of the Alzheimer's Association Greater Pennsylvania Chapter. "To do this well, it all starts with listening to the community and understanding what's important to them."

Meeting communities where they are

Although Alzheimer's affects people of all races, backgrounds and genders, there are some populations at greater risk. Women and communities of color are more likely to develop Alzheimer's disease than other groups. Approximately two-thirds of those living with Alzheimer's are women. African Americans are twice as likely to get the disease, and Latinos are 1.5 times more likely to develop Alzheimer's or other dementias.

"Alzheimer's puts families and individuals in an extremely vulnerable position, and they need an organization that they can reach out to for guidance and support," said John Rudy, board chair, Alzheimer's Association Greater Pennsylvania Chapter, adding that one of the biggest challenges in helping those with



Clay Jacobs



Jacqueline Fisher

"When people come together within their communities around a common cause, we've seen how powerful that collaboration can be."

— Clay Jacobs,
executive director, Alzheimer's Association Greater Pennsylvania Chapter

the disease and their caregivers is finding a way to meet them where they are.

Unfortunately, there are a number of reasons, including access, language barriers, lack of representation among health care workers, and a lack of trust in medical research by minority communities, that can make it difficult to reach underserved populations with information about the disease, and to encourage them to participate in support groups, programs and clinical trials.

"When it comes to reaching the community, language plays a big part in communicating on both ends," explained Jacqueline Fisher, president of the Spanish American Civic Association (SACA) and director of Behavioral Health Nuestra Clinica. "Needs that cannot be expressed cannot be met.

"This causes frustration for individuals

searching for services," she added. "The availability of bilingual services is paramount to members of the community so they can feel engaged and empowered while navigating the system."

The Spanish American Civic Association of Lancaster works with the Alzheimer's Association to educate the Latino community about Alzheimer's disease, reaching out to the population through radio broadcasts and social media. Staff often volunteer throughout the community spreading the word about what resources are available.

This is especially important as the number of people in Pennsylvania affected by the disease is expected to rise to more than 320,000 by 2025. And medical costs are soaring as well; in 2020, the Medicaid costs of caring for people with Alzheimer's totaled almost \$3.7 billion,

and they are projected to increase by more than 10 percent in the next five years.

Even more important, however, is the human cost: not only to those with the disease, but for their caregivers.

In Pennsylvania alone, there are approximately 500,000 caregivers who provide more than 622 million hours of unpaid care taking care of people with Alzheimer's and other dementias. Of these, 62% have their own chronic health conditions, 24% suffer from depression, and more than 16% are in poor physical health. Yet all too often, and for myriad reasons, they don't ask for help.

"Many people often hide the fact that someone they love is experiencing the disease," said Fisher. "Some deny the fact that they have Alzheimer's, instead attributing the behaviors and memory loss to old age. Education is key in helping people learn how to deal with and support those who have been diagnosed with the disease."

"All too often, people will just think that mom or their uncle is just acting crazy," agreed Claudia Galdamez, general manager of SACA Broadcasting and its Spanish radio station WLCH, 91.3 FM. "Caregivers need to know that there are resources that can help them cope, since the majority of Alzheimer's patients receive care at home, often by a spouse or close relative."

WLCH, also known as Radio Centro, is reaching out to the community with broadcasts in Spanish, as well as printed and online materials. A recent testimonial on the radio station featured the wife of a man living with Alzheimer's, who as his caregiver, could not leave him even for a short time. It is hoped that this type of message will help remove the stigma of talking about Alzheimer's and other dementias, and will encourage caregivers to reach out for the support they need.

In African American communities, outreach efforts include Purple Sunday, an annual AME-sponsored event in which trained church leaders and educators share key Alzheimer's research with their congregations, along with information about caregiving and support. The Association also hosts community

forums to get feedback on how specific groups want to receive information and learn about Alzheimer's and dementia resources.

All of these efforts are about advancing these important conversations and working together as a community.

"To truly engage with a community means a few things to me," said Jacobs. "People need to know us, trust us and help inform everything we do. Collectively, we can make a difference. When people come together within their communities around a common cause, we've seen how powerful that collaboration can be."

For more information on how you can help make a difference in your community, visit alz.org/pa or call the Alzheimer's Association Helpline at 800-272-3900.

6 million

Americans living with Alzheimer's disease.

ALZHEIMER'S DISEASE BY THE NUMBERS

280,000

People over the age of 65 in Pennsylvania currently living with Alzheimer's.

320,000

Projected number of Pennsylvanians living with Alzheimer's by 2025.

500,000

Alzheimer's caregivers in Pennsylvania.

622 million

The number of unpaid hours caregivers spend taking care of people with Alzheimer's and other dementias.

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WALK TO END ALZHEIMER'S | THE LONGEST DAY

Meaningful ways to honor loved ones

As one of hundreds of walks held annually across the country, the Walk to End Alzheimer's (WTEA) in Lancaster County typically draws more than 1,500 participants to Overlook Park. With limits on large gatherings last year, however, WTEA Director Fran Gibbons wasn't sure that the event would be able to meet the organization's \$300,000 goal.

"The walk is used in Lancaster to grow our programs and services; this is how we fuel the things that we do," said Gibbons of the signature event that funds Alzheimer's research, care, support and education.

Not willing to give up, Gibbons and her team of dedicated volunteers decided that instead of bringing participants to the walk, they would take the walk to participants.

"We asked our constituents to walk everywhere — to get out in their communities with their teams and their family members, and to wear masks and wear purple and to walk for the Alzheimer's Association," Gibbons said.

And walk they did. Starting with the opening ceremony, which was virtual, participants shared photos of themselves on social media as they walked in their neighborhoods, on county trails and even in other states.

"The Walk to End Alzheimer's is a wonderful opportunity for our residents, team members, families and friends to unite and raise awareness and funds to fight Alzheimer's disease," said Amy Kenn, communications director for Luthercare, a walk sponsor and participant. Luthercare offers memory care services at its Luther Acres and Spang Crest communities.

"We are a strong supporter of the Alzheimer's Association, because we know the profound impact that Alzheimer's disease has on families," she added.

In Pennsylvania alone, more than 280,000 people aged 65 and older are living with Alzheimer's, and that number is expected to increase to 320,000 by 2025. More than 500,000 caregivers support those with the disease, providing more than 622 million hours of unpaid care.

Luckily, the people of Lancaster came out in force — even during COVID-19 — to let them know that they were not



alone.

"Lancaster was very fortunate," Gibbons said of such enthusiastic participation. "We were hoping to reach at least 60% of our goal and we raised more than \$262,000!"

"The Lancaster community did a fantastic job of supporting us during the Walk and the Extraordinary Give," she added of the one-day fundraising event sponsored by the Lancaster County Community Foundation. "They are the heart and soul of our mission here in Lancaster county."

The best of both worlds

In 2021, the Walk to End Alzheimer's will return to the traditional in-person walk on Saturday, Sept. 25, in Overlook Park, while also keeping some of the more successful features of the 2020 event.

"This will include live-streaming the opening ceremonies, and continuing the option of letting people walk wherever

they are at a time that's most convenient to them," said Diane Dayton, Lancaster Walk Chair and Executive Director of LCTV66.

Participants can walk on that Saturday, or walk during the week and send in photos. If a long-term care community wants to keep its residents out of crowds, it can host its own walk on campus.

"If you don't feel comfortable, walk wherever you feel comfortable," said Dayton, adding that the Overlook Park walk will require participants to wear masks and maintain social distancing.

The walk will also continue its tradition of presenting each participant with a Promise Garden flower in a color that symbolizes their connection to the disease: blue for those living with Alzheimer's or dementia; yellow for caregivers; purple for those who have lost someone to the disease, and orange for those who support the cause and the vision of a world without Alzheimer's.

Individual walk participants are encouraged to raise at least \$100, which

"There has to be a cure out there, and I'm determined to help find it in my lifetime. I am hopeful that one day very soon there will be a white flower being held in the air by our first Alzheimer's survivor. That will be an incredible day!"

*— Melissa Bloom DePietro,
walk participant*

will earn them a T-shirt, and there are additional incentives to raise even more. While some teams make a straight donation to the cause, others find more creative ways to raise money, ranging from Facebook fundraisers to chicken barbecues to lip-syncing contests.

Dayton is hoping for at least 800 participants this year, and to reach the fundraising goal of \$275,000.

"I know that we can get there, because Lancaster is so giving. Together we can make a difference and help raise funds to support those we love," she said.

The Longest Day

For those who are looking for a different sort of activity to take action, or who want to do even more to help raise funds for Alzheimer's research, care, support and education, The Longest Day, held on the summer solstice, provides a unique opportunity and is right around the corner on June 20.

"The goal of this fundraising event is to raise awareness while participating in an activity that is special to a loved one with

Alzheimer's or to the person participating in the event," said Gibbons, adding that it can be something as simple as cooking or gardening to organizing a golf tournament or a motorcycle ride.

"We encourage people to select any activity that they love," she said. "It's a do-it-yourself fundraiser and you can find all the information you need to get started at alz.org/tld."

For example, Emily Mumma created her own Longest Day event, Motorin' for Memories, which this year will be held on June 20 at Wacker Brewing Company. "I started it last year to honor my grandmother, Jane, who was passionate about riding her motorcycle all over the U.S.," said Mumma, adding that she's hoping that the first public Motorin' for Memories ride will raise both awareness and funds to combat the disease.

The Longest Day event takes place on the summer solstice because it's the day with the most light, Gibbons said. "It's more of a recognition for caregivers," she explained. "It can be a very long day every day taking care of someone who is living with the disease."

Teaming up to end Alzheimer's

Whether riding a motorcycle, holding a golf tournament or walking with family and friends to honor a loved one, every bit of participation helps.

"There has to be a cure out there, and I'm determined to help find it in my lifetime," said Melissa Bloom DePietro, a team captain who will be participating in her 18th Walk to End Alzheimer's this year in memory of her "Mommom" Irene Bloom.

"I am hopeful that one day very soon there will be a white flower being held in the air by our first Alzheimer's survivor. That will be an incredible day!" she added. "Until then, I will continue to take an active approach to fight this disease as hard as I can and as long as it takes to protect my family and everyone else's families and friends."

For activity and fundraising ideas for The Longest Day, visit act.alz.org. For more information or to register for The Walk to End Alzheimer's, visit act.alz.org/Lancaster2021.



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ALZHEIMER'S SUPPORT

Resources abound for those seeking help

When Deb Schleh first began providing community education programs and facilitating Alzheimer's support groups more than 20 years ago for the Alzheimer's Association, the certified activity director and memory care specialist did it because she has a passion for working with people with dementia. What she didn't realize was how much she'd gain from helping others learn how to navigate the disease.

"Making this journey a little easier for people as they walk it with a loved one is so important to me," she explained. "If I can tell them about something that works — give them a tip or advice that makes things even a little bit easier, even in a small way — then I am empowering those with the disease and their care partners. You never know how the information you provide can help someone else."

While many people living with Alzheimer's and their caregivers feel like they are facing this uphill battle alone,

"Taking an active role to educate yourself about how your life may be impacted by a diagnosis of Alzheimer's disease or other dementia can be an empowering first step in taking control after a diagnosis."

— Jessica Hill,

senior program manager Alzheimer's Association Greater Pennsylvania Chapter

the truth is, more than 6 million Americans — 280,000 just in Pennsylvania — are living with this progressive, neurodegenerative disease that causes individuals to slowly lose their cognitive skills. Though there is not a cure yet, through the efforts of Alzheimer's Association volunteers, staff and researchers, more progress is being made every day.

But for people who need help now, the Alzheimer's Association is there, educating about risk reduction and early detection, accelerating global research, and

reaching out with quality care and support.

Education the key

The Alzheimer's Association offers a number of free consumer education programs provided by volunteer community educators like Schleh on subjects such as "Understanding Alzheimer's & Dementia," "Know the 10 Warning Signs," "Healthy Living for Your Brain & Body" and more.

"Taking an active role to educate yourself about how your life may be impacted by a diagnosis of Alzheimer's disease or other dementia can be an empowering first step in taking control after a diagnosis," explained Jessica Hill, senior program manager for the Alzheimer's Association Greater Pennsylvania Chapter. "The Association offers a number of education programs to help those with Alzheimer's and their families understand what to expect, so they can be prepared to meet the changes ahead and live well for as long as possible."

"Early diagnosis is key to providing a family with the tools to overcome financial, legal and medical concerns," she added. "This is a disease that doesn't just impact the person living with the diagnosis, but family and friends as well. So it is important to have a support system in place and to start planning in order to know the wishes of the person living with the disease. It is also important



Willow Valley Communities salutes the Alzheimer's Association for its work to eliminate Alzheimer's disease through research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health.

Willow Valley Communities is honored to support the Alzheimer's Association as a 2021 sponsor of the Walk to End Alzheimer's in Lancaster.

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for caregivers to remember to care for themselves.”

While community education programs and support groups are traditionally offered in-person, during the pandemic, the Association created virtual options to ensure that those seeking information or help still had access to the support they needed.

“This was especially important because many seniors with Alzheimer’s and their caregivers are already so isolated, and all of a sudden, those caregivers lost any outlet they had to go out and get a break,” said Schleh. “Sometimes what they wanted was just for someone to listen to them; other times, I came up with suggestions of things that their loved ones could do so that they could take a few minutes for themselves. It is incredibly difficult to provide in-home care 24/7.”

Schleh also continued to check in on the people who were in her support group but who did not want to participate online. “I talked with many of them on regular basis,” she said. “One of the things that draws people to support

groups is that they feel like they are all alone, and I wanted them to know someone was there.”

Lauren Renehan, development coordinator with the Willow Valley Communities Charitable Foundation, volunteers for the Alzheimer’s Association as a support group facilitator, working directly with people to lead supportive conversations, refer them to local resources and encourage them to reach out to the Association for support via its website, one-on-one support or the 24/7 Helpline.

“My job is to provide emotional support, encouragement and education,” Renehan said, noting that Willow Valley Communities has also partnered with the Alzheimer’s Association to sponsor the Walk to End Alzheimer’s. The organization hosts a Memory Support Group on a monthly basis where residents, family members and caregivers from the community can discuss the challenges of memory loss and caregiving while offering mutual support and understanding.

“The Alzheimer’s Association has a great deal of information that can help with each stage of dementia, along with

free educational seminars and interactive activities that people can participate in with their loved ones,” Renehan said. “Our goal is to ensure that no one feels alone on this journey.”

Finding the right resources

One of the most important tools the Alzheimer’s Association offers is a free, 24/7 Helpline where specialists and master’s-level clinicians offer confidential support and information to people living with dementia, their caregivers, their families and the public. This service is offered in over 200 languages and dialects.

The Association also offers free e-learning workshops; an online Alzheimer’s Navigator that helps caregivers create a personalized action plan using tips and local resources; and ALZConnected, a free online community/message board where individuals living with Alzheimer’s can ask questions, get advice and find support.

The Community Resource Finder, offered in partnership with the AARP, helps families locate care-at-home op-

tions, as well as personalized care consultation and information regarding services from independent and state-funded sources.

“If people don’t know where to start, I recommend calling the Helpline as a first step,” said Schleh. “You can find a listening ear if you’re feeling stressed out, or find help if you’re looking for information. They can connect you to a support group — virtually or in-person — or even point to places on the website where you can find information on everything from food and eating advice, to activities, to what dementia is and how it presents.

“It’s said that, ‘If you’ve met one person with dementia, you’ve met one person with dementia,’” she added. “While there are some similarities, everyone has a slightly different journey. That’s why it’s so important to have these resources available.”

For more information, contact the 24/7 Helpline at 800-272-3900 or visit the Community Resource Finder at www.communityresourcefinder.org. To learn more about volunteer opportunities, visit alz.org/pa/volunteer.

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