

PANEL 3

Caregivers: What is Needed to Sustain and Support their Role?

Moderator:

Bob O'Connell,
CAPTAIN CHS Board &
Senior Services Committee



CAPTAIN
Community Human Services

Here Come the Boomers

A Community Forum on
the Future of Aging in
Southern Saratoga County





Office for the Aging



Caregivers: What is Needed to Sustain and Support their Role?

May 19, 2023

Deana Prest, NYSOFA

Who Are Family Caregivers?

If you routinely provide help to a friend or family member, then you are a caregiver. This can include many activities: household tasks, transportation help, assisting with medical or self-care needs, and more



Family Caregivers in New York State

There are an estimated 4.1 million caregivers in New York State who provide 2.68 billion hours of unpaid care that if paid at the market rate would cost \$39 billion annually.



And more than half don't even self-identify as caregivers!

Working Caregivers

Many are working caregivers who face unique stresses, which is why NYSOFA launched a working caregivers' initiative.



Purpose of Initiative

1. To make caregiving a statewide, all systems issue – public and private sector – data driven
2. To educate the workforce generally and leadership (public and private sectors) of the impact on their businesses due to employees caregiving responsibilities and provide them tools/resources to help their employees
3. To help individuals self-identify as caregivers and link them to services and supports IF they need them
4. To help HR departments understand the impact of caregiving on employees and to provide resources to link to services/supports
5. To understand better the impact of caregiving on employees from their perspective, who, what, where, how often, tasks, etc

Working Caregivers

- Survey – public and private workforce –seriously impacting state workforce – productivity, turnover, etc.

CDC Data during Pandemic – 2020-2021

- 90%+ of HR departments want to do more to support working caregivers but are not sure what to do
- 85% of caregivers with children and caring for an older person experienced mental health symptoms – 52% reported suicidal thoughts
- 75%of people trust their employer and are more likely to use information provided by their employer
- 70% of working caregivers suffer work related difficulties due to their dual roles
- 70% of working caregivers reported at least one mental health symptom (anxiety, depression, suicidal thoughts, COVID induced trauma)
- 69% of caregivers report having to rearrange their work schedule, decrease their hours, or take unpaid leave in order to meet responsibilities

CDC Data During Pandemic

- 61% of caregivers worry about caring for a family member, friend or neighbor
- 55% don't self-identify as caregivers
- 50% use food to cope and reduce stress
- 49% of working caregivers report arriving to work late, leaving early or taking time off
- 33% use substances to cope vs. 6% of general population
- 31% contemplated suicide vs. 3% of general population
- 15% have taken a leave of absence
- 14% switched from full-time to part-time
- 10% left the workforce completely

NYS State Agency/Non-State Agency Data

State Agency Data

- Gender
 - Female – 70%
 - Male – 24%
- Age
 - 25 and under – 1%
 - 26-35 – 9%
 - 36-45 – 24%
 - 46-55 – 32%
 - 56-65 – 26%
 - 66-75 – 3%
- Race/Ethnicity
 - White – 75%
 - Asian – 3%
 - African-American – 6%
 - Hispanic – 4%

Non-State Agency Worker Data

- Gender
 - Female – 76%
 - Male – 19%
- Age
 - 25 and under – 1%
 - 26-35 – 8%
 - 36-45 – 19%
 - 46-55 – 34%
 - 56-65 – 31%
 - 66-75 – 1%
- Race/Ethnicity
 - White – 65%
 - Asian – 1%
 - African-American – 12%
 - Hispanic – 8%



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Conditions Being Cared For

State Agency Data

- Alzheimer's/Dementia – 26%
- Emotional/Mental Health – 26%
- ID/DD – 13%
- Long-term health condition – 49%
- Other (heart attack, surgery, etc) – 34%
- Aging/frail/mobility issues – 64%

Non-State Agency Worker Data

- Alzheimer's/Dementia – 41%
- Emotional/Mental Health – 28%
- ID/DD – 11%
- Long-term health condition – 54%
- Other (heart attack, surgery, etc) – 31%
- Aging/frail/mobility issues – 68%

Hours of Care Per Week

State Agency Data

- 0-7 – 46%
 - 8-14 – 23%
 - 15-21 – 12%
 - 22+ - 19%
-
- Care Receiver (93% live in the community)
 - Lives with state worker – 40%
 - Lives alone – 30%
 - Lives with another family member – 21%

General Public Data

- 0-7 – 21%
 - 8-14 – 23%
 - 15-21 – 16%
 - 22+ - 39%
-
- Care Receiver (94% live in the community)
 - Lives with caregiver– 46%
 - Lives alone – 27%
 - Lives with another family member – 20%

How Long Providing Care to Loved One

State Agency Data

- Less than 1 year – 15%
- 1-5 years – 52%
- 6-10 years – 15%
- 11-15 years - 7%
- 16+ years – 10%
- Those indicating need additional help – 31%

Non-State Agency Worker Data

- Less than 1 year – 15%
- 1-5 years – 52%
- 6-10 years – 18%
- 11-15 years - 7%
- 16+ years – 9%
- Those indicating need additional help – 49%

Caregiving Tasks – Older Adult

State Agency Data

- Driving to Doctors appointments – 55%
- Arranging/preparing meals – 44%
- Grocery Shopping – 51%
- Assistance with home repairs/maintenance - 44%
- Personal Care – 24%
- Completing forms/documents – 46%
- Looking/applying for support services – 24%
- Money management/bill paying – 34%
- Housekeeping Tasks – 47%
- Medication assistance – 34%
- Assisting with nursing/medical tasks – 21%
- Financial support – 26%
- Other care due to illness, disability, age – 38%

General Public Data

- Driving to Doctors appointments – 77%
- Arranging/preparing meals – 70%
- Grocery Shopping – 76%
- Assistance with home repairs/maintenance - 60%
- Personal Care – 52%
- Completing forms/documents – 71%
- Looking/applying for support services – 44%
- Money management/bill paying – 59%
- Housekeeping Tasks – 74%
- Medication assistance – 62%
- Assisting with nursing/medical tasks – 37%
- Financial support – 38%
- Other care due to illness, disability, age – 58%

Caregiving Tasks – 17 or Younger

State Agency Data

- Driving to Doctors appointments – 16%
- Personal Care – 8%
- Completing forms/documents – 13%
- Looking/applying for support services – 7%
- Coordinating activities and educational services – 11%
- Medication assistance – 11%
- Assisting with nursing/medical tasks – 5%
- Other care due to illness, disability, – 9%
- Scheduling appointments/coordinating care – 12%

Non-State Agency Worker Data

- Driving to Doctors appointments – 15%
- Personal Care – 10%
- Completing forms/documents – 14%
- Looking/applying for support services – 10%
- Coordinating activities and educational services – 12%
- Medication assistance – 11%
- Assisting with nursing/medical tasks – 6%
- Other care due to illness, disability, – 7%
- Scheduling appointments/coordinating care – 12%

Impact of Caregiving on Employment

State Agency Data

- No Impact – 9%
- Arrive Late – 42%
- Leave early – 65%
- Miss days – 60%
- Take leave of absence – 10%
- Unable to focus at work – 45%
- Use break time or lunch to arrange services – 49%
- Respond to emergencies/calls during work – 53%
- Rearrange work schedule – 51%
- Reduce hours working – 10%
- Turn down work travel – 7%
- Turn down promotion – 5%
- Consider changing employers – 15%
- Consider leaving workforce entirely – 16%

Non-State Agency Worker Data

- No Impact – 5%
- Arrive Late – 51%
- Leave early – 69%
- Miss days – 69%
- Take leave of absence – 16%
- Unable to focus at work – 64%
- Use break time or lunch to arrange services – 54%
- Respond to emergencies/calls during work – 66%
- Rearrange work schedule – 55%
- Reduce hours working – 21%
- Turn down work travel – 10%
- Turn down promotion – 10%
- Consider changing employers – 22%
- Consider leaving workforce entirely – 32%



Information That Would Be Helpful To Caregiver

State Agency Data

- Juggling work and caregiving – 46%
- Finding and hiring help – 38%
- Legal, financial, health care planning – 39%
- Caregiving benefits through employer – 50%
- Coping with caregiver responsibilities/stress management – 40%
- Understanding how the relationship changes during journey – 28%
- Exploring residential care – 26%
- LTC Insurance – 25%
- How to balance family life and caregiving – 29%
- Strategies to deal with difficult decisions – 29%
- Dealing with grief/loss – 22%
- Communicating with family members – 26%
- Communicating with supervisor and work colleagues – 21%
- Community resources to assist – 28%
- Dealing with challenging behaviors – 27%

Non-State Agency Worker Data

- Juggling work and caregiving – 57%
- Finding and hiring help – 50%
- Legal, financial, health care planning – 45%
- Caregiving benefits through employer – 45%
- Coping with caregiver responsibilities/stress management – 55%
- Understanding how the relationship changes during journey – 36%
- Exploring residential care – 30%
- LTC Insurance – 28%
- How to balance family life and caregiving – 39%
- Strategies to deal with difficult decisions – 29%
- Dealing with grief/loss – 23%
- Communicating with family members – 28%
- Communicating with supervisor and work colleagues – 24%
- Community resources to assist – 40%
- Dealing with challenging behaviors – 28%



Best Method to Receive Information

State Agency Data

- Online – 69%
- Email – 60%
- Fact sheets – 35%
- Printed directory of services – 30%
- Lunchtime seminars – 27%
- Employee newsletter – 26%
- Onsite support groups – 11%
- Before and after work seminars – 8%

Non-State Agency Worker Data

- Online – 66%
- Email – 60%
- Fact sheets – 33%
- Printed directory of services – 31%
- Lunchtime seminars – 20%
- Employee newsletter – 22%
- Onsite support groups – 66%
- Before and after work seminars – 13%

What's Next? – Resource Sharing

- The [*Caregivers In the Workplace Guide*](#) with partner agencies, public and private employers.
- The newly released [Caregiver Guide Video](#) that helps individuals self-identify as caregivers and directs them to supports and other resources.
- **NYS Employees Only** - The [working caregivers survey](#) with colleagues, friends, family and employees.
- **All other employees** - Send the working caregivers survey to all of your contacts, including colleagues, friends, family and employees at <https://aging.ny.gov/help-working-caregivers>
- [Caregiver Intensity Index](#) with all caregivers, including working and non-working caregivers.
- The [Evidence-Based Caregiver Education and Training Portal](#), which is available free of charge for any caregiver in New York through a partnership between Trualta and the State Office for the Aging.
- [The NY Connects Statewide Resource Directory](#) to help individuals search for local services by zip code or service.
- Any Care Counts NY Campaign – effort to boost Trualta and Caregiver Intensity Index and connect to resources – Testing campaign in 80 Dollar General/Dollar Tree stores via store receipts with QR code to connect to CII and Trualta

National Family Caregiver Support Program (NFCSP)

NFCSP – Eligible Caregivers

CAREGIVERS OF OLDER ADULTS

- An adult family member, or another individual
- Informal provider of in-home and community care:
 - Older individual
 - Individual with Alzheimer's disease or a related disorder

OLDER RELATIVE CAREGIVERS

- Caregiver who is age 55 or older
 - Provides support to a child under 18 and is not a parent
 - Provides support to an adult ages 18-59 with disability (may be a parent)



**Office for
the Aging**

NFCSP Service Categories

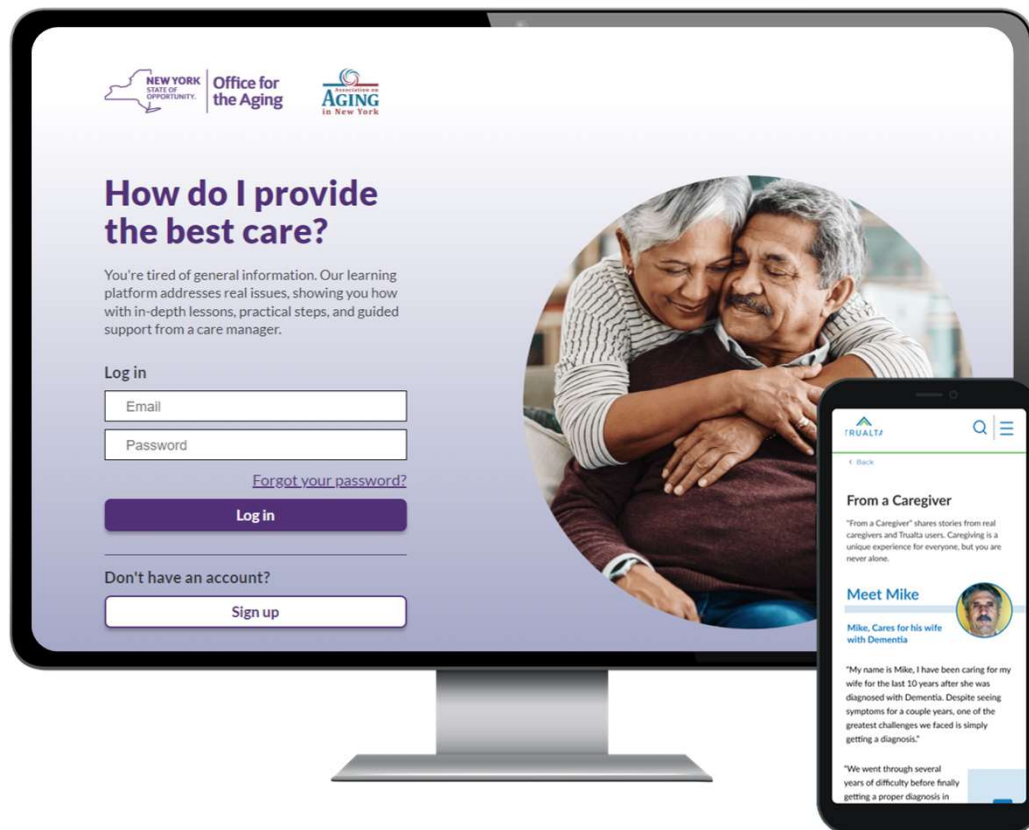
- Caregiver Information (Public)
- Assistance: Information and Assistance
- Assistance: Case Management
- Caregiver Counseling
- Caregiver Support Groups
- Caregiver Training
- Respite Care (in-home, out-of-home, overnight)
- Supplemental Services

New York Caregiver Portal

Free, family caregiver training for all New Yorkers



Trualta helps caregivers learn skills to manage care, provided for FREE by NYSOFA & Aging-NY



- Register today to access an **interactive eLearning environment**
- Short, quick lessons created by experts in aging
- Easy to use for all ages, completely private, and **accessible 24/7**
- **No app required**, view on any browser, computer, laptop, phone or tablet

Professionals – Help us spread the word!

Best Practices for Implementation

- ❑ Speak about Trualta in internal staff meetings and instruct them to sign up to familiarize themselves with content.
- ❑ Encourage real-time signups through the portal link and QR code in support groups and town meetings.
- ❑ Integrate Trualta as part of staff or provider workflow (post intake, home visits).
- ❑ Partner with community organizations (senior centers, advisory councils, hospitals, libraries, faith-based groups, etc.) to promote the portal.



**Share
With Your
Caregivers!**



<http://newyork-caregivers.com/>

How Trualta Can Help

- ❑ Postcards for support groups, home-delivered meals, etc.
- ❑ Pre-made Trualta caregiver email templates to save staff time
- ❑ Flyers for libraries, hospitals, senior centers, newsletters, etc.
- ❑ Head to newyork-caregivers.com/r/newyorkresources for digital copies.

To request promotional materials:



Matt Krzyzynski
matt@trualta.com



New York State Caregiving and Respite Coalition (NYSCRC)

How NYSCRC Can Help

- Caregiver Simulation
- Respite Worker Training Curriculum
- Respite Registry
- Respite Voucher Program
- Employed Caregiver Survey
- Caregiver Training

New York Online Respite Training



Free Training Courses For Respite Providers

Respite Care Provider Training



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Core Competencies aligned with the National Respite Guidelines



RESPIRE CARE PROVIDER CERTIFICATE AND REGISTRY



Powerful Tools for Caregivers



Class 1: Taking Care of You

Class 2: Identifying and Reducing Personal Stress

Class 3: Communicating Feelings, Needs, and Concerns

Class 4: Communicating in Challenging Situations

Class 5: Learning from Our Emotions

Class 6: Mastering Caregiving Decisions

Join NYSCRC in 2023

- Become a follower on our social platforms
-Facebook, Twitter, YouTube, and LinkedIn
- Join the NYSCRC Advisory Board Advocacy and Legislative Committee
- Share your Caregiving Story

Learn more at www.nyscrc.org

NYSCRC Respite Voucher Program

Caregiver-Directed Respite Voucher Program

- Available statewide: <https://www.nyscsrc.org/respite-voucher-program>
- Caregivers can apply for a respite voucher in the amount of \$600
- Caregivers choose the provider, which can be family members or friends
- For Kinship families, the voucher can pay for programs/classes for the kids
- Caregiver is considered the employer and must act as such (hiring, firing training, etc.)
- NYSCRC, managed by Lifespan acts only as a Fiduciary



Adult Day Services

Felicia Segelken, LMSW

she/her/hers

Director of Community and Support Programs

fsegelken@lifepathny.org

518-817-5262



General Overview



- Types of Day Programs
- Eligibility
- Benefits
- Transportation

Adult Day Services



- Structured program that provides functionally impaired adults with a variety of services for a portion of the day
 - Provides caregivers a break (respite) or help to maintain at home longer
-

Types of Day Programs

- Social Model
- Medical Model

Eligibility

55+ who are physically frail or cognitively impaired and needs assistance with activities of daily living (ADLs)

Funding:
Private Pay
Department of
Aging
MLTC
Grants

Assessment of the level of needs of the client

Mandatory trial visits (3 hours)

Benefits of Adult Day Services

Health and Wellness

- Exercise
- Health Discussions
- Nutritious meals
- Supervision by trained staff

Socializing with Peers

- Reduces isolation
- Promotes social engagement
- Decreases risk of depression

Purposeful Recreation

- Intergenerational activities
 - Age-appropriate games boost memory
 - Arts and Crafts
 - Outdoor activities
-

Transportation

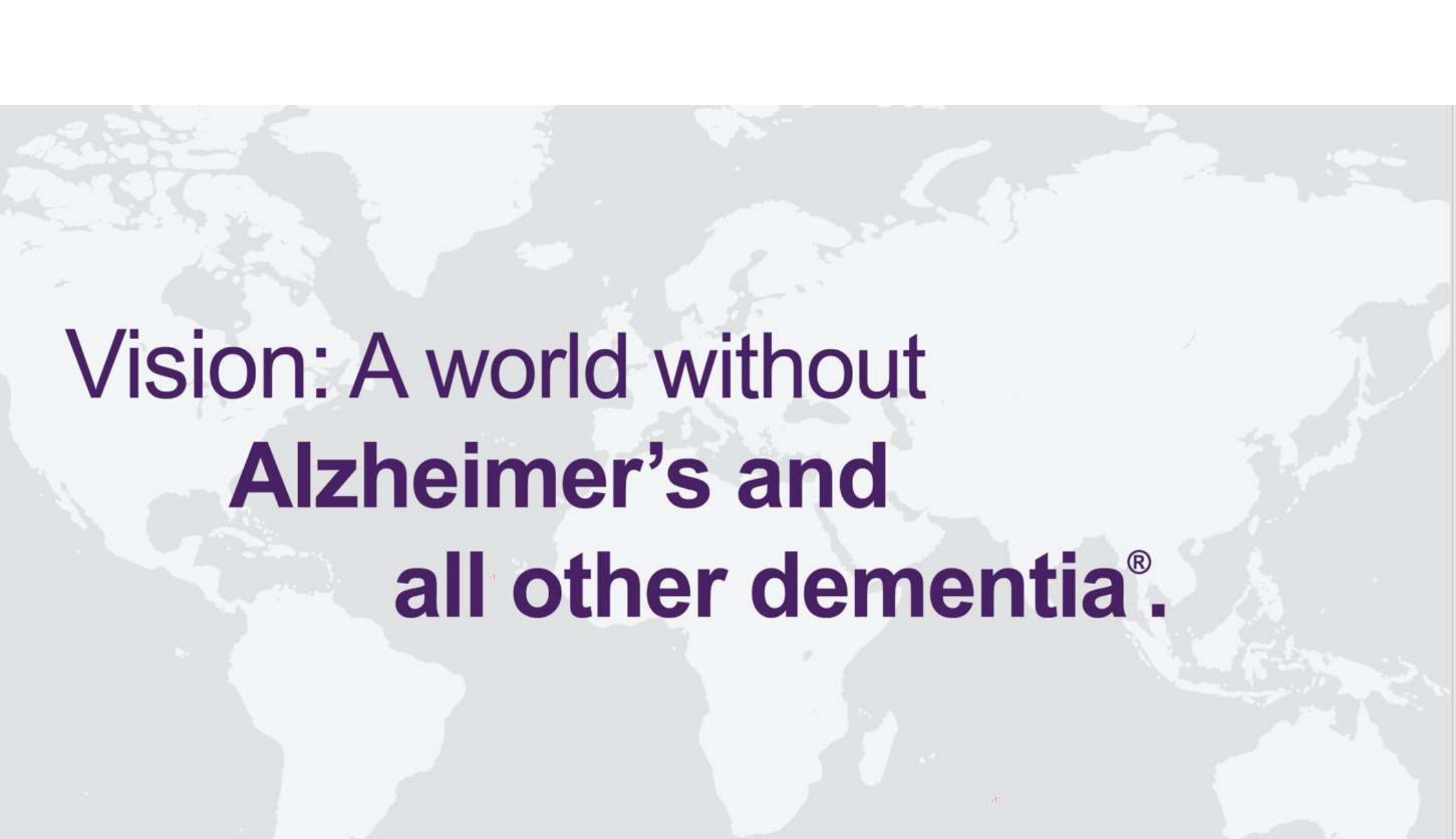
Day Program Transportation

Private Pay

Department of Aging

MLTC

Questions?
Thank you!

A light gray world map is visible in the background of the slide, showing the continents of North America, South America, Europe, Africa, Asia, and Australia.

**Vision: A world without
Alzheimer's and
all other dementia®.**

Mission:

The Alzheimer's Association leads the way to **end Alzheimer's and all other dementia** — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

Strategic goals



Providing and enhancing
care and support.



Accelerating
research.



Increasing concern
and awareness.



Strengthening diversity,
equity and inclusion.



Advancing public
policy.



Increasing
revenue.

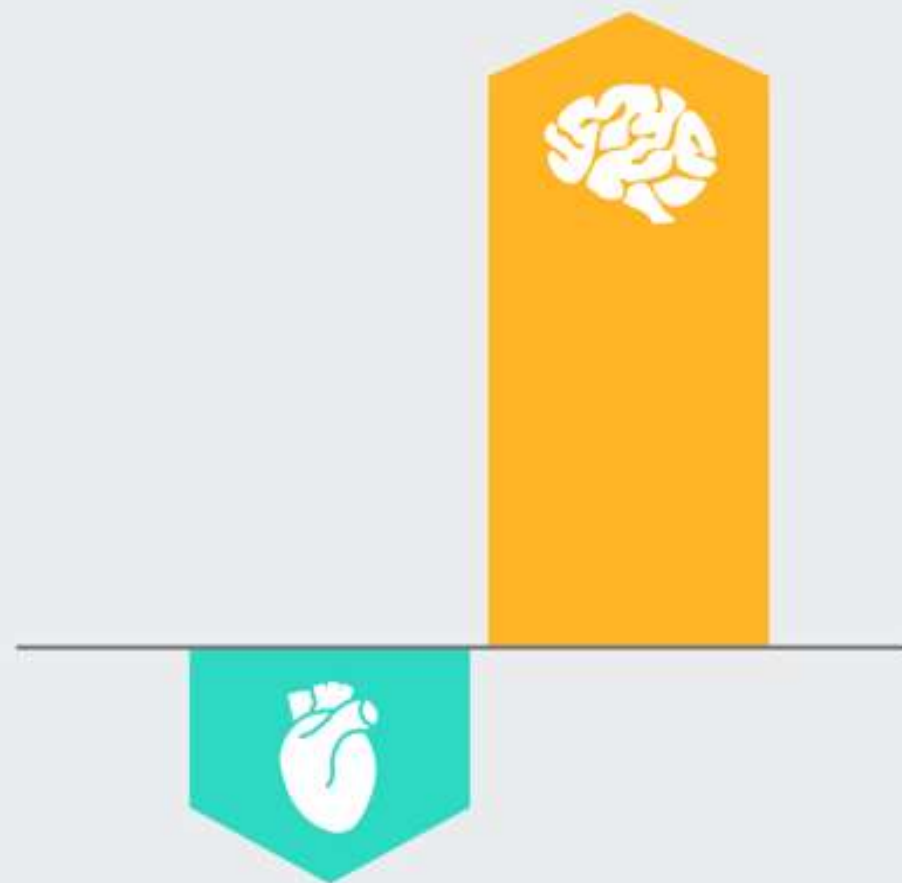


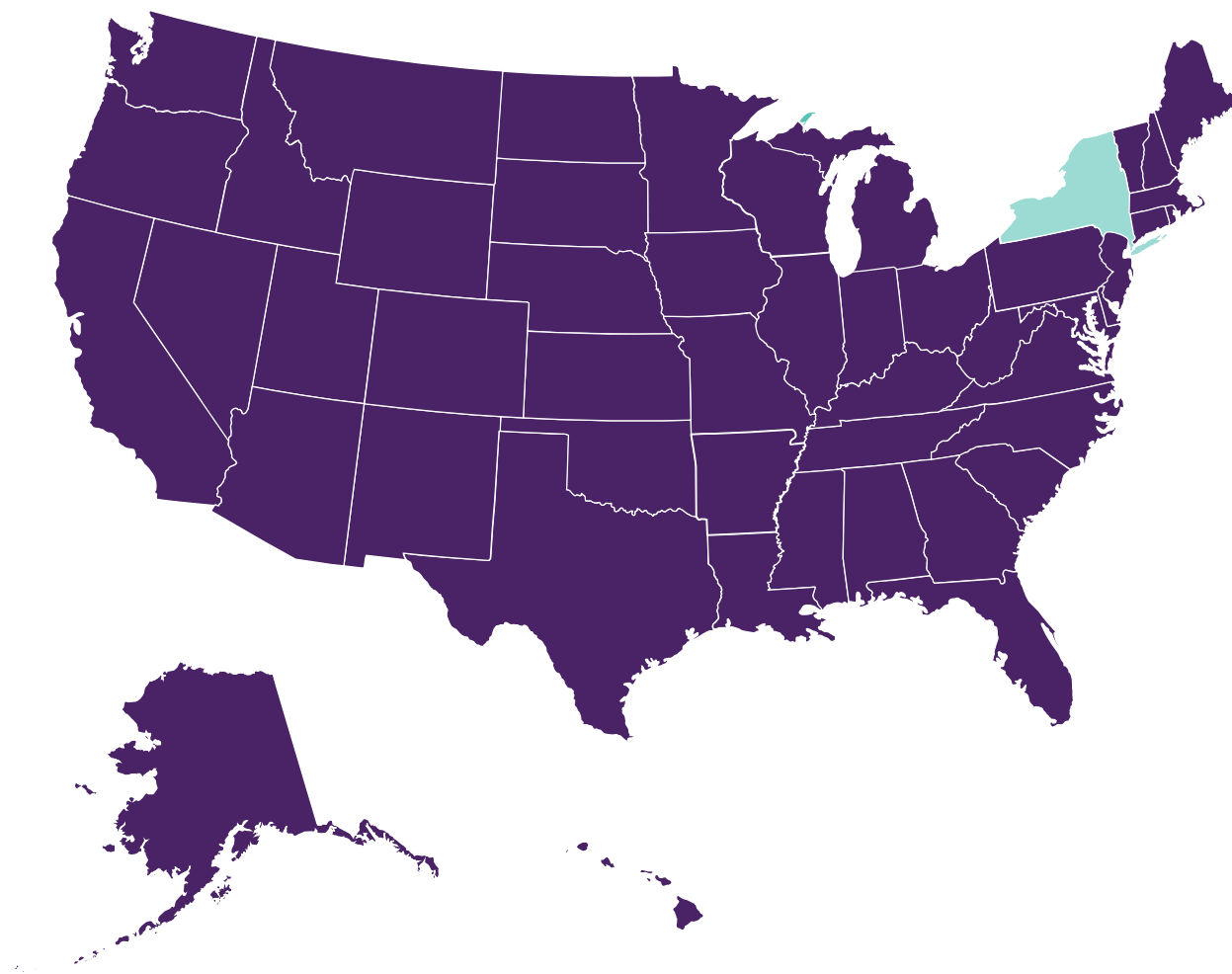
More than
6 million Americans
are living with
Alzheimer's.



Over 11 million Americans
provide **unpaid** care for people
with Alzheimer's or other
dementias. These caregivers
provided more than
16 billion hours valued
at over **\$271 BILLION.**

Between 2000-2019,
deaths from **heart disease**
have **decreased 7.3%**,
while deaths from
Alzheimer's disease
have **increased 145%**.





NEW YORK

2023 ALZHEIMER'S STATISTICS

There are more than

410,000

People aged 65 and older with
Alzheimer's Disease

By 2025 we estimate a 12.2%
increase in prevalence of
Alzheimer's disease totaling
460,000 individuals living with AD



NEW YORK

2023 ALZHEIMER'S STATISTICS

UNPAID CAREGIVERS (2022)

546,000 # OF CAREGIVERS

884,000,000 TOTAL HOURS
OF UNPAID CARE

\$19,089,000,000 TOTAL VALUE
OF UNPAID CARE

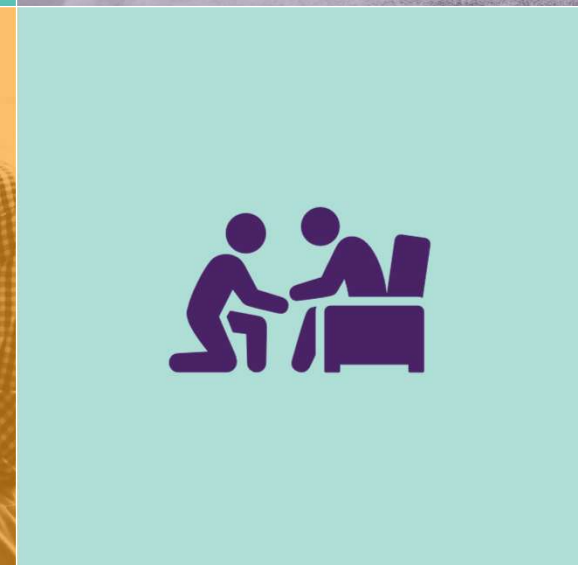
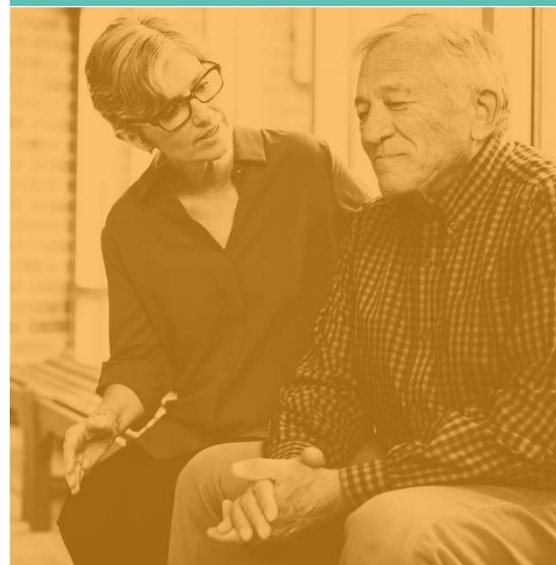
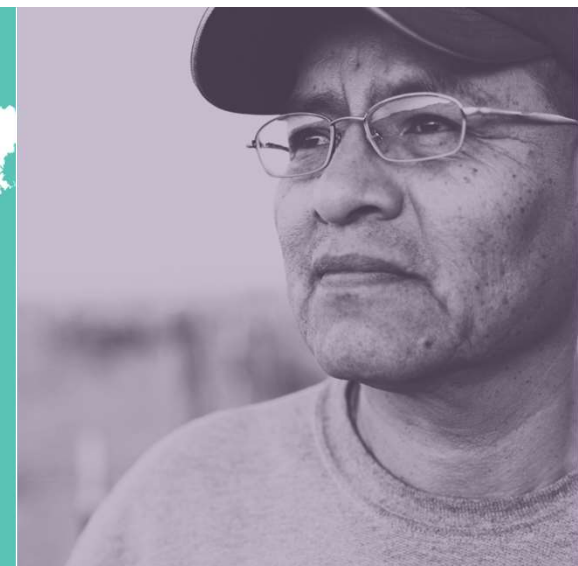
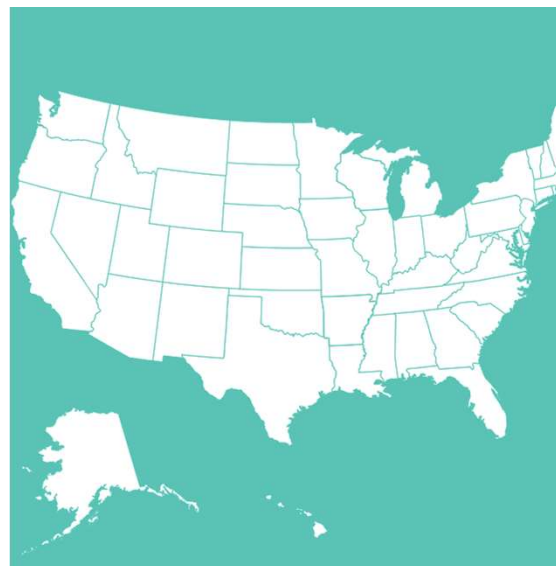
CAREGIVER HEALTH (2021)

59.0% OF CAREGIVERS
WITH CHRONIC
HEALTH CONDITIONS

24.7% OF CAREGIVERS
WITH DEPRESSION

12.0% OF CAREGIVERS
IN POOR PHYSICAL
HEALTH

CAREGIVING





The Alzheimer's Association is the world's largest nonprofit funder of Alzheimer's disease research. Currently, the Association is investing **\$300 million in 920 active best-of-field projects in 45 countries.**



The Alzheimer's Association
offers free **online** and
in-person education
programs for people living
with the disease and their
caregivers.

[alz.org/education](https://www.alz.org/education)





ALZConnected®, powered by the Alzheimer's Association,
is a free online community for everyone
affected by Alzheimer's or other dementias.

alzconnected.org

Upcoming Alzheimer's Association Memory Cafes and Support Groups

Find additional programs and support groups at alz.org/crf

EARLY STAGE SUPPORT GROUP— THIS GROUP IS INTENDED FOR THOSE IN THE EARLY PHASES OF MILD COGNITIVE IMPAIRMENT, ALZHEIMER'S DISEASE OR OTHER FORMS OF DEMENTIA AND THEIR CARE PARTNERS

Presented by:
Alzheimer's Association
Northeastern New York

FACILITATORS Lindsay Stanislawsky and Gwen Rowland

DATE Third Thursday of the month

TIME 10:00AM-11:30AM

ADDRESS "STRIVE" 4255 Route 50 Saratoga Springs, NY 12866

To register contact Tony Rivera at 518-675-7214 or tarivera@alz.org

Build a support system with people who understand.

Alzheimer's Association® support groups, conducted by trained facilitators, are a safe place for people living with dementia and their care partners to:

- Develop a support system.
- Exchange practical information on challenges and possible solutions.
- Talk through issues and ways of coping.
- Share feelings, needs and concerns.
- Learn about community resources.

alzheimer's  association®

Caregiver Support Groups in Saratoga County

2nd Thursday of the month | 3:00-4:00pm
Corinth YMCA

119 Gabriel Road, Corinth NY 12822
Facilitator: Gwen Rowland, LMSW

2nd Wednesday of the month | 1:00-2:00pm

Christ Community Reformed Church
1010 NY-146 Clifton Park, NY 12065
Facilitators: Roy Scott and Jody Dayter

3rd Thursday of the month | 12:00-1:00pm

Halfmoon Senior Center
287 Lower Newtown Rd, Halfmoon NY 12065
Facilitators: Fran Gordon and Beverly Ross

2nd Friday of the month | 11:00-12:30PM

Saratoga Senior Center
5 Williams Street, Saratoga Springs NY 12866
Facilitators: Roy Scott and Jody Dayter

For more information or to register for one of the above support groups contact our 24/7 Helpline 800.272.3900 | alz.org/crf | Tony Rivera at 518.675.7214 | [email tarivera@alz.org](mailto:tarivera@alz.org)

This program is supported in part by a grant from the New York State Department of Health

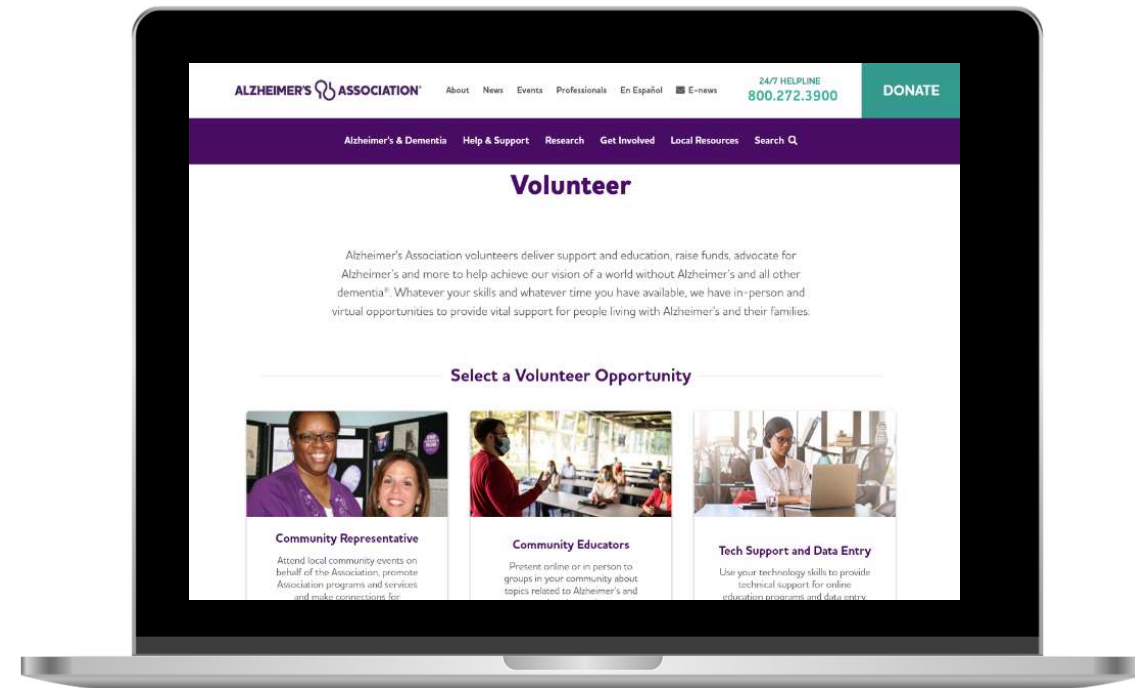


Virtual Caregiver Support Group
FOR CAREGIVERS OF THOSE WITH YOUNGER ONSET
DIAGNOSED BEFORE 65

ALZHEIMER'S  ASSOCIATION®

Get involved!

- Connect with your local chapter
- Use us as a resource
- Share our resources with your networks
- Visit our website alz.org
- Participate in an event
- Become an advocate
- Volunteer
alz.org/volunteer





Alzheimer's Association of Northeastern New York Chapter

1003 New Loudon Road, Suite 201
Cohoes, NY 12047

518-867-4999

24/7 Helpline: 800-272-3900

Gwen Rowland, LMSW

Saratoga County Program Manager

Call/Text: 518-888-5846

growland@alz.org