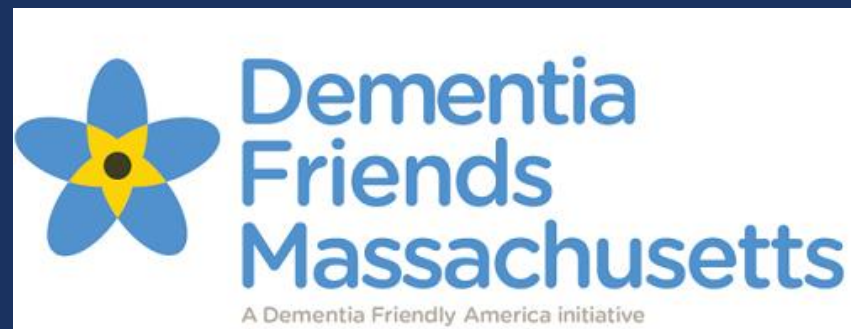


YOUTH ENGAGEMENT IN ALZHEIMER'S DISEASE ADVOCACY AND CAREGIVING

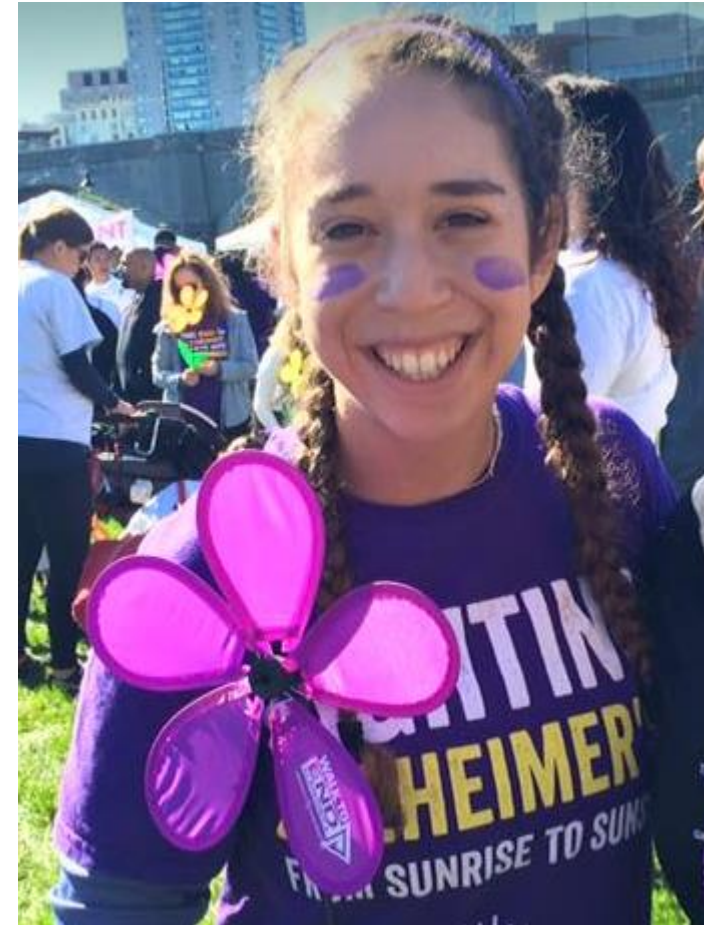
PANEL DISCUSSION AT THE 2017 **CREATING WELCOMING COMMUNITIES** SYMPOSIUM

DEMENTIA FRIENDLY MASSACHUSETTS INITIATIVE



MODERATOR: LEAH LEVINE

- Recruitment Assistant at the Center for Alzheimer Research at Treatment at Brigham and Women's Hospital
- Graduated in May 2017 from Brandeis University with degrees in Public Health and Psychology
- Former president of Brandeis Students to End Alzheimer's Disease (SEAD)
- Interned at the Alzheimer's Association in Hispanic/Latino Outreach
- Volunteered at the Memory Café at JF&CS Waltham



PANELISTS: KATHLEEN FADDOUL AND ELLEN SANTOS

Ellen Santos MSN, RN, CNE



Ellen Santos started her career as a staff nurse in pediatrics and maternal newborn nursing. She began working as a clinical instructor for Assabet Valley Regional Technical School in 1991 and is currently Director of Practical Nursing. She has a BSN from St. Anselm College, an MSN from St. Joseph's College, a CAGS from Assumption College and is a National League for Nursing-Certified Nurse Educator.

Kathy Faddoul, RN, BSN, M. ED



Kathy Faddoul has been a nurse for over 30 years working in acute care, long term care, and home care. She is currently an instructor at Assabet Valley Regional Technical High School teaching high school sophomores and juniors a Certified Nursing Curriculum in the Health Technology Shop.



ASSABET VALLEY REGIONAL TECHNICAL HIGH SCHOOL

DEMENTIA FRIENDLY SCHOOL





ASSABET VALLEY REGIONAL
TECHNICAL HIGH SCHOOL

Massachusetts' First
Dementia Friendly School

ASSABET

MAIN OFFICE
ALL VISITORS MUST
CHECK IN WITH
RECEPTIONIST

NO TRESPASSING
BY AUTHORITY
UNLESS ACCOMPANIED
BY A SCHOOL EMPLOYEE
OR AUTHORIZED PERSONNEL
NO. 1000-10-01-10

ASSABET

Superintendent Ernie Houle

Principal Mark Hollick

Vocational Director Russ Mangsen

Academic Director Rob McCann



DEMENTIA FRIENDLY SCHOOL- HOW IT BEGAN

- PN students volunteered to participate in a Mental Health Wellness Day for Senior Citizens at the Marlboro Senior Citizen Center
- Invited to join the newly formed Come to Be Dementia Friendly Committee in Marlboro
- Student Nurses Class of 2016 did community surveys
- Idea came to be a Dementia Friendly School
- Culinary and Cosmo serving seniors now but all trades people will be working in the community
- PN students and Health Tech Students are trained in Habilitation
- PN students and Health Tech students have clinical expertise in caring for patients with dementia.
- Class of 2017 worked with Health Tech Juniors for peer to peer education

GOALS FOR DEMENTIA FRIENDLY SCHOOL 2016-2017

1. Increase awareness and understanding about dementia.
2. Decrease stigma,
3. Provide concrete strategies to work with people with dementia.

HOW IT WAS ACCOMPLISHED

Students researched concrete strategies for four areas at Assabet

Epicurean Restaurant (Culinary Arts)

Sheer Techniques Salon (Cosmetology)

In the home (HVAC, Plumbing, Carpentry, Electrical Wiring)

In the community (Drafting, Business Technology, Biotechnology,)

CURRICULUM FOR ALL SHOPS

- Why learn about this?
- What is dementia
- How does this affect me/my shop/my life
- Signs and symptoms/recognizing dementia
- Brain changes
- Communication strategies

OTHER AREAS COVERED

- Shop specific strategies
- Dementia related diseases
- Healthy living
- Research being done for prevention and cure
- Resources available

STUDENT FEEDBACK

A pre survey and a post survey were completed by the students receiving the training.

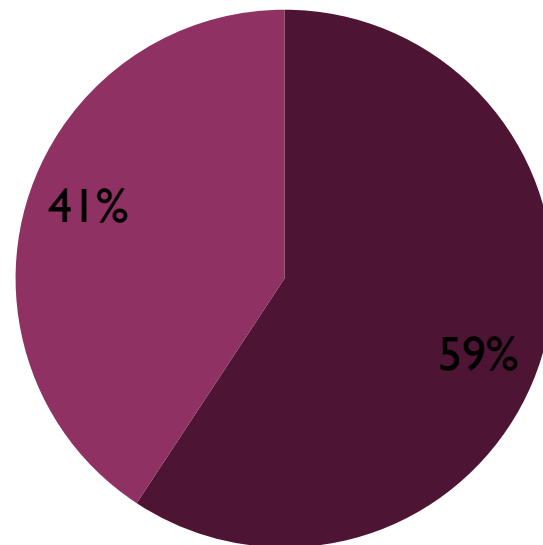
PRE TRAINING SURVEY RESULTS

I HAVE HEARD OF DEMENTIA BEFORE



PRE TRAINING SURVEY RESULTS

I THINK I KNOW WHAT DEMENTIA MEANS



■ YES
■ NO

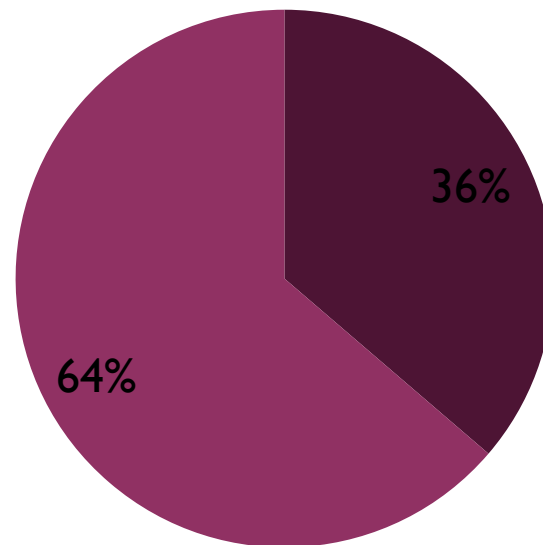
PRE TRAINING SURVEY RESULTS

I KNOW DISEASES THAT HAVE DEMENTIA AS A SYMPTOM



PRE TRAINING SURVEY RESULTS

I KNOW SOMEONE WITH DEMENTIA



■ YES
■ NO

PRETRAINING SURVEY RESULTS

WHAT DO YOU WANT TO KNOW ABOUT DEMENTIA?

- What is the best way to help someone with dementia?
- Is there research for this disease?
- How does it affect the brain?
- Has anyone beat dementia?
- What are the symptoms of dementia?



Students created a presentation for each shop with power points, videos and skits.

Shop specific strategies were included.

Junior HT and PN students then did peer to peer teaching with all Juniors in all shops.

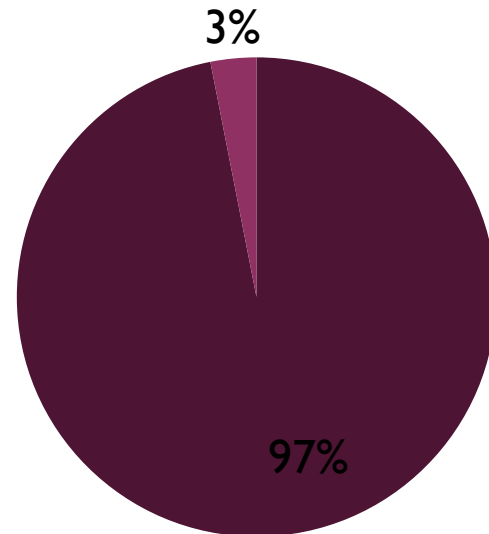
POST TRAINING SURVEY RESULTS

I KNOW MORE ABOUT DEMENTIA NOW



POST TRAINING SURVEY RESULTS

I THINK I COULD USE ONE OF THE STRATEGIES I LEARNED TODAY IN MY SHOP OR ON MY JOB



■ YES
■ NO

POST TRAINING SURVEY RESULTS

THE BEST THING ABOUT THE TRAINING WAS...

- How clear things were explained.
- Learning how to deal/communicate with customers with dementia.
- How to interact with someone with dementia.
- Presented in layman's terms, not medical.
- My Pepe has dementia so now I can help out more.

POST TRAINING SURVEY RESULTS

SOMETHING I WOULD LIKE MORE INFORMATION ON...

- If it will ever be curable? Why is there no cure?
- How many people are affected?
- Facilities to volunteer at/ the Walk for Alzheimer's
- How can I help find a cure?
- What other police departments keep a list of people with dementia?

ALL SHOPS



COME 2 B
Dementia Friendly



Assabet LPN
LICENSED PRACTICAL NURSE
Be. More.



HEALTH TECHNOLOGY
ASSABET DO. MORE.

This Shop Is Dementia Friendly!

AT COMPLETION OF 17 SHOPS

COME 2 B

Dementia Friendly

Assabet LPN
LICENSED PRACTICAL NURSE
Be. More.

HEALTH TECHNOLOGY

ASSABET DO. MORE.

**This school is
Dementia
Friendly!**

DEMENTIA FRIENDLY SCHOOL



OTHER ACTIVATES RELATED TO DEMENTIA FRIENDLY SCHOOL

Walk to End Alzheimer's



Dolls for Dementia

Students organized a drive to collect baby dolls, doll clothing and doll blankets to donate to a local long term care facility.



GOALS FOR 2017-2018

- Continue peer to peer education of all juniors in all shops on dementia
- Purple Table Certification of Assabet restaurant *The Epicurean Room*
- PN students will provide all pharmacies and walk in clinics in Marlborough with Marlborough Police Department flyers and education on the Dementia Registry at the Police department.
- First Memory Café offered at Assabet this Spring!

PANELISTS: BECCA EPSTEIN

- Becca Epstein is the Co-President of Brandeis University Students to End Alzheimer's Disease (SEAD). This is her second year being involved in the club, which she became involved in after her grandfather developed and passed away from Alzheimer's Disease. At Brandeis, Becca is a senior majoring in Economics and minoring in Social Policy and Global Studies. Aside from classes and SEAD, Becca is a peer academic advisor and plays on the Ultimate Frisbee team.



Brandeis SEAD



PANELISTS: MELODY MCLAUGHLIN

Melody McLaughlin, CDP is the Early Stage Engagement Programs Manager at the Alzheimer's Association MA/NH Chapter. In her role, Melody develops and identifies meaningful social, volunteer and advocacy opportunities for individuals impacted by mild Alzheimer's disease. This work includes coordinating social engagement activities, managing and advisory group of persons living with an early stage diagnosis, fulfilling speaker requests for both persons living with a diagnosis and care partners as well as coordinating the Alzheimer's Association youth engagement program, AlzKidz.

Alzheimer's Association MA/NH Chapter

AlzKidz

alzheimer's  association®

THE BRAINS BEHIND SAVING YOURS.®

AlzKidz

A social program for families who have children 18 years of age and younger that are impacted by having a parent or grandparent living with Alzheimer's disease or a related dementia

Pilot

- History
- Offerings
- Attendance
- Social engagement and observations
- Recommendations and moving forward

History

- Increased participation from individuals with mild Alzheimer's disease and Younger-Onset Alzheimer's disease
- Initially acknowledged service gap for their children and grandchildren
- Gathered input from families regarding needs and interests
- Developed pilot program for children and grandchildren 18yo or younger who are living with a parent or grandparent with dementia

Offerings

- Quarterly
- Successfully offered two AlzKidz in the community
 - City Street in Waltham
 - Indigo Fire Studio in Belmont
- Cancelled two AlzKidz due to low attendance

Attendance

- 35 participants
- Children ages 6 - teen
- Parents with and without dementia
- Grandparents with and without dementia

Social Engagement & Observations

Engagement

- Ice breakers
- Encouraged mingling
- Built in social time

Observations

- Younger children more open to talking with the larger group
- Teens more apprehensive
- Program did not greatly benefit parents/grandparents in the later stages of the disease

Challenges

- Scheduling and retention
- Recruitment
- Identifying programs for all ages and stages

Recommendations and moving forward

Recommendations

- Further develop recruitment strategies
- Include all children 18yo and younger who are impacted by having a parent or grandparent with dementia; not just those living with a parent/grandparents

Moving Forward and the next AlzKidz

- Saturday, January 6th at the American Repertory Theater for Charlotte's Web

PANELISTS: JEFFREY ROBBINS AND IOANA DOBRE

Jeff Robbins, LICSW



Jeff Robbins is a clinical social worker in Neurology at Brigham and Women's hospital and a Teaching Associate in Neurology at Harvard Medical School. He is the co-founder of and senior advisor to the Harvard College Alzheimer's Buddies program and president and founder of National Alzheimer's Buddies.

Ioana Dobre, A.B.



Ioana graduated from Harvard University in 2017 with a major in Chemical and Physical Biology and a Foreign Language Citation in Spanish. Throughout her four years of undergrad, she was very involved in the Alzheimer's Buddies program, serving first as Symposium Director and then as Co-Director. The symposium she spearheaded at Harvard drew a wide range of support from the community and included addresses by television host Meredith Vieira, Governor Charlie Baker, and Senator Elizabeth Warren. After graduating, Ioana joined the National Alzheimer's Buddies team and is also currently working full-time at Massachusetts General Hospital on a clinical research project. She hopes to attend medical school in the future and her experience in the Alzheimer's Buddies program has been instrumental to shaping her interest in geriatrics.

NATIONAL ALZHEIMER'S BUDDIES

- Eleanor Robbins Community Program
- Harvard College Alzheimer's Buddies
- NAB

WHAT IS NAB?

- A non-profit company
- Volunteer program for college undergraduates
- Addresses social isolation and disengagement



NATIONAL ALZHEIMER'S BUDDIES

- Harvard College
- Gordon College
- U Mass Dartmouth
- Cal Poly Pomona
- Yale
- University of Pennsylvania
- U. C. Davis
- University of Minnesota
- Carleton College
- Vanderbilt University
- University of Illinois, Chicago
- Rice University
- M.I.T.
- Scheduled for the spring: Stanford University, Wellesley College, U Mass Amherst, and NYU



NAB – HOW IT WORKS

- Student run and administered
- Relies on help from Advisors
- Student expresses interest
- Student is interviewed by Board
- Recruits 2 Co- Chapter Directors
- Locate facility
- School approves program
- Students invited to apply
- Chapter Directors Receive Training
- Student Volunteers Receive Training

NAB – HOW IT WORKS (THE DETAILS)

- Students visit buddies for one hour/week
- Maintain online journal
- Attend Reflection Meeting
- Attend events organized by chapter directors
- Send letters to Family
- Organize an activity that brings student volunteers, buddies and family members together
- Research

CHAPTER DIRECTORS TRAINING

- Identify Components
- Emphasizes:
 - Good Communicator
 - Responsible/Reliable/Accountable
 - Approachable
 - Organized
 - Committed
 - Flexible
 - Passionate/Focus/Creative

STUDENT VOLUNTEER TRAINING

- How many of you are convinced...
- MMSE
- Presentation
- Do's and Don'ts
- Role Plays
- Q & A
- Facility provides bios
- Tour of the facility
- Meet and greet

STUDENT VISITS 2



WHY IT WORKS

- Students want to expand the scope of their college experience
- Knowledge based on who the resident is
- Work through relationships with lost grandparents
- Are motivated by the enhancement of their CV – enhancing an interest in Neurology
- Learn life and communication skills
- Provide management/leadership skills to motivated chapter directors
- Students inspire one another fostering a sense of ownership and responsibility for the program
- “I get more out of this than I give”

AN ARMY OF EXPERTS

- Student volunteers develop expertise in the art of communicating effectively with people living with dementia in the late moderate to late stage of the illness
- This is bolstered by their positive energy, their warmth and their perspective, i.e. knowing and building on what is there, rather than on what is lost.
- Family members who visit infrequently express their helplessness and grief when visiting their loved one.
- Program currently provides over 350 hours of care/week.

IMPLICATIONS

- Students have potential to mentor primary caregivers
- Students have potential to mentor LTC non-professional staff

NEW DIRECTIONS

- Service learning course
- African American population
- Visits in the home
- Continue program expansion
- New research
 - Impact of program on students and caregivers
 - Impact of program on family visits

PANEL QUESTIONS!

