

Respite for Families Affected by MS:

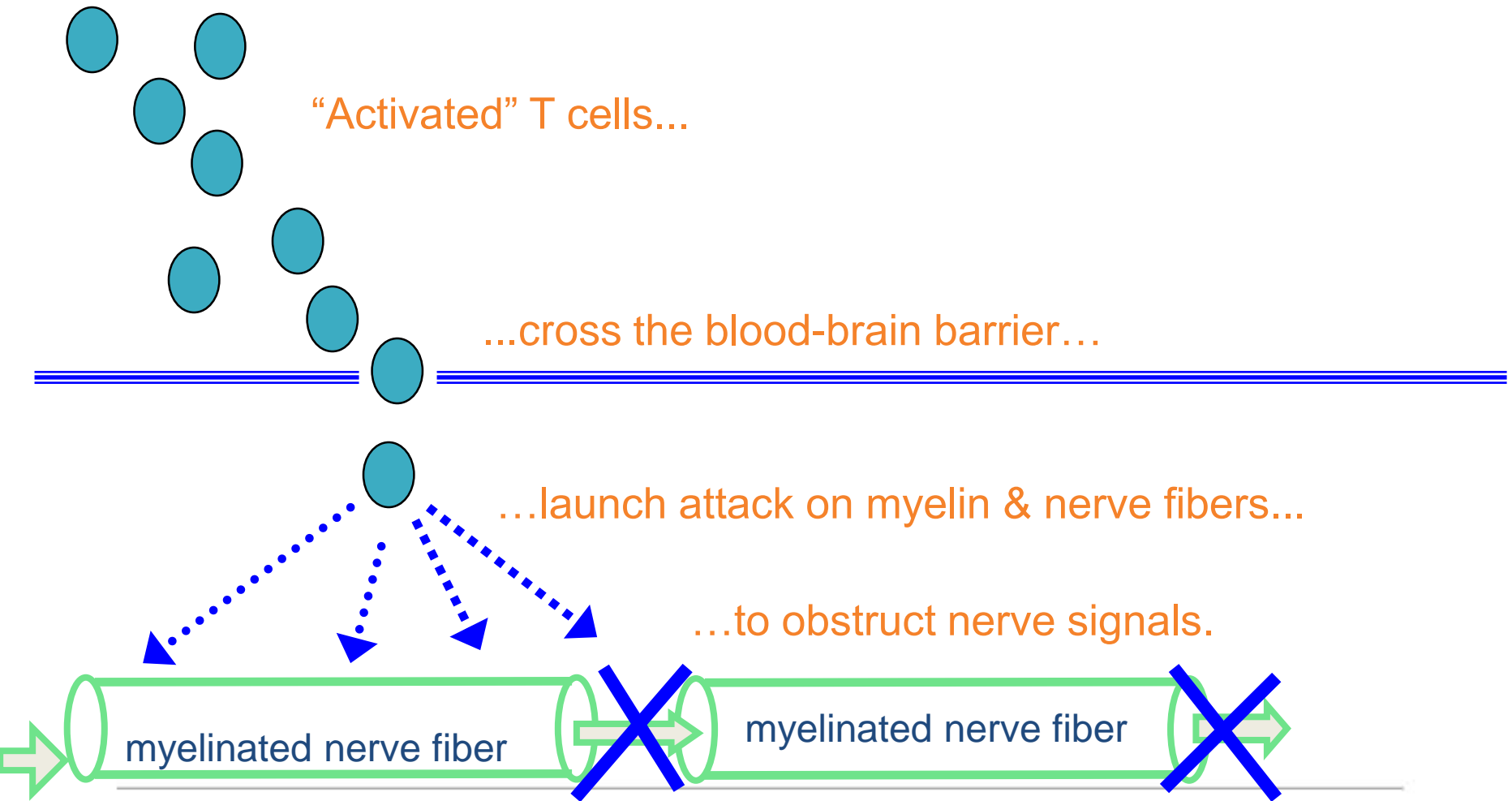
Models of Program Delivery and Advocacy Partnerships to Serve Younger Adults with Disabilities



Multiple Sclerosis: What Is It?

- Thought to be a disease of the immune system.
- Primary targets: myelin coating around the nerves in the central nervous system (CNS—brain, spinal cord, and optic nerves) and the nerve fibers themselves.
- Its name comes from the *scarring* caused by inflammatory attacks at *multiple* sites in the central nervous system.

What happens in MS?



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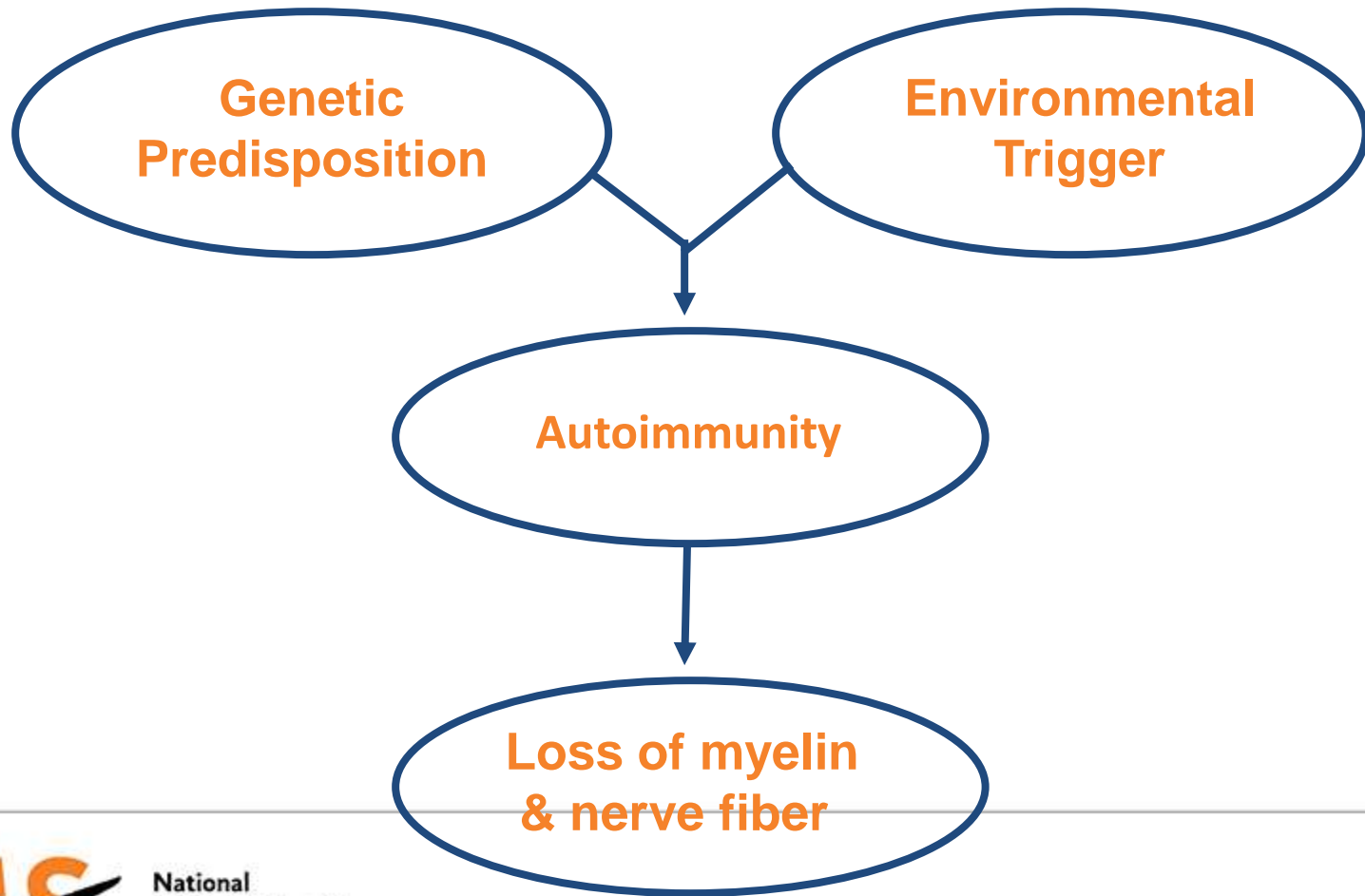
What happens to the myelin and nerve fibers?

to



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What Causes MS?



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Who gets MS?

- Usually diagnosed between 20 and 50
 - Occasionally diagnosed in young children and older adults
- More common in women than men (2-3:1)
- Most common in those of Northern European ancestry
 - More common in Caucasians than Hispanics or African Americans; rare among Asians
- More common in temperate areas (further from the equator)

Symptoms Vary Person-to-Person

- Fatigue (most common)
- Vision problems
- Bladder/bowel dysfunction
- Sensory problems (numbness, tingling)
- Emotional changes (depression, mood swings)
- Walking difficulties
- Stiffness (spasticity)
- Pain (neurogenic)
- Sexual problems
- Speech/swallowing problems
- Tremor
- Breathing difficulties
- Impaired temperature control
- Cognitive changes (memory, attention, processing)

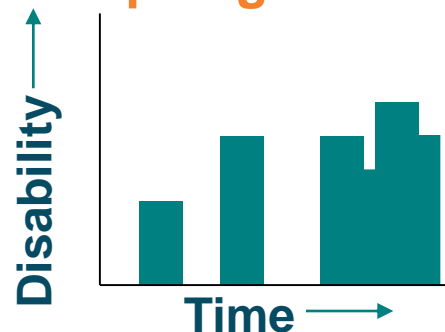


MS = Unpredictable

- Approximately 1/3 will have a very mild course
- Approximately 1/3 will have a moderate course
- Approximately 1/3 will become more disabled

4 Disease Courses

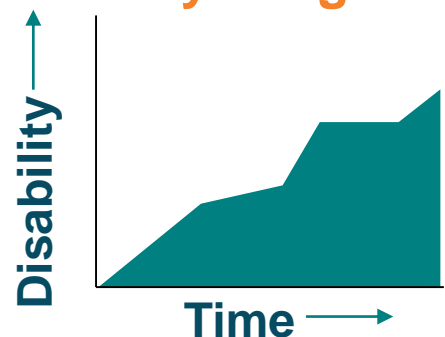
Relapsing-Remitting



Secondary-Progressive



Primary-Progressive



Progressive-Relapsing



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Adapted with permission from Lublin FD et al.
Neurology. 1996;46:907-911.

What are the treatment strategies?

While we continue to look for the cure, management of MS includes:

- Treating *relapses* (aka exacerbations, flare-ups, attacks—that last at least 24 hours)
- Managing the disease course – 12 FDA-approved drugs
- Managing symptoms
- Maintaining/improving function
- Enhancing quality of life



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Why is MS such a challenging disease?

- Chronic disease with no known cure or completely effective treatments
- Tends to impact people in the prime of their life
- Variable and unpredictable—with no clear roadmap
- Involves ongoing change and loss
- Very expensive
- Impacts the entire family

MS: The Real People

- **Julia** - a 35yo white married mother of 3 who is exhausted all the time and can't drive because of vision problems and numbness in her feet
- **Jackson** - a 25yo African-American man who stopped working because he can't control his bladder or remember what he read an hour ago
- **Loretta** - a 42yo white single woman who moved into a nursing home because she can no longer care for herself
- **Sam** - a 47yo divorced white man who has looked and felt fine since he was diagnosed seven years ago
- **Richard** - who was found on autopsy at age 76 to have MS but never knew it
- **Jeannette** - a 55 year old widow whose tremors are so severe that she cannot feed herself

What happens when one member in a family is diagnosed with MS?

MS is like an uninvited guest.

- Shows up without warning
- Has its own way of doing things
- Takes up space in every room
- Is a stranger to everyone
- Doesn't go home

2011-2012 National Alliance for Caregiving Report: Multiple Sclerosis Caregivers

421 individuals who provide care to a friend or family member with MS

- Average 24 hours/week
- Help with activities of family living
 - 82% with getting in and out of bed/chairs
 - 73% getting dressed
 - 51% bathing
 - 46% feeding
 - 44% incontinence or diapers
 - 43% help with toileting

2011-2012 National Alliance for Caregiving Report: Multiple Sclerosis Caregivers

Impact on the Caregiver:

- 43% impacted overall financial situation
- 64% feel emotionally drained
- 32% suffer from depression because of providing care
- 49% get physically exhausted
- 31% have suffered physical injuries as a direct result of providing care
- 25% can't focus at their job
- 22% have lost a job due to caregiving responsibilities

2011-2012 National Alliance for Caregiving Report: Multiple Sclerosis Caregivers

Opportunities to Keep Care Recipients at Home Longer:

- 82% ability to pay for in-home care
- 75% medical paid (or more medical paid) care at home
- **66% respite care**
- 59% more accessible home
- 58% more support from family and friends
- 46% more education on how to provide care

MS & the Lifespan Respite Care Program

The National MS Society has supported the program since its inception.

Why?

- Program is to serve regardless of age or disability
- Many existing respite services are targeted for children with special needs or the aging population
- MS is typically diagnosed between the ages of 20-50
- 56% of all care recipients are under age 75; 28% are under age 50

The Society's Involvement – National Level

- National office in Washington, D.C. lobbies each year for continued funding for the program.
- 113,000 members of the MS Activist Network contact their members of Congress to advocate for annual funding.
- In the past 5 years, has been an issue at two Society Public Policy Conferences.

The Society's Involvement – State & Local Level

- The Society has a 50-state network of chapters.
- Some work with their state agency and state partners on the grant application for federal funding.
 - Helps ensure that Lifespan Respite programs are structured to meet the needs of families affected by MS, including families with younger adults with more progressive MS.
 - The needs of younger adults with disabilities are very different than children's/the aging populations' needs.

The Society's Involvement – State & Local Level

Arizona Example – MS Activists helped...

- Create a standardized training for professional non-medical caregivers
- Form coalitions and raise awareness about family caregivers and their needs with state legislators
- Get state Lifespan Respite legislation passed in 2007 with a \$500,000 appropriation, making AZ the 5th state in the nation to sign such legislation into law

The Society's Involvement – State & Local Level

Bonnie, MS Activist, Arizona

- Husband Jim was diagnosed in 1971 – “He was not the only one who got the diagnosis. So did I. It changed our lives.”
- “Though in near constant pain, he found an indisputable inner strength. Jim's journey took me on mine.”
- “I became an advocate at the state capitol and our nation's capitol to better the lives of people with MS and other chronic illnesses and their families. It was time to bring the invisible caregiver out of the shadows into the light to be recognized and supported.”



The Society's Involvement – State & Local Level

New Hampshire & Massachusetts

- Society staff and MS Activists serve on the Massachusetts Lifespan Respite Coalition to ensure that the needs of people with MS are fully represented in their program and future planning
- MS Activist served as volunteer leader of the NH Lifespan Respite Coalition and helped launch NH's first respite care locator (NH Provider Link Directory)

The Society's Involvement – State & Local Level

Virginia – Society staff...

- 2010 – helped reignite discussions around Lifespan Respite with stakeholders including staff
- Sat on grant committee
- Chaired the Voucher Committee that helped design the voucher component of VA's Lifespan Respite program
- After receiving the grant, helped spread the word about the availability of respite vouchers in the state
- Chaired the VA Caregiver Coalition's Advocacy Committee and worked with state legislators to introduce a budget amendment for more funding for the voucher program; this amendment failed but helped raise awareness and advocacy efforts will continue



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Real Help for Real Families

Pam & Ray Heron, Virginia

- Pam diagnosed over 15 yrs ago
- Has needed round-the-clock care since the late 1990s
- Ray works full time and provides care for Pam in the AM & PM
- Lifespan Respite voucher allowed Ray to visit his aging parents for the first time in many years



Real Help for Real Families

The Sinclair Family, Virginia

- Stacy was 15 when her mom Christine was diagnosed
- Stacy's brother has Down's Syndrome
- Family shares caregiving responsibilities
- Voucher covered 16-18 hours of respite



“Don’t give up hope. There is help like the Lifespan Respite Voucher Program out there.”



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How to Connect to Your Local MS Society Chapter

We are here to help and partner!

<http://www.nationalmssociety.org/Chapters>
or contact laura.weidner@nmss.org

Questions?

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National
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Connecticut
Chapter

MS Vacation Week

A program benefiting people
with multiple sclerosis and their
family members

What is MS Vacation Week?

A six-day, five-night camp for people with MS that combines an educational, recreational and social experience for disabled adults with a respite opportunity for family caregivers.

- Partnership between the Connecticut and Greater New England Chapters of the National MS Society
- Established 26 years ago
- Campers come from all over New England
- Held at a fully handicapped accessible camp facility in Hebron, Conn.



Who Attends

The Connecticut Chapter aims to serve 20-23 people with MS, 6-10 direct caregivers and approximately 40 additional family members who will benefit from respite.

Participants:

- aged 30 to 80
- come from many different backgrounds
- vary in their level of ability and disease progression
- live with family, live alone, or come from nursing homes



Program Goals

Program goals for MS Vacation week are to:

- improve participants' knowledge and understanding of MS
- improve participants' self-confidence
- reduce isolation and depression among all individuals who attend the program, including caregivers
- provide a respite opportunity for family members and caregivers



Activities

At MS Vacation Week, participants - despite their level of disability - participate in a variety of activities including:



- Arts and crafts – painting, flower arranging, tie-dying, sculpture
- Classic “camp” activities – boating, fishing, nature walks, archery, scavenger hunt
- Exercise – swimming, aquasize, field games, yoga, morning stretches
- Educational presentations – symptom management, research, animal therapy
- “Day of Beauty” – massages, haircuts and styling, manicures, makeup application
- Just plain fun! – campfire karaoke, bingo, costume party, talent show, “drive-in” movie night

Care

- Camp Hemlocks personal care assistants and nurses
- Some vacationers bring their own personal care assistant or a family member. We cover the cost of room and board for all PCAs.
- An MS certified nurse is on-site 24 hours a day
- National MS Society staff and volunteers



Funding

- Grants from companies and charitable organizations
- Camper contributions
- Chapter contributions
- Memorial fund



The challenge of caring for a loved one with a chronic illness

Caregivers who have the daily challenge of caring for a disabled loved one often become overwhelmed with their responsibilities and need respite.

Having a break can allow them to relieve the stress of the physical and psychological strain of caring for a person with a debilitating disease.

The National Caregivers Association has documented that caregivers who care for people with chronic illness suffer from depression and physical injuries, which can result in the forced institutionalization of the disabled family member.



Benefits caregivers who attend

- Camp provides a supportive network of people able to relate to the stresses of caregiving responsibilities.
- The person with MS and the caregiver can participate in activities and events together.
- Caregivers learn how to help their loved one manage MS and live life more fully through art, exercise and positive mental health.



100% of survey respondents agreed or strongly agreed with the statement "I found new ways to enrich the life of the person I care for."

Benefits caregivers who do not attend

- Provides a week of respite from caregiving duties
- 83% of survey respondents stated that the program gave their spouse/partner/primary caregiver a break from their care giving duties
- Share in their loved one's happiness
- Campers often experience improved mood and increased social connections

"I cannot overstate what camp means to Casey and for us, his family, to see how he returns to us absolutely glowing!"



MS Vacation Week: The Best Week of the Year!



B.Fit! Outpatient Respite and Wellness Program for People with Multiple Sclerosis

Marva Serotkin, MPH
President and CEO
The Boston Home
Boston, MA

October 8, 2014



The Boston Home

The Boston Home for Incurables founded in 1881.

Beechwood Home for Incurables (Cincinnati) and
Inglis House (Philadelphia) opened in same era.



The Boston Home

Between 1874-1884 over 5,000 patients were turned away from Boston hospitals because their cases were:

“chronic and incapable of relief or incurable”

The Boston Home

Mission Statement declared The Boston Home
“open to all classes of the worthy poor without
distinction of race or religion...men, women,
children suffering from an incurable trouble but
specified that no contagious diseases or cases of
mental derangement.”

THE BOSTON HOME TODAY

Always An Innovator, TBH Has Extended
Its Mission Beyond Its Residents
To Those Living In The Community With
Similar Conditions.



Taking Our Learning On The Road

SERVING THE COMMUNITY— CONSUMERS, PROFESSIONALS, POLITICIANS AND ADVOCATES

- B.FIT! Outpatient Respite and Wellness Program
- Outpatient Rehabilitation Services
- Seating Clinic
- Wheelchair Enhancement Center
- REquipment DME Reuse Program

SERVING THE COMMUNITY— CONSUMERS, PROFESSIONALS, POLITICIANS AND ADVOCATES

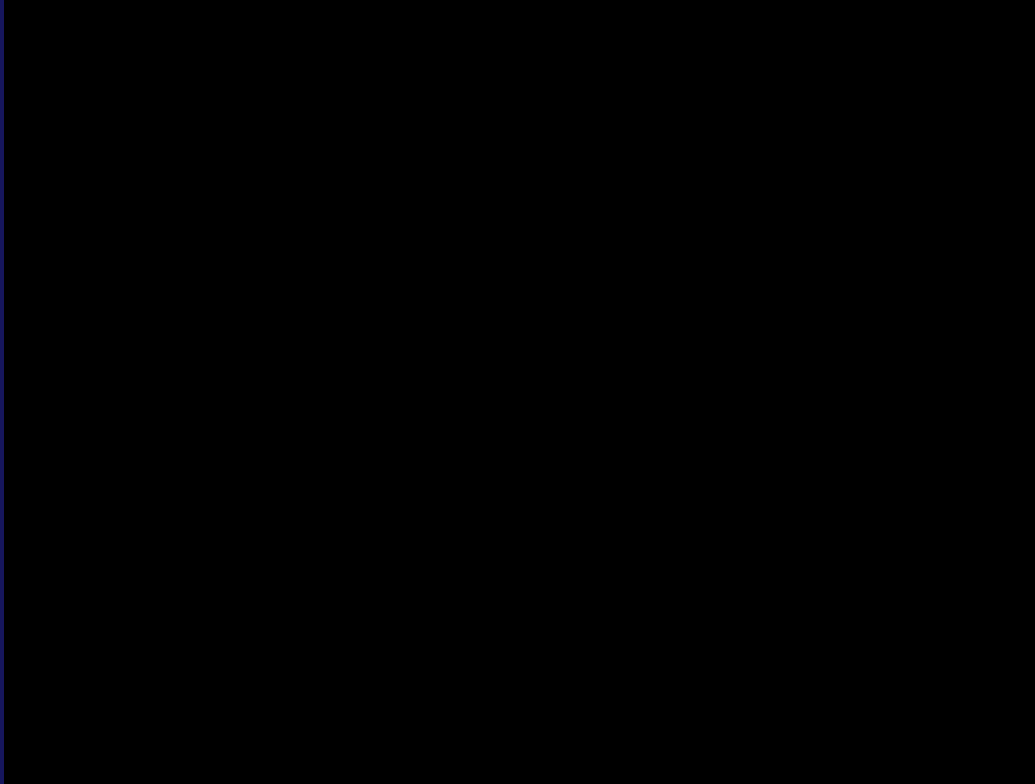
- Academic Partnerships - MIT Computer Science Artificial Intelligence Laboratory
- NMSS - Course For MS Fellows
- Research Opportunities
- Internships



SERVING THE COMMUNITY – CONSUMERS, PROFESSIONALS, POLITICIANS AND ADVOCATES

- Frequent Visits To The State House
- Sponsor Legislative Events At TBH
- Join Advocates To Speak Out For Services For People With Disabilities
- Partner With NMSS
- The Boston Home Institute

B.FIT! OUTPATIENT RESPITE AND WELLNESS PROGRAM



B.FIT!

- Offers A Safe Leisure Experience That
 - Promotes Empowerment And Independence
 - Provides Respite For Caregivers and Clients
- Participants' Caregivers, Personal Care Attendants And Family Members Attend Outings
- Participants Have Access To The Boston Home's AT And Rehab Services

B.FIT!

- Wellness Is More Than Treatment Of Disease
- Investment Brings Big Returns
- The **B.Fit!** Model

B.FIT!

WELLNESS IS MORE THAN TREATMENT OF A DISEASE

B. Fit! Incorporates

- Exercise
- Nutrition
- Compensatory Cognitive Training,
- Health Education and
- Community Engagement



B.FIT!

INVESTMENT BRINGS BIG RETURNS

MS QOL Inventories Were Administered Twice Each Year To Participants of **B. Fit!**

Preliminary Data Suggests
Perceived Stabilization And Improvement
In Physical Functioning And Quality Of Life

Testing Our Preliminary Findings

Study goal is to determine whether a more systematic evaluation of **B.Fit!** will replicate preliminary findings of improved mental and physical functioning.

Dominique Burke, MS

Helen T. Machado

Sarah Minden, MD

Department of Psychiatry, Brigham & Women's Hospital, Boston, MA

Findings

Analysis of participant surveys show positive change on all measures, especially social support. Research questions:

- ☐ Does participation improve perceived social support?
- ☐ Does participation improve overall QOL and physical functioning?
- ☐ Does length of time in the program contribute to better outcomes?
- ☐ Does participation improve particular aspects of physical and mental functioning?

B.FIT!

THE MODEL

- Partnerships With Museum Of Fine Arts, Huntington Theater, Museum Of Science, Farmers Markets, YMCA, Student Interns
- Powerful Tools For Caregivers— A Six Week Course
- Information And Education With Topics Such As Healthy Eating, Spirituality, Treatments And Medications, Assistive Technology, Empowerment

B.FIT!

FUNDING AND REPLICATION OPPORTUNITIES

CURRENT FUNDING

- Jointly Funded By Greater NE Chapter Of NMSS And TBH
- Grants Supplement Core Funding

FUNDING RESOURCES

- Adult Day Care License
- Achievement Center Model
- Home And Community-Based Waiver Programs
- Partner With Traditional Adult Day Centers

B.Fit!@Boston Home
Caring for the Caregivers

Massachusetts Lifespan Respite Coalition
Mini Grant

Caregiver Support System
A Team Networking Process

Program Goals and Objectives

- **Provide opportunity to strengthen family relationships**
- **Foster relaxation and rejuvenation**
- **Encourage participation in community programs that promote physical and emotional health**

Plan of Respite Program—Scope and Format

15 Caregivers Participated in the 16 week program

Sessions Held Twice Each Month

Respite Companion for Weekend Events

Program Content

- **Dance and Expressive Self Relaxation Techniques**
- **Message Therapy**
- **Yoga and Expressive Self Relaxation**
- **Expressive Writing**



Program Content

- **Expressive Writing**
- **Health Care and Disability Laws**
- **Long Term Care Options**
- **Emergency Preparedness**



Factors Affecting Employment Among Informal Caregivers
Assisting People with MS (PwMS)—Recommendations
from Study in International Journal of MS Care (2013)

- **30% of PwMS require assistance at home**
- **80% of support provided by informal caregivers**
- **Poor cognitive ability of PwMS correlated with increased unemployment of caregiver**
- **Reducing cognitive difficulties could help offset negative impact of caregiver unemployment**

VOICES OF SUCCESS

My name is Shirley. I have been a caregiver for my daughter Alicia since 1999. She attends B.Fit!, a wellness program at The Boston Home. This service provides me with respite as well for 4 days a week....provid(ing) me with emotional and physical respite. I enjoyed them very much. My favorite session was the personal massages therapy and Zumba class...both a new relaxing and energizing experience.

The educational sessions were very resourceful...provid(ing) me with a better understanding of the disability rights and laws in Massachusetts from a lawyer, also knowledge of new support services in the community from an Options Counselor.

Thank you for caring for the caregivers!





There is no force so powerful as an
idea whose time has come.

Everett Dirksen