How Our Advocacy Inspires Action

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Agenda

My story
Intro to advocacy
Where YOU can make a difference
My Story
My Journey

- Family caregiver for 20+ years for both parents
- 3-out-of-4 parents and in-laws have/had dementia
- Two caregiver household
- Outspoken advocate for Alzheimer’s families and other family caregivers
<table>
<thead>
<tr>
<th>My Experience</th>
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<tr>
<td>Healthcare system unprepared for Alzheimer’s and family caregivers</td>
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<td>Healthcare and social services are impossible to navigate</td>
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<td>Technology is not designed for family caregivers</td>
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<td>Care coordination for seniors is non-existent</td>
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<td>Care transitions = critical points of failure</td>
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<td>I was the only reliable source of my mom’s medication list</td>
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<td>I had to be a 24x7 advocate</td>
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<td>Nobody communicates</td>
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Resulting in...
What I Do...

Write
Serve
Speak
Lobby
Connect
Share my story
Teach others
What I Care About...

- Alzheimer’s research and education
- Support and solutions for family caregivers
- Re-thinking aging and longterm care
- Person-centered care
- Care coordination and care transitions
- Health literacy and plain language
- Patient Centered Outcomes Research (PCOR)
- Health information technology (for patients and families) and usability
How I Got Started…

Through a local Alzheimer’s caregiver support group…

...telling my story on Capitol Hill and my state capitol in 1998

Asking lawmakers to support designated legislation

Writing letters to the editor

Realizing that I couldn’t fix the disease, but I could help others
My Advocacy Roles

Advisory Council, National Alzheimer’s and Dementia Patient and Caregiver Powered Research Network

Alzheimer’s Association/UsAgainstAlzheimer’s advocate on Capitol Hill

Column writer, Caring for the Ages

Data and Safety Monitoring Board (DSMB), STRIDE Study on Falls Prevention

Global Patient and Family Advisory Board, The Beryl Institute

PCORI Ambassador and Patient Research Partner

Technical Expert Panel, PCOR Translation Center

The Walking Gallery of Healthcare and #pinksocks
Intro to Healthcare Advocacy
Personal Advocacy

Advocating for a loved one who is...
- Seriously ill
- Has a Disability
- At end of life

By...
Interacting with the healthcare system
Coordinating care and resources
Other Types of Advocacy...

- Healthcare delivery
- Medical research and drug development
- Health policy (it touches everything!)
- Technology
Healthcare Advocates Share Common Experiences

Health condition they struggle with
Frustrated by challenges of navigating healthcare and social services
Unable to obtain their health information when they ask for it
Insurance refuses to cover a procedure
Caregivers can’t find services and support
Bad experience with healthcare system
Unable to afford medication
Medical mistakes

Passionate About Change
Advocacy Takes Many Forms

Writing, speaking, listening, tracking
Committees, boards, working groups
In-person meetings, virtual events
Spreading the word on social media
Across federal, state, local, personal issues

You don’t have to leave your house!
Skills Required

Your personal story
Determination
Willingness to learn
Computer/phone
What Advocacy Can Accomplish

- New legislation (policy) at the local, state, and national levels
- Changes to existing policy
- Awareness of important issues
- Social movement
- Revolutionary change
- Personal enrichment
Healthcare Delivery
Who Delivers Healthcare?

- Assisted living facilities
- Clinics/urgent care
- Doctors/Nurse practitioners
- Home health
- Hospice providers
- Hospitals
- Nursing homes
- Pharmacies
- Rehabilitation facilities
- VA, Indian Health Service
What are we trying to accomplish?

Accessibility of healthcare and our own health information

Coordinated care. Smooth care transitions.

Healthcare based on the patient’s goals, not the doctor’s

Improved patient experience

Improved quality of care in all care settings

Affordable insurance and prescription drugs

Family caregivers as recognized, informed, trained members of the care team

Living wage for home care workers

Patient safety in all care settings

End of life care that respects our wishes
Culture of Healthcare Today

Provider and payer-centric

1 in 3 Americans don’t have the ability to understand and act upon their health information

Healthcare and social services silo’d and fragmented...

...both systems difficult to understand and navigate

Care coordination is left to patients and families

Medical records incomplete/difficult to access (paper and electronic)

Care transitions = critical points of failure

Family caregivers struggle to care for loved ones

No accountability

Medical errors, including wrong diagnoses, botched surgeries and medication mistakes, are the third leading cause of death in the United States...
Culture of Healthcare Tomorrow

Person-centered healthcare

Use of plain language by healthcare professionals

Coordinated healthcare, social services, community supports

Navigators and care coordinators in every community

Seamless access to your medical records in the format you choose—free

Care transitions are a model of crisp communication, education, coordination

Family caregivers treated as key members of the patient’s care team

Infrastructure in place for family caregiver support
Where to Get Involved
Start Here.

Movements to learn about

- GetMyHealthData
- Health Literacy
- Learning Health System
- Patient engagement
- Patient experience
- Patient safety
- Person-centered care
- Price transparency
- The Walking Gallery
- #pinksocks
And Here.

Organizations to check out
- The Beryl Institute
- Caring Across Generations
- Coalition for Compassionate Care of California (CCCC)
- Coalition to Transform Advanced Care (C-TAC)
- Institute for Healthcare Improvement
- Right Care Alliance
- Society for Participatory Medicine
Local Opportunities

Tell your story...
- in a letter-to-the-editor for your local newspaper
- to your Congressman in their district office

Apply to join a Patient and Family Advisory Council (PFAC)
- Does your local hospital have one? Find out!

Join local organizations working on issues you care about: i.e. Maryland Family Caregiver Council
Medical Research and Drug Development
What are we trying to accomplish?

Changing the culture of research from being researcher-driven to patient-driven

Making research more transparent and easier to participate in

Incorporating the patient and family caregiver voice

Bringing research to the people
Where to Get Involved
"A" List

Diverse assembly of advocates committed to advancing clinical trials by:
- signing up for focus groups that respond to researcher queries
- consumer testing mobile health applications
- participating in virtual clinical trial cohorts and online registries

Currently = 6000+ and growing

alist4research.org
Surveys: What Matters Most?

Home care
Technology
Clinical trials
Caregiver respite
Personal health data
At the doctor

Survey

What Matters Most?

In the early stages of dementia, there is great sensitivity around issues of independence and dependency for those living with the disease, and for caregivers figuring out how to best to support their loved ones.

Don’t miss the opportunity to be heard. The A-List is helping researchers understand more about Alzheimer’s disease so they can focus their work on the symptoms and issues that we care about most.

This short survey (2-3 questions) is for individuals who are diagnosed with Alzheimer’s disease and Mild Cognitive Impairment, and family caregivers. It asks a key question about what matters most when it comes to maintaining one’s independence.

CLICK HERE TO TAKE THE SURVEY →
Brain Health Registry – Caregiver and Study Partner Portal

Allows a study partner of a BHR participant to separately register, consent, and complete questionnaires

As of July 2017, over 4200 participant-study partners have joined the BHR CASPP

Over 13,000 caregivers have completed the Caregiver Experience questionnaire, designed to elicit feedback from the caregiver themselves

brainhealthregistry.org/studies/caspp
PCORI

WHAT IS PCORI?

Patient-Centered Outcomes Research Institute

Created as part of the Affordable Care Act (yep, Obamacare)

Investigates what works, for whom, under what circumstances

Considers patients’ needs and preferences, and the outcomes most important to them

HOW CAN I GET INVOLVED?

Suggest a patient-centered research question

Provide input on draft reports, policies, and initiatives

Become a Merit Reviewer

Join an Advisory Panel

Participate in PCORI events and webinars

Become a PCORI Ambassador
Precision Medicine Initiative

**PRECISION MEDICINE**

Healthcare tailored to YOU.
Takes into account individual differences in people’s genes, environments, and lifestyles
Already being used in cancer treatment

**ALL OF US℠ RESEARCH PROGRAM**

Driven by NIH
Goal: develop more effective ways to prolong health and treat (all) disease
Enrolling one million or more volunteers
Needed: diverse social, racial/ethnic, ancestral, geographic, and economic backgrounds, from all age groups and health statuses
More Ideas.

Eli Lilly (Pharmaceutical Company)
- Visit LillyTrialGuide.com to learn more about clinical research and find a clinical trial
- Write a guest blog post for Lilly Trials
- Follow @LillyTrials and @AlzReadiness on Twitter
- Join/follow online movements such as #WhyWeDoResearch, #WhyClinicalTrialsMatter and #HerosJourneyArt

Food and Drug Administration (FDA)
- FDA Patient Network
- Patient Engagement Advisory Committee
- Consumer representative on other FDA advisory committees (50 of them)
Research-focused organizations

Alzheimer’s Association
Autism Speaks
Genetic Alliance
Faster Cures
Michael J. Fox Foundation for Parkinson’s Research
National Institutes of Health (NIH)
Patients Like Me
PCORI
UsAgainstAlzheimer’s
Women’s Brain Health Initiative
National Institutes of Health (NIH)

Largest research organization on the planet

Funds more internal and external research than any other organization

The National Institutes of Health is made up of 27 different components called Institutes and Centers

Each has its own specific research agenda, often focusing on particular diseases or body systems

All but three of these components receive their funding directly from Congress
Important topics to follow

Clinical trials for your disease/condition or health research studies for family caregivers

Learning Health System (via the Learning Health Community)

Precision Medicine

Publishing of ALL research results (not just positive results)

Reproducible science: improving the reproducibility and transparency of pre-clinical research
Health Policy
What are we trying to accomplish?

Educating elected officials on our challenges and priorities
Influencing the content of health policy
Getting legislation sponsored and passed
Influencing implementation of policy once it is law
Important Legislation (and laws)

Federal
- Affordable Care Act (Obamacare)
- Alzheimer’s Beneficiary and Caregiver Support Act
- BOLD Infrastructure for Alzheimer's Act
- Care Planning Act
- HOPE for Alzheimer’s Act
- National Care Corps Act
- RAISE Act
- 21st Century Cures Act

State:
Legislative Advocacy Basics

Everyone has 1 House member and 2 Senate members on Capitol Hill and they want to hear from you!

Call or email to schedule a meeting

You can find their contact info online – for local offices near you AND offices in Washington DC

They use “standard” email addresses

- FirstName.LastName@mail.house.gov
- FirstName_LastName@senatorlastname.senate.gov

Meetings on the Hill are usually held with staff members, but your Representative or Senator may “pop in”
In the Meeting

Start local!
Tell your personal caregiving story
Describe why this issue is important to you
Make the Ask
  ◦ Congress.gov
  ◦ Disease-specific advocacy organizations

Remember, Congress works for YOU!
You don’t have to be a Congressional expert
Follow up with a thank you email to staff
Connect with the Congressional staff in your district and home state
Where to Get Involved
Jump in!

Schedule meetings with your Congressman and Senators (start local!)
- Talk about healthcare issues important to YOU and your family
- Encourage them to make caregiving part of their platform for re-election

Learn more about current legislation that’s important to you

Connect with policy-focused organizations and sign up for their newsletters

Connect with your state legislators to ensure the CARE Act is the law in your state
Policy-focused organizations

AARP
Altarum (Family Caregiver Platform Project)
Alzheimer’s Association
Autism Speaks
Coalition to Transform Advanced Care (CTAC)
Community Catalyst
Family Caregiver Alliance
LEAD Coalition (organizations as members)
National Partnership for Women and Families
UsAgainstAlzheimer’s
Facebook: #EndAlz - Alzheimer's Advocacy Group
National Alzheimer’s Project Act (NAPA)

Advisory Council on Alzheimer’s Research, Care, and Services (HHS)

- Responsible for implementing the National Plan
- Quarterly meetings (in-person or webinar)
- Public comment (submitted via email prior to each meeting)
- Join listserv for notifications (just type-in your email address)
- Website: [https://aspe.hhs.gov/national-alzheimers-project-act](https://aspe.hhs.gov/national-alzheimers-project-act)
Important topics to follow

- Affordable Care Act (Obamacare) changes
- Medicaid expansion/cuts
- Medicare-for-all
- Prescription drug pricing
- Cuts to local programs (e.g. meals-on-wheels)
- VA: privatization of healthcare for veterans
Technology
What are we trying to accomplish?

Accessibility of our health data (aka Gimme My Damn Data)

Providing medical information in a format that patients and family caregivers understand

Including patients and family caregivers of all abilities in the creation and usability testing of Health IT tools

Educating our citizens on how to use Health IT to take command of their health and their health information

Creating a culture of accessible and usable Health IT
Where to Get Involved
Important topics to follow

Accessibility of broadband in rural areas
Data blocking
Electronic Health Record “interoperability”
OpenNotes: making physician notes available to patients
Patient record matching
Patient safety
Start Here.

Office of the National Coordinator for Health Information Technology (ONC)
Healthcare Information and Management Systems Society (HIMSS)

Try out your doctor’s/hospital’s/clinic’s patient portal

- Give them feedback... whether they want it or not
- What did you like?
- What was challenging or not user friendly?
- Was your health information or lab test result provided in an easy-to-use format?
- Were you able to share this information with other doctors?

OpenNotes Project
• Transforming the way people provide care and support to their aging, disabled or chronically ill loved ones

• We deliver an intelligent, customized, interactive assistant that brings together a complete personal support network
The Solution

- Manage Daily Activities
  Keep a daily checklist, plan for upcoming events and appointments, stay connected

- Coordinate With the Whole Team
  Keep friends and family up to date, get alerts and notifications if needed, ask for help, and chat with team members

- Ensure the Safety of Your Loved One
  Track home environment, health measurements and recent test results, get help adding accommodations in the house

- Find Activities & Support
  Locate community and online activities and services to be engaged and support caregiving needs

- Maintain Complete Health Record
  Connect to your doctors, pharmacies and labs to automatically maintain an active record of all health data

- Plan for the Care Journey
  Organize important information, plan for future care support, think through finances, and prepare for advanced care issues
LIVPACT PLATFORM

• Single Point of Entry for complete care coordination
• Highly personalized for the care recipient with role-based views adjusted to care family members
• Robust assessment tools to match services and resources to the specific social and health situation of each person
• Available on Multiple Devices – iOS, Android, Web, Alexa Skill, Google Action
Additional Ways to Get Involved
Peer-to-Peer Support

Facebook (closed groups):
- Support for Caregivers
- Support for Dementia & Alzheimer’s Caregivers
- UsAgainstAlzheimer’s Community
- Care Givers of Elderly Parents Support Group.
- Support for Vascular, Alzheimer’s & Mixed Dementia
- Dementia Through Daughters Eyes
- Alzheimer’s And Dementia Support
- The Purple Sherpa Basecamp (Dementia Family Caregiver Support Group)
- Alzheimers and Dementia Caregivers Support
- Dementia Caregivers Support Group

Imerman Angels: one-on-one cancer support
Patient and Family Caregiver Experts

Your experiences can translate into paid gigs

I'm a Patient Leader
looking to help others & improve healthcare

- I’m an activist or advocate
- I’m a blogger or writer
- I’m a subject matter expert
- I help patients online

The future of healthcare is co-designed with patients.
Sharon Hall
MaryAnne Sterling
Denise Brown
Julie Fleming
Karen Garner
Our Mission and Focus

MISSION

Leverage the extensive knowledge and experience family caregivers have acquired through caregiving to transform health research, health policy, and healthcare delivery

FOCUS

Advocacy
Education and Thought Leadership
Innovative Pilot Programs
Research Partnerships
Our Goals

Connect family caregivers with initiatives where their voices can be heard

Educate researchers, policy makers, and healthcare providers on a range of caregiving issues through thought leadership

Provide guidance from a “boots-on-the-ground” perspective on challenges we face across the healthcare continuum

Spearhead caregiver-centric pilot programs

Partner with researchers, policy makers, and healthcare providers to solve problems from the family caregiver perspective
What’s Next?

Stay connected with us at: teamicare.org

Join our mailing list

Seeking diverse family caregivers and innovative partners to join us
Contact Info

Email: msterling@sterlinghealthit.com
Websites: livpact.com; teamiCare.org
Twitter: @SterlingHIT

Participatory Healthcare:
A Person-Centered Approach to Healthcare Transformation (Chapter 7)