

Advocating for Caregiving:

8th Annual National
Conference of Caregiving
Coalitions



March 12, 2014
San Diego, California



#CareAdvocate14 @NA4Caregiving

About the Alliance

- Nonprofit coalition of over 50 national organizations focused on family caregiving issues
- Established in 1996 to support family caregivers and the professionals who work with them
- NAC Activities:
 - Conduct research and policy analysis;
 - Develop national programs;
 - Strengthen state and local coalitions;
 - Increase public awareness;
 - International work and awareness.



Our Conference Sponsors



ARCHSTONE
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Genentech

2014 Scholarship Winners

Arizona Caregiver Coalition

California Coalition for
Caregivers

Caregiver Coalition of
Northeast Florida

Caregiver Support Network
of Ashland and Bayfield
Counties, Wisconsin

Caregivers Respite,
Tennessee

Community Senior Services,
Claremont, California

Hawaii Family Caregiver
Coalition

Ocean County Caregivers of
New Jersey

Outagamie Caregiver
Coalition, Wisconsin

The Senior Sage,
Nevada



*Discussion Panel:
Engaging Family
Caregivers in
Education &
Advocacy*



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caregiveractionnetwork.org

Engaging Family Caregivers in Education and Advocacy

John Schall

Chief Executive Officer
Caregiver Action Network

March 12, 2014

JSchall@CaregiverAction.org



caregiveractionnetwork.org

Who We Are

CAN's Mission...

...is to promote resourcefulness and respect for the more than 90 million family caregivers across the country.





caregiveractionnetwork.org

What CAN Does

CAN Connects Caregivers with

- ✓ Valuable Free Resources
- ✓ Advice from Caregiver Voices
- ✓ Peer Support
- ✓ Caregiving Information
- ✓ Educational Webinars





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CAN's Goals

- ✓ **Create Resourceful Caregivers**
Serve an increasing number of family caregivers with practical help, support and information.
- ✓ **Reduce Caregiver Stress**
Improve the quality of life for family caregivers by reducing their day-to-day stress and financial distress.
- ✓ **Create Respect for Family Caregivers**
Advance the case for family caregiver recognition and support.
- ✓ **Create Capable Caregivers**
Build family caregiver confidence and capability through the dissemination of educational programs that demonstrate a positive impact on the lives of family caregivers.





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CAN's Interactive Website

CaregiverAction.org organized by Four Profiles:

- ✓ I just realized I'm a family caregiver now.
- ✓ I have been a family caregiver for years.
- ✓ I live far away and I'm on the caregiving team.
- ✓ I have a job and I'm the caregiver for my loved one.

Inspiration, perspective and advice for you from family caregivers of loved ones with Alzheimer's.

Take 5 minutes to watch the videos now!



Get started here! Click one of the caregiving situations below.



I JUST REALIZED I'M A FAMILY CAREGIVER NOW

"I can't believe this just happened!"
 "Since he came back from Iraq, he depends on me."
 "My wife has been diagnosed with MS."
[We CAN help you be resourceful in your new role as a caregiver.](#)



I HAVE BEEN A FAMILY CAREGIVER FOR YEARS.

"My husband has Parkinson's and I'm his primary caregiver."
 "Since my wife's stroke, I handle everything."
 "It's been 10 years and I don't know how much longer I can do this."
[We CAN help you manage the many challenges of higher-burden caregiving.](#)



I LIVE FAR AWAY AND I'M ON THE CAREGIVING TEAM.

"How do I know that my parents are OK living alone?"
 "Since mom died, I am all dad has."
 "It's so hard to make things happen for him when I don't live nearby."
[We CAN help you provide care from afar.](#)



I HAVE A JOB AND I'M THE CAREGIVER FOR MY LOVED ONE.

"I'm what they call a 'sandwich generation' caregiver."
 "I care for my mother with Alzheimer's in addition to my three children."
 "I can't stop working so how do I manage?"
[We CAN help you be both an employee and a caregiver.](#)





caregiveractionnetwork.org

10 Tips for Family Caregivers

1. [Seek support](#) from other caregivers. You are not alone!
2. [Take care of your own health](#) so that you can be strong enough to take care of your loved one.
3. [Accept offers of help](#) and suggest specific things people can do to help you.
4. Learn how to [communicate effectively](#) with doctors.
5. Caregiving is hard work so [take respite breaks](#) often.
6. [Watch out](#) for signs of depression and don't delay in getting professional help when you need it.
7. [Be open](#) to new technologies that can help you care for your loved one.
8. [Organize](#) medical information so it's up to date and easy to find.
9. [Make sure](#) legal documents are in order.
10. Give yourself credit for doing the best you can in one of the toughest jobs there is!



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Family Caregiver Toolbox

The screenshot shows a web browser window with the URL caregiveraction.org/resources/toolbox/. The page is divided into two main sections: 'Help for Caregivers' on the left and 'Toolbox' on the right.

Help for Caregivers
A wealth of resources at your fingertips

- [Family Caregiver Forum](#)
- [Peer Network](#)
- [Story Project](#)
- [Family Caregiver Toolbox](#)
- [10 Tips for Family Caregivers](#)
- [Agencies and Organizations](#)
- [Coping with Alzheimer's](#)

Toolbox

Coordinate the Care Powered by Saturing	Manage the Medications Powered by Saturing
Track the Progress Powered by Saturing	Plugged-In Caregiving Technology for Family Caregivers
Communicating Effectively with Healthcare Professionals Webinar On-demand	Safe and Sound: How to Prevent Medication Mishaps Webinar On-demand
Financial Planning for Family Caregivers	Create a Community of Help Lotsa Helping Hands
How to Talk to Your Parents The 40/70 Rule Home Instead Senior Care	Incontinence Assessment

National Family Caregivers Month

✓ Theme

“Family Caregivers –
Now More Than Ever!”

✓ Presidential Proclamation

President honors family caregivers every November

✓ State of the Union Address

NATIONAL
FAMILY CAREGIVERS
MONTH
November 2013



Army Ranger Cory Remsburg,
father/family caregiver Craig
Remsburg, and the First Lady
Michelle Obama



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National Family Caregivers Month

✓ Some CAN Events

National Kidney Foundation Panel Discussion, 11/10 in VA

3M Caregivers Discussion, 11/12 in MD

Altarum Behavioral Health Twitter Chat, 11/13 in DC

Caregiving in America, 11/14 in IL

Leeza Gibbons Care Connectors Event, 11/14 in CA

Stepping Stones Program, 11/14 in CA

USCIS Health Benefits and Wellness Fair, 11/20 in DC

Genzyme RARE CAN Webinar, 11/21 in DC

NIH Clinical Center Caregiver Day, 11/21 in MD





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More CAN Resources

✓ Plugged In Caregiving

http://nfca.typepad.com/pluggedin_caregiving/

✓ Help for Cancer Caregivers

www.HelpForCancerCaregivers.org



HELP FOR
CANCER **CAREGIVERS**

✓ Rare Disease Caregivers

www.RareCaregivers.org





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How to Connect with CAN

www.CaregiverAction.org



www.facebook.com/CaregiverActionNetwork



@CaregiverAction



Caregiver Coalition of San Diego

www.CaregiverCoalitionSD.org

Alejandra Ceja-Aguilar

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Beyond the Sky Solutions

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Caregiver Advocacy/Participation

Collaboration is Key!

- 50+ Actively Involved Agencies
- No Membership Fees
- Action Oriented Committees

Caregiver Panels

- Caregiver Conferences
- General Coalition Monthly Meetings

Webinars

- Targeting Working Caregivers
- Caregiver Interaction

Caregiver Feedback

- Evaluations

Caregiver Handbook





Southern Caregiver Resource Center
Caring for those who care for others

Education & Advocacy

Martha Rañón

Director of Education & Outreach
Southern Caregiver Resource Center

March 12, 2014



Southern Caregiver Resource Center

Caring for those who care for others

History

1977

Organize

Grassroots movement



Southern Caregiver Resource Center

Caring for those who care for others

Family Survival Project

AB 2913 (Agnos)



Southern Caregiver Resource Center

Caring for those who care for others

Project to California Law

1984

Comprehensive Act for
Family Caregivers of Brain-
Impaired Adults



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Outcomes

Educate community

Reach out to elected
officials

Continue the movement



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Maintain the Momentum

Family Advocates

Caregiver Stories

Public Awareness



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Next Steps

Reinstate State Cuts



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Interact with elected officials





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Southern Caregiver Resource Center

Caring for those who care for others

Southern Caregiver Resource Center

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San Diego, CA 92123

(858) 268-4432 • 1800-827-1008

www.caregivercenter.org



**LISTENING
TO
CAREGIVERS**



A STRATEGY FOR STATE & NATIONAL ADVOCACY

LISTENING SESSIONS LED TO FORMATION OF ORGANIZATION

- ◉ State agency provided seed funding to identify voice
- ◉ Eight sessions held across state to identify leaders and hear their issues
- ◉ Conversations with Iowa important to our philosophy
- ◉ Intentional decision that individual is the member. We wanted no voice to be louder than one individual
- ◉ First Leadership Council caregiver-advocates later became Board of Directors

WHAT DID WE FIND IN 2009?

- Promote education and training for professional caregivers and for those working as unpaid family caregivers
- Promote better wages and benefits
- Provide opportunities for social and professional networking to share challenges and successes
- Advocate on variety of issues for caregivers

LISTENING SESSIONS TODAY

- Health foundation funded NMDCC to carry out sessions again in 2013 as means of validating what we learned in 2009
- Continue to identify new leaders
- Space to share and advocate on issues of importance to professional and family caregivers
- Opportunity to educate (e.g., FMLA, health insurance)

NMDCC TODAY

- ◎ Only organization in New Mexico representing family and professional INDIVIDUAL caregivers
- ◎ Network consists of 7,500 family and professional caregivers, including agency directors



NMDCC TODAY

- ◉ State and national leadership development training
- ◉ Financial Education for Caregivers training
- ◉ Ongoing job announcement and connecting with agencies and recipients
- ◉ Customized workplace training (current workers and family caregiver too)
- ◉ Opportunity to earn the Direct Care Alliance Personal Care Support Credential
- ◉ Directly participate in advocacy

HOW-TOS OF LISTENING SESSIONS

- Identify locations, legislators and/or leaders who for help with outreach
- Partner with local organizations
- Start session with how caregivers' work fits within the larger landscape (demographic)
- Explain how you're helping build a movement/organization



HOW-TOS OF LISTENING SESSIONS

Share your purpose and passion, THEN ... LISTEN

Ask attendees why they came and what they hope to gain

Ask attendees to talk about their work

Encourage conversation from every single person

Ask how a larger group of caregivers might help that person



FOR MORE INFORMATION

New Mexico Direct Caregivers Coalition

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AdrienneRSmith@aol.com
Ph. 505-867-6046

www.nmdirectcaresupport.org

facebook.com/NewMexicoDirectCaregiversCoalition

twitter.com/NMCaregivers

NMDCC advocates for direct care workers' education, training, benefits, wages and professional development so they may better serve people who are elderly and those with disabilities

*Questions
&
Comments*



#CareAdvocate14 @NA4Caregiving

Discussion Panel:

*The Rise of the “e-Caregiver”:
How Technologies Can Support
Family Caregiving*



#CareAdvocate14 @NA4Caregiving





Marcus Grindstaff

Vice President, International Markets

care innovations™
an Intel • GE company

Reimagine
Healthcare



\$471B

Belgium



View all 4 care circle messages. Add +

Add +

▼

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ons

ness

Connect Caregiver is a FREE care planner that helps you:

- ✓ **Coordinate**
appointments, & view schedules at a glance.
- ✓ **Organize**
medications, set reminders, & track dosages.
- ✓ **Monitor**
vital signs, set goals, & track progress.

Sign Up FREE Today!

Learn More

learn more content is
vided by your care team

Items:

Blood Pressure
g with Congestive Heart
re

[View more items](#)

Caregiver Wellness

by

ringcom

Local Services

Task Rabbit

MagicKitchen.com

Ride Connection

Alzheimer's Forum

provided by

alz connected

Caring)com

WebMDSM



UnfrazzleTM

careinnovationsTM | connect caregiver
an Intel • GE company

A Better Plan
reflect, monitor, act



kinergyTM
health

CarePlanners



Lotsa Helping Hands
create community



**These solutions must work together
FOR caregivers.**

**Traditional healthcare and
caregivers must collaborate tightly.**

The Care Innovations™ Guide and the Care Innovations™ Connect RCM application each require an Internet connection to enable communications with the patient's care team and back-end data hosting. The Guide and Connect RCM are intended for use by patients who are able to operate the devices in accordance with the applicable instructions for use and who are under the guidance of a healthcare professional. Neither the Guide nor Connect RCM are intended for emergency medical communications or real-time patient monitoring. Videoconferencing capability requires a broadband connection for best performance. Available for over the counter use.

The Care Innovations™ Connect Caregiver application is not intended for clinical use, life-saving or life-sustaining interventions. Connect Caregiver users are solely responsible for the information that they choose to share within Connect Caregiver and for determining the access provided to authorized users they invite into the application.

The Guide–Data Bridge Module does not provide real time information to the health- care provider. Data in the reports generated from the Guide–Data Bridge Module is currently intended for administrative purposes only.

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The Rise of the eCaregiver

Andy Cohen, Founder and CEO, Caring.com

March 12, 2014

Caring.com is the #1 Site for Family Caregivers

- **Leadership Position:**
 - 2 million unique visitors per month
 - Free traffic from repeat, SEO and content partnerships with Yahoo!, MSN, US News and others (i.e. Vitals)
- **Award Winning Content:** 500,000 pieces of content across all caregiving and eldercare topics
- **Subscribers:** 250,000 subscribers to free weekly email newsletters
- **Community:** Largest, most active Alzheimer's forums in US
- **Directory:** Ratings and Reviews of 100,000 local senior care resources

The screenshot displays the Caring.com website interface. At the top, the logo is followed by the phone number (866) 824-8174 and social media icons. A search bar is present with the text 'Search caring.com'. Below the header is a navigation menu with categories: Senior Care, In-Home Care, Health Conditions, Money, Caregiver Wellness, and Your Account. A large banner features a group of smiling people and a 'Call Us for Help' button with the phone number (866) 824-8174. Below the banner are several featured articles with images and titles: 'One Minute to Fight Alzheimer's', 'Call Us for Help', 'Time for Assisted Living?', and 'Top Assisted Living Reviews'. A search bar for 'Find Senior Care' is located below the banner, with a 'Get Help Now' button. The main content area is titled 'Senior Care Reviews & Resources' and contains six columns of content: 'Assisted Living', 'Memory Care', 'In-Home Care', 'Independent Living', 'CCRC', and 'Nursing Homes'. Each column includes a representative image, a brief description, and a link to read more reviews.

Who Are the Family Caregivers?

Family caregivers are the decision makers for senior care

43 million
Americans care for
an elderly loved

67% Female

50% Age 50+

60% have smart
phones (Android
and iPhone)

50% find professional
care for their parents



Internet is the #1 information
source for Boomers

48% report
household income
>\$100k per year

72% attend doctor
visits with their
loved one

64% manage their
loved one's
finances


Sources: NAC/AARP/MetLife-Study (2009), AARP-Study (2004) & Caring.com-User survey (2009), Ipsos / Google (2013)



YouTube
34M Boomers
9.5M Seniors



LinkedIn
18.1M Boomers
6M Seniors

 748K Boomers
476K Seniors



Facebook:
42.2M Boomers
13.2M Seniors

64% of caregivers on
Caring.com use Facebook



Twitter
10.1M Boomers
2.5M Seniors



Pinterest
7.8M Boomers
2M Seniors

 900K Boomers
150K Seniors

How to Support e-Caregivers?

- Website
- Facebook Page
- Mobile
- Link Lift and Leverage!!

The Rise of the “eCaregiver”: How Technologies Can Support Family Caregiving

David Besst

Caregiver Support Specialist

Arizona Division of Aging and Adult Services



DEPARTMENT OF ECONOMIC SECURITY

Your Partner For A Stronger Arizona

AZ **Caregiver.org**

Lifespan Respite Program

AZ Caregiver.org



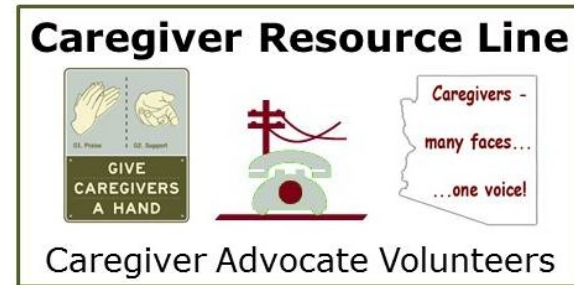
DEPARTMENT OF ECONOMIC SECURITY

Your Partner For A Stronger Arizona

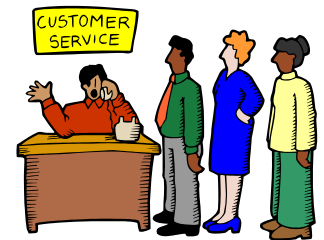
- State passed law in 2007
- Arizona Caregiver Coalition
- Original LRP grant from 2009 - 2012
 - “Give Caregivers a Hand!” awareness campaign
 - Caregiver Resource Line (CRL)
 - Caregiver Assessment Tool (CAT)



Caregiver Resource Line

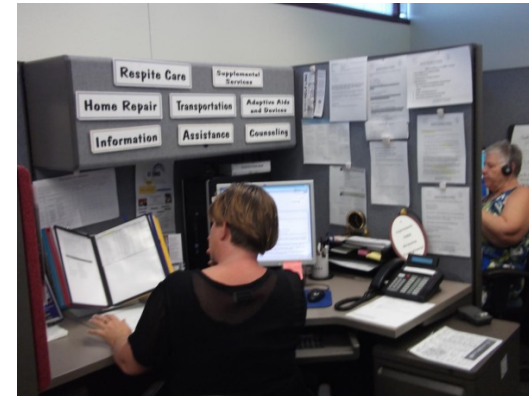


- Volunteer based Hotline
- Answered live during business hours
- After hours calls recorded and returned in 1-2 days (3 referrals)
- Staff trained and coordinated by grant funded worker (will be ACC staff)



Caregiver Resource Line

AZ Caregiver.org



- Currently averages 10 -15 calls a day
- Serves as the “caregiver specific” component of AZ Links, Arizona’s ADRC
- Total of 12 volunteers currently trained as “Caregiver Advocates”



Aging Network Software



- Development of new statewide Aging Network data system with coordinated I&R module
- Allows CRL workers to serve caregivers on behalf of AAAs and other AZ Links partners
- Web-based system encourages collaboration through sharing of resources and data
- Tracks follow-up of I&R contacts and referrals made through the system



New Resource Database



- Taxonomy-based online resource database
 - Linked to I&R tool for AAAs integrated with client data tool
 - Accessible to public via www.azlinks.gov
 - Allows CRL workers to serve caregivers
 - Tool for DDD support coordinators
 - Potential use by other programs, including Vocational Rehabilitation, State Talking Books Library, Community Action Programs



2012 Lifespan Respite Grant - Integration and Sustainability

- Major deliverables include:
 - Develop and implement Respite Voucher Program
 - Addresses need for participant-directed services
 - Helps overcome cultural barriers and provider issues in rural areas
 - Streamlines access to respite services
 - Respite Registry with Rewarding Work
 - Online resource to help families connect with respite providers
 - Promotes workforce development in support of family caregivers
 - www.arizonarespiteregistry.org



Online Respite Registry

AZ Caregiver.org

Rewarding Work

- Registry with Rewarding Work
 - Primarily for respite services (voucher and other)
 - DCW workforce development
 - DDD independent providers
 - VD-HCBS
- Each caregiver receiving a respite voucher gets a code to use the Arizona Respite Registry



Thank You!

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DEPARTMENT OF ECONOMIC SECURITY

Your Partner For A Stronger Arizona

AZ Caregiver.org



Using Technology to Support Family Caregivers Veterans Health Administration, US Department of Veterans Affairs

Thomas Edes, MD

Executive Director, Office of Geriatrics & Extended Care Operations

8th Annual National Conference of Caregiving Coalitions

March 2014



Agenda – Technology and Family Caregivers

1. Active Website for Caregivers
2. Classroom Based Learning on Technology
3. iPads for Caregivers
4. VA Mobile Applications
5. Questions & Contact Information

Active VA Website for Direct Outreach

U.S. Department of Veterans Affairs

VA » Health Care » VA Caregiver Support

VA Caregiver Support

- ▼ Caregiver Program
 - VA Caregiver Support Home
 - Caregiver Services
 - Services for Caregivers of Post-9/11 Veterans
 - ▶ What's New
 - ▶ Staying Strong
 - ▶ Caregiver Toolbox
 - Help Near Home
 - ▶ Caregiver Connections
 - Additional Resources

You're there to support your Veteran. We're here to support you.

We're Here to Support You
Get started by learning about the services and support available to you as the Family Caregiver of a Veteran.
[Learn more >](#)

Services | Staying Strong | Partners

Many Services & Supports for Caregivers:

- Caregiver Toolbox
- Local Resources “*Help Near Home*”
- *Caregiver Connections*
- *Caregiver Chronicles*
- Caregiver Support Line

<http://www.caregiver.va.gov>

Using Technology to Expand Caregiver Outreach and Promote Caregiver Wellness

- VA to release class-based course for Veteran Caregivers - Utilizing Technology
- One in a Four Part Series of educational offerings for Caregivers of Veterans
- Some topics to be covered :
 - Types of Technological Tools
 - Finding the Right Technology for your Situation
 - Including computers, tablets, mobile devices
 - Healthy vs. Unhealthy Internet Use
 - Identifying Technologies and Tools by Task
 - Glossary of Terms and Resources



VA Caregiver Support Program
**Utilizing
Technology**
A Caregiver's Guide
Version 1



Using Technology to Enhance Caregiver Access to Services Long Term Services and Supports Website

- VA Office of Geriatrics and Extended Care supports site to facilitate understanding of services and promote access
- <http://www.va.gov/GERIATRICS/Guide/LongTermCare/index.asp>
- Program descriptions
- Benefits and eligibility
- Connections for local services
- Shared decision making



- [Paying for Long Term Care](#)
- [For Caregivers](#)
 - [Locate Caregiver Services](#)
- [Locate Veteran Services](#)

Using iPads with Veteran Caregivers & VA's Mobile Applications

- VA has distributed 879 iPads to Caregivers in the VA's Family Caregiver Program
- Average age of both Caregiver and the Veteran recipient is 40 years old
- Majority of Caregivers in this program are female (95%) and the spouse of the Veteran (90%).

Examples of VA Mobile Applications



Stay Quit Coach (iOS, Android available soon) - is designed to help Veterans with Post-Traumatic Stress Disorder (PTSD) quit smoking.



PTSD Coach (Android and iOS) – helps the Veteran assess and monitor symptoms of PTSD and provides some coping strategies

VA Caregiver Support Contacts

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*Questions
&
Comments*



#CareAdvocate14 @NA4Caregiving

*Update from the
National Alliance
for Caregiving*



#CareAdvocate14 @NA4Caregiving

About the Alliance

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- Established in 1996 to support family caregivers and the professionals who work with them
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 - Develop national programs;
 - Strengthen state and local coalitions;
 - Increase public awareness;
 - International work and awareness.



Advocacy Update

➤ Federal Legislation

- The Family and Medical Leave Act of 2013
- Older Americans Act Reauthorization
- Patient-Centered Quality Care for Life Act
- The Palliative Care & Hospice Education and Training Act

➤ State Legislation

- The Care Advise, Record, and Enable Act

Great News for Caregivers

- Long-Term Care Commission
- Congressional Budget for FY2014 includes:
 - \$122 Million for Alzheimer's Research
 - Including \$3.3 Million for Alzheimer's Caregivers
- President's Budget for FY2014 includes \$3 Million for a White House Conference on Aging

NAC News

- International Alliance of Carers Organization (IACO)
- ReACT Employer Toolkit
- From Plan to Practice: Implementing the National Alzheimer's Plan in Your State
- Caregiving and Technology Roundtable
- New Research
 - Persons with Mental Illness
 - Technology & Caregiving

What is a Caregiving Coalition?

- Community that addresses needs of family caregivers across the lifespan
- Includes families of origin and families of choice
- Typically offer information and referral services, educational outreach, and advocacy
- United community voice to meet social, medical, physical, financial, spiritual, and emotional needs of family caregivers

How Do We Support Coalitions?

- Coalition Guidebooks
- Annual Conference
- Quarterly Webcasts with Caregiving Experts
- Presentations
- One-on-One Coaching
- Online News & Outreach: Caregiving Exchange Newsletter, Listserve, Facebook, Twitter & LinkedIn

Website Button



**Member of the
National Network of
Caregiving Coalitions**



Volume II: Coalitions Guidebook



- Volume II: Growing Your Coalition – What to Do After You’ve Planted the Seed
- Covers Advocacy, Strategic Planning, and More!
- Spring 2014 Release

Quarterly Webinar Series

Better Work, Better Care: How Employers Can Support Family Caregiving



Please join the National Alliance for Caregiving for a free webinar on building caregiver-friendly workplace policies in your state. Bringing together caregiving experts and employers from the national ReACT Coalition, we'll discuss the ReACT Employer Toolkit and how advocates can work with employers to raise awareness of the needs facing working family caregivers.

Webinar Details

Thursday, February 27th
3:00 – 4:00 pm Eastern Time
[Register now by clicking here!](#)

Featured Speakers



Brooks Kenny, Executive Vice President & Chief Marketing Officer
Lotsa Helping Hands
A founding member of Lotsa Helping Hands and nationally recognized expert in cause marketing and strategic partnering. Brooks Kenny's expertise lies in caregiving, social media and nonprofit relationships.



Jordan Green, M.S., Project Coordinator
AARP Public Policy Institute
Jordan Green was the primary drafter of the ReACT Employer toolkit. Currently serving as a Project Coordinator at the AARP Public Policy Institute, Jordan provides program research, program analysis, as well as counsel and functional support on strategic issues with a focus on family caregiving and social media.



Jack T. Watters, M.D., Vice President for External Medical Affairs
Pfizer
Dr. Jack Watters, as a member of the Pfizer team, is responsible for relations with medical societies, academic institutions and government health bodies around the globe. Dr. Watters has also represented Pfizer on matters of corporate responsibility and human rights, especially relating to raising political will for the plight of people with HIV/AIDS and the older citizen.



About the ReACT Coalition
ReACT (Respect A Caregiver's Time) is an employer-focused coalition dedicated to addressing the challenges faced by employee caregivers and reducing the impact on the companies that employ them. In November 2013, ReACT, in partnership with AARP, the National Alliance for Caregiving, and Pfizer, launched a free online resource for front-line managers and human resource professionals. Find out more about the ReACT's [Employer Resource Guide: Four Steps for Supporting Employees with Caregiving Responsibilities](#) at www.respectcaregivers.org and www.aarp.org/react.

- ➔ Ongoing Webinar Series
- ➔ Recent webinars on Caring for Veterans, the Long-Term Care Commission, and the ReACT Employer Toolkit
- ➔ Open to topic ideas!




Caregiving Champions



- 50 State Map
- Write to state lawmakers about caregiving
- Launch Summer 2014

Caregiving Champions

CAREGIVING CHAMPIONS IN ILLINOIS



Michelle Obama
First Lady of the United States
<http://www.whitehouse.gov/administration/first-lady-michelle-obama>

"When people ask First Lady Michelle Obama to describe herself, she doesn't hesitate to say that first and foremost, she is Malia and Sasha's mom.

But before she was a mother – or a wife, lawyer or public servant – she was Fraser and Marian Robinson's daughter.

The Robinsons lived in a brick bungalow on the South Side of Chicago. Fraser was a pump operator for the Chicago Water Department, and despite being diagnosed with multiple sclerosis at a young age, he hardly ever missed a day of work. Marian stayed home to raise Michelle and her older brother Craig, skillfully managing a busy household filled with love, laughter, and important life lessons..."

TELL MS. OBAMA WHY CAREGIVING IS IMPORTANT TO YOU.

Name *

First Last

Email *

Comment *

SUBMIT

➔ 50 State Map

➔ Write to state lawmakers about caregiving

Caregiving Champions

SIGN OUR PLEDGE TO SHOW YOUR SUPPORT FOR THE WORK OF FAMILY CAREGIVERS.

CAMPAIGN MEMBERS

John Doe, Maryland
Bill React, Texas
Claudette Colbert, New York

SIGN THE PLEDGE

I support the work of family caregivers, unpaid individuals who support a loved one with activities of daily living and medical needs. I support research that provides new information on caregiver populations, including spouses and partners, family members, friends, or neighbors. I am an advocate for change in my community, state, and nation.

Name *

First Last

Email *

Comment *

SUBMIT

➔ Caregiver Pledge

➔ Scrolling List of Signors

www.caregiving.org



Advancing Family Caregiving

Through Research, Innovation and Advocacy



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Caregiving touches almost every family and in very different ways – different health conditions; different situations; even different cultures. [Understanding the family](#)

TAKE ACTION NOW TO PROTECT MEDICARE DRUG COVERAGE - COMMENTS DUE THIS FRIDAY, MARCH 7TH AT 5PM ET -

The Centers for Medicare & Medicaid Services (CMS) has proposed a rule to change the Part D prescription drug coverage available to seniors under the Medicare program. The rule would remove the “protected class” status of antidepressants and immunosuppressant drug classes, and potentially remove protection for antipsychotics after 2015. (For the CMS fact sheet on the rule, [please click here.](#))

This issue is critical for family caregivers, especially those who care for patients facing mental illness and/or challenged immune systems. Patients with lupus, multiple sclerosis, Crohn’s disease, rheumatoid arthritis, HIV/AIDS, psoriasis and other immune disorders may lose access to prescriptions that are needed to treat their conditions. Likewise, patients and caregivers over the age of 65 facing major depressive disorder and other mental health conditions will have less access to the drugs they need and less flexibility to change drugs if their medication isn’t working.

The National Alliance for Caregiving has joined numerous organizations in asking CMS to reject the proposed rule. [Please see the letter from the Healthcare Leadership Council](#), which the National Alliance for Caregiving signed and supports, by [clicking here.](#)

We encourage you to take action by writing to CMS to let them know your concerns about the proposed changes to the Medicare Part D program. Write to CMS by clicking here. Comments are due by 5pm ET on Friday, March 7, 2014.



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&
Comments*



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*Workshop:
Growing Your
Coalition – What
To Do After You've
Planted the Seed*



#CareAdvocate14 @NA4Caregiving

Workshop

Your coalition has identified _____ as a priority for the 2014 year. Develop a strategy with action steps to identify how you would accomplish and support this priority.

Workshop

Identify

- Goals
- Action Steps
- Measures of Success
- Communications Strategy
 - Audience
 - Publicity

Consider

- External Partners
- Funding
- Types of Measurement
- Communication Tools

*Questions
&
Comments*



#CareAdvocate14 @NA4Caregiving

*Workshop:
Coalitions –
Communicating
Impact*



#CareAdvocate14 @NA4Caregiving





Communicating Impact

Brian M. Duke
Secretary

Pennsylvania Department of Aging



Communicating Impact

- Of coalition

- Of specific services, project or idea

Impact of Coalition

- Meeting needs identified during planning
- Achieving vision/fulfilling mission
- Progress on goals and objectives
- Projects and activities
- Advocacy
- Education and training
- Research
- Public awareness
- Initiatives now part of the norm*

12 Keys to Building Caregiver Coalitions, AARP Foundation/Caregiver Coalition Research Project, supported in part by a grant, No. 90-CG2627, from the Administration on Aging, Department of Health and Human Services, 2003

*Tom Wolff, Healthy Communities Initiative

Health of Coalition

- Collaboration levels
- Communication effective within and to other audiences
- Membership/capabilities assessment
- How are meetings going?
- Decision making
- Leadership
- Financial management and funding

Planting the Seed: Establishing and Growing Your Family Caregiver Coalition, National Alliance for Caregiving 2013

▶ Communicating Impact of Projects and Activities

- Definition of issue or opportunity
- Description of service, program or idea
- Ways to measure and present impact
- Communicating to others
- Other uses

Definition

- A refined focus
- Dependent upon members' contributions
- Hits on today's talking points but goes deeper
- Aims toward end result

Description of Service

- Answers journalistic questions
 - Who, what, when, where, how, why
- Responds to anecdotal but also defined need
- Includes goals with measures of success

Ways to Measure and Present Impact

- Measures
- Percentage of population
- Population vs control group
- “What difference does it make?”

Communicating to Others

- Solo vs chorus
- Demonstrates utilization of resources
- Explains differences
- Messaging relates to person or audience
- Format and frequency
- Impact drives change

Other Uses

- Advocacy
- Budgets/fundraising
- To support next steps

Issues to Consider

- Shared systems
- Some things are not measurable

Resources

- Charting Impact www.independentsector.org
- Outcomes Indicator Project, Urban Institute, www.urban.org
- Expertise at local universities and colleges

Contact

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Keynote Presentation

*Supporting California
Caregivers through Expanding
Paid Family Leave*

*The Honorable Hannah-Beth
Jackson (D-19, CA)*



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Thank you!

National Alliance for Caregiving

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