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.
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

#CareAdvocate14   @NA4Caregiving
Engaging Family Caregivers in Education and Advocacy

John Schall
Chief Executive Officer
Caregiver Action Network
March 12, 2014
JSchall@CaregiverAction.org
Who We Are

*CAN’s Mission...*

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

CAN **Connects** Caregivers with

- Valuable Free Resources
- Advice from Caregiver Voices
- Peer Support
- Caregiving Information
- Educational Webinars
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.
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.
Get started here! Click on the caregiving situations below.

**I JUST REALIZED I'M A FAMILY CAREGIVER NOW**

"It can't be this just happened!"

"Since he came back from Iraq, he depends on me."

"My wife has been diagnosed with HS."

We CAN help you be successful 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 high-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 married, 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 when she needs me."

We CAN help you be both an employee and a caregiver.
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!
Family Caregiver Toolbox

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
- Safe and Sound: How to Prevent Medication Mishaps
  Webinar On-Demand
- Financial Planning for Family Caregivers
- Create a Community of Help
  Lettsa 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**

![Image of Army Ranger Cory Remsburg, father/family caregiver Craig Remsburg, and the First Lady Michelle Obama]
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
More CAN Resources

✓ Plugged In Caregiving
  http://nfca.typepad.com/pluggedin_caregiving/

✓ Help for Cancer Caregivers
  www.HelpForCancerCaregivers.org

✓ Rare Disease Caregivers
  www.RareCaregivers.org
How to Connect with CAN

www.CaregiverAction.org

www.facebook.com/CaregiverActionNetwork

@CaregiverAction
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
Engaging Family Caregivers in Education & Advocacy

Martha Rañón
Director of Education & Outreach
Southern Caregiver Resource Center

March 12, 2014
History
1977
Organize
Grassroots movement
Family Survival Project

AB 2913 (Agnos)
Project to California Law

1984

Comprehensive Act for Family Caregivers of Brain-Impaired Adults
Outcomes

Educate community
Reach out to elected officials
Continue the movement
Maintain the Momentum
Family Advocates
Caregiver Stories
Public Awareness
Next Steps
Reinstate State Cuts
Interact with elected officials
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)
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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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
Discussion Panel:

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

#CareAdvocate14  @NA4Caregiving
Marcus Grindstaff
Vice President, International Markets
$471B
Belgium

AARP: Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving
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!
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
Who Are the Family Caregivers?

Family caregivers are the decision makers for senior care

- 43 million Americans care for an elderly loved one
- 50% find professional care for their parents
- 48% report household income >$100k per year
- 72% attend doctor visits with their loved one
- 64% manage their loved one’s finances
- 50% Age 50+
- 67% Female
- 60% have smart phones (Android and iPhone)
- Internet is the #1 information source for Boomers

Facebook:
42.2M Boomers
13.2M Seniors

64% of caregivers on Caring.com use Facebook

Sources: comScore Nov. 2013; Caring.com, May 2013; Flowtown, Nov. 2011
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
Lifespan Respite Program

- 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

AZ Caregiver.org

- 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

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](http://www.arizonarespiteregistry.org)
Online Respite Registry

- 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!

David Besst
Caregiver Support Specialist
Arizona Division of Aging and Adult Services

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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

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
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
- 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
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
- NAC Activities:
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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
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

 svensk text

- 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

50 State Map
Write to state lawmakers about caregiving
Caregiving Champions

Caregiver Pledge

Scrolling List of Signors
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.
Questions & Comments

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

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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
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
• 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
• 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

www.Caregiving.org