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Care for the Caregiver

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Objectives



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- Increased awareness of scope/range of family care-giving in U.S.
- Barriers to WHO whole health in female care-givers
- How providers/clinicians best support for caregivers
- Tools for thriving - not just surviving - as a caregiver



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*I may
look idle,
but on a
cellular
level I'm
very busy.*

Scope - Who are caregivers?



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Spouses - Aging and Dementia Care

- Live with care receiver, poorer
- 2/3 women, 34% are 65+
- 70% felt no choice to become caregiver
- Has own health issues
- Experience stress, least likely to get help from family/friends
- Feel “ground-down”, isolated, depressed



Scope - Who are caregivers?



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Mothers – Adults with Special Needs

- 72% women
- Average 45.8 years
- Four in 10 caregivers live with young adult care recipient
- 75% of working caregivers make changes to their work schedule or situation



Scope - Who are caregivers?



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Women - Aging Parents

- 66% are women
- Average 49 y.o.; works outside home; provides 20 hr/wk unpaid care to mother
- Female caregivers may spend as much as 50% more time providing care than male caregivers

Scope of Family Care-giving in US



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In 2013, 40 million
family caregivers gave
\$470 BILLION in care

(In 2013, **Walmart** net about
\$465.6 BILLION)

Range of Needs Met

- Shops, cooks, cleans house, laundry
- Assists with dressing, showering, medications
- Transfers in/out of bed, with physical therapy, injections, feeding tubes or other medical procedures
- Makes, coordinates, attends and follows up on medical appointments; drives to the doctor and drugstore

Range of Needs Met

- Talks with the doctors, care managers and others to understand what needs to be done
- Spends work time handling crises/making plans
- Is the "on-call" family member for problems
- Is overnight "staff"
- Answers endless, repetitive questions
- Is "on" 48/7

Barriers to WHO Whole Health for Caregivers



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From Insight to Advocacy:

Addressing Family Caregiving as a National Public Health Issue



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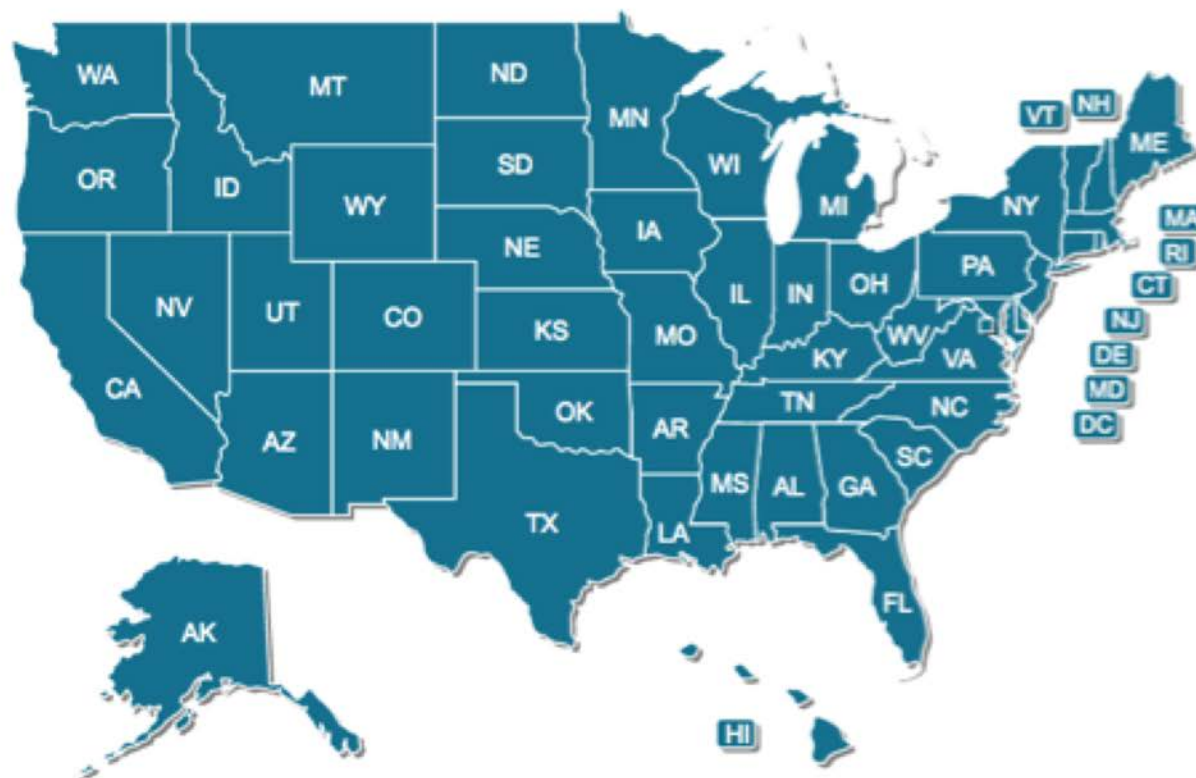




Family Care Navigator

State-by-State Help for Family Caregivers

Our Family Care Navigator helps family caregivers locate public, nonprofit, and private programs and services nearest their loved one—living at home or in a residential facility. Resources include government health and disability programs, legal resources, disease-specific organizations and more. Caregiving is challenging, but there are resources to help. Click on a state below for those available to you. View national resources and organizations [here](#).



Social Determinants of Health



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- May also be living on a fixed/reduced income and removed from family supports
- May lack understanding of diagnosis
- May have always been the Beta of the 'team'
- May become socially isolated due to care-giving pressure



What you can expect from me

I don't want this to be happening!

I might be cranky or angry.

Anger = Fear + Pain

I will be sad sometimes - I am
grieving

I will be tired



What you can expect from me

I am stronger if I take care of
myself

I can learn. I can grow

Self-efficacy - an incredible
self-sustaining state of being

Why should front-line health care providers listen to Caregivers?



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Caregiver Tools for Self-Efficacy and Support

- Primary Care Provider – Empathetic response and message delivery
- Accurate, understandable information about diagnosis and options
- Caregiver Support personnel in the system
- Resource catalogs and directories
- Support groups
- Other good stuff...



How Clinicians Can Interact Effectively with Caregivers



4 modules that address the roles and challenges of care-giving, how to better participate in shared decision making with caregivers, how to more effectively communicate with caregivers, and how to help caregivers take better care of themselves.



Powerful Tools FOR Caregivers

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Questions? Need assistance?

1-503-719-6980



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Welcome to Powerful Tools for Caregivers

We provide a self-care education program for family caregivers. The Powerful Tools for Caregivers program will provide you with tools and strategies to better handle the unique caregiver challenges you face.



State of Rhode Island

Department of Health



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Community Health Network Programs

Powerful Tools for Caregivers

We can help . . .

- Caregivers communicate more effectively in challenging situations, recognize the messages in their emotions, deal with difficult feelings, and make tough caregiving decisions.
- Caregivers to develop a wealth of self-care tools to reduce personal stress, change negative self-talk, and communicate their needs to family members and healthcare or service providers.

How this works

Facilitated by two certified peer leaders in group sessions of 2 1/2 hours per week for six weeks. Class participants will receive a copy of The Caregiver Help Book, developed specifically for the class.

Who we help

Anyone 18 years and older who is a caregiver to an older adult

Cost

Free

Where to get Powerful Tools for Caregivers

- Statewide: ✉ [Community Health Network at the RI Parent Information Network](#)

CONFIDENCE AND AWARENESS OF PERSONAL HEALTH IN CAREGIVERS OF SPECIAL NEEDS CHILDREN

Carla M. Hagen, PhD, MPH, RN, Oregon Health & Science University
Melissa N. LaRue, BA, BSN, RN, Providence Health & Services



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WHAT WE LEARNED

After participation in **Powerful Tools for Caregivers (PTC)**, a 6-week psycho-educational series designed to help family caregivers take care of themselves, caregivers reported: **Overall increased confidence in their caregiving role and increased attention to their personal health.**

BACKGROUND

- Caregiving demands met by caregivers of children with disabilities or special health care needs can cause chronic stress and have a negative effect on the caregivers' physical and emotional health.
- Caregivers of children with disabilities describe negative physical, emotional, and functional health consequences of long-term informal caregiving.
- Powerful Tools for Caregivers (PTC) is a psycho-educational program that is rooted in Bandura's Social Cognitive Theory, which posits that a high degree of self-efficacy will increase the likelihood that certain tasks, particularly health promoting behaviors will be performed successfully.

AIMS

- To explore the levels of caregiver confidence in their caregiving role.
- To explore caregivers level of awareness of their personal health.
- To explore what caregivers consider their most important concerns related to their caregiving.

METHODS

- 42 caregivers of special health/behavioral needs children participated in six, two-hour classes, in four different states representing four different regions of the country. The content was focused on: reducing personal stress, practicing self-care, communicating effectively in challenging situations, dealing with difficult emotions, making tough caregiving decisions, setting goals, and problem solving.
- Powerful Tools for Caregivers (PTC) content and survey materials originally created for caregivers of older adults was revised to address the caregiver population of children with special needs.
- Participants completed a pre- and post-intervention (PTC course) survey. The post survey was completed immediately after the sixth PTC class.
- The domain of caregiver confidence was based on eight questions, which were calculated on a 5-point (0-4) Likert scale.
- Caregiver health was assessed through a series of ten binomial (yes/no) questions related to caregiver attention to their own health needs.
- An open-ended question was utilized to determine caregivers most important concern related to their caregiving.

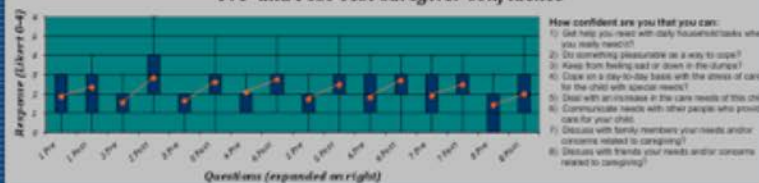
Pre- and Post-Test Response to Caregiver Attention to Health



FINDINGS

- N = 37 (of 42 participants with complete data) reported overall increased confidence ($P < .02$) from pre-intervention of PTC ($M = 1.74$) to post ($M = 2.52$).
- N = 32 (of 42 participants with complete data) reported overall increased attention to health ($P < .02$) with pre-intervention of PTC ($M = 0.56$) to post ($M = 0.39$).
- N = 30 (of 42 participants) provided 78 concerns related to their caregiving.

Pre- and Post-Test Caregiver Confidence



Caregivers Most Important Concerns:

- "[The] most important concerns is being taken for granted, not appreciated; not taking care of myself, ie. no sleep, no exercise, too much eating."
- "Being able to continue caregiving as I get older & my son grows."
- "I'm aging, he's getting bigger. How it affects my health physical/mental."
- "Challenges related to advocating for care, healthcare (dealing with bureaucracy, inefficiency & unlistening ear of those in power)"
- "Making preparations for when I am no longer here. Getting assistance while I am here."
- "Making sure both children have what they need to reach their full potential and still be a kid."

IMPLICATIONS

- Caregivers of children with special needs children benefit by participation in the psycho-educational program of Powerful Tools for Caregivers.



- Learning more about caregivers individual identified concerns allows health care providers and educators the opportunity to assess additional strategies of support.

School of Nursing
A Passion for Nursing





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aging**wello****hub**

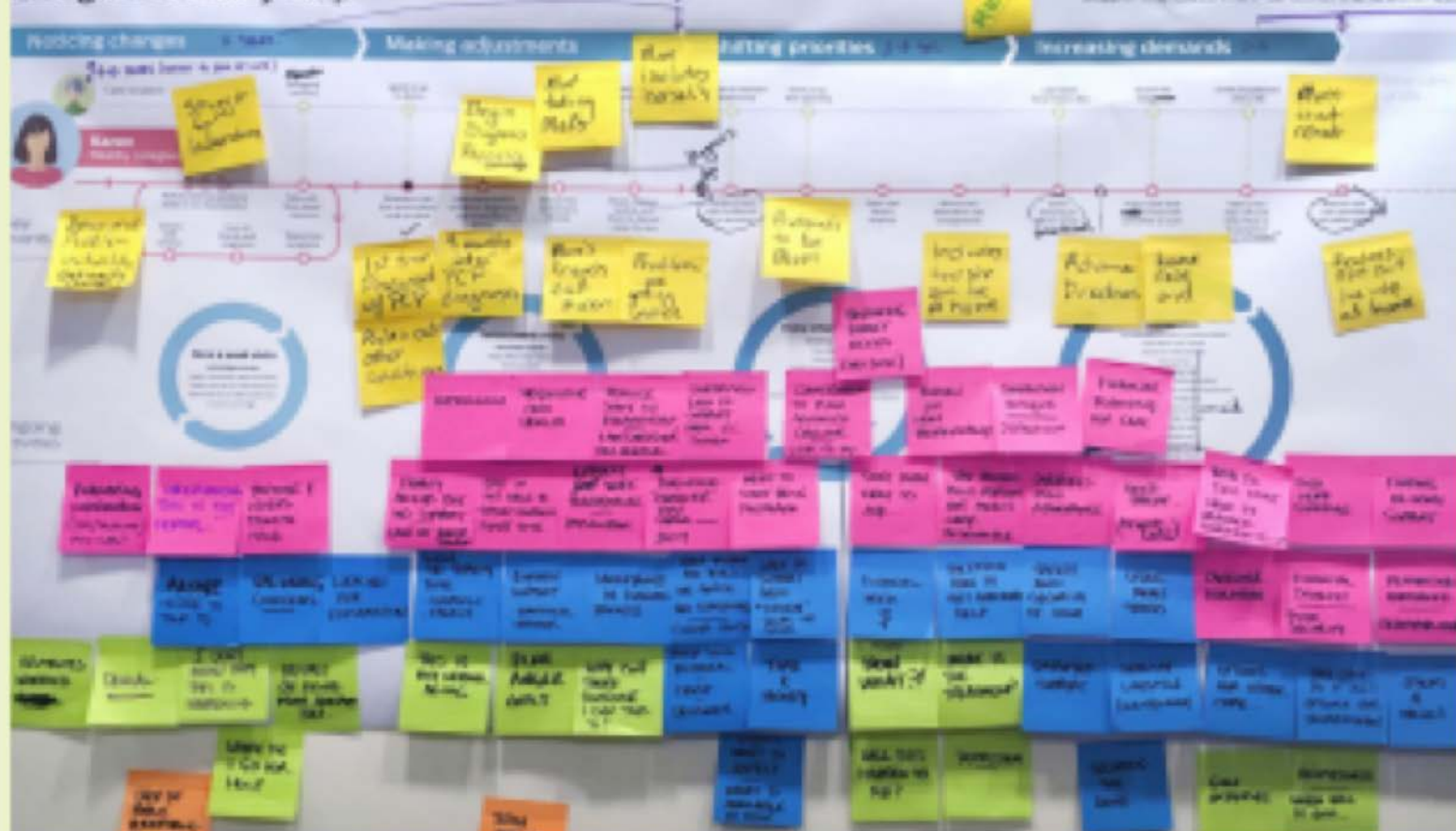
Caregiver journey map

Supporting those with
Alzheimer's and other dementias



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Caregiver Journey Map



Notes from October workshop

Technology to Support Caregiver Self-Care

- Primary care reminders from patient portals that help meet system Meaningful Use objectives
- Atlas of Caregiving
- Lotsa' Helping Hands
- Personal physical activity trackers



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Atlas of Caregiving

Person-Centered Planning
For the Caregiver

Villages



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The Providence Village of Rhode Island

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We are inspired by neighbors helping neighbors
We are committed to an inclusive, community-based
network of mutual support
We call our endeavor The Providence Village

Our Village is based on a model developed in Boston 15 years ago, when a group of Seniors decided they had no intention of moving to a "retirement home." So they created a way to stay in their own homes as they aged. Since then, over a 150 grass roots organizations based on their Village model have sprung up around the country, as well as a national organization dedicated to supporting these Villages.

Through a large pool of member-volunteers and a small paid staff, we aim to provide access to services and programs that make it possible for Seniors to stay in their homes and communities - safely and comfortably - for as long as possible.

CONTACT US

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Special Events:

**Atwater-Donnelly
Concert:**
[- Reserve Now](#)

Around Town:

References



- [Atlas of Caregiving](#)

“Atlas of Care-giving’s mission is to catalyze a transformative change for family care-giving through innovative research, practical solutions and rich collaboration. Atlas CareMaps help you better understand and strengthen your care ecosystem.”

- [Confidence and Awareness of Personal Health in Caregivers of Special Needs Children.](#)

Poster presentation. Slide #21

- [Family Caregiver Alliance](#)

“FCA’s work intersects three key areas: caregiver services, policy, and research. But across all agency programs, the services and products developed and delivered are based on real needs of real caregivers – those families we hear from and work with every day.”

References



- [How Clinicians Can Interact Effectively with Caregivers. HRSA](#)

This module was developed under contract from the U.S. Department of Health and Human Services, Health Resources and Services Administration. This work was funded by the U.S. Department of Health and Human Services, Office of Women's

- [Lotsa Helping Hands](#)

An on-line support Community.

- [National Alliance for Caregiving.](#)

“Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation and advocacy. The Alliance conducts research, does policy analysis, develops national best-practices programs, and works to increase public awareness of family care giving issues.”

References



- Powerful Tools for Caregivers

An evidence-based, 6-session series on self-efficacy for caregivers.

- Self-And-Caregiver-reported experiences of young adults with developmental disabilities. J Social Work Disabilities and Rehabilitation 2007;6(4):53-73. Roush SE, Fresher-Samways K, Stolgitis J, Rabbitt J, Cardinal E.

- The Providence Village of Rhode Island

- State of Rhode Island, Department of Health, Community Health Network Programs