Capacity to Care: Caregiver Services Replication Guide

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Contents

Introduction 1
Background 2
Programs 3
- Outreach Awareness Campaign 3
- Mobile outreach 5
- Chronic Disease Self-Management Program (CDSMP) for Caregivers 7
- Caregiver Café 10
- Peer support—*P.S. I Understand* 12
- Building community capacity 14
  - Faith Community Learning Collaborative 14
  - LGBTQ Caregiver Support 16
  - National Night Out Outreach 17
- Caregiving Network On The Web (CaregivingNOW) 18
- Social media 21
  - Blog posts 23
  - Facebook 24
  - Twitter 25

Appendix 26
- Campaign Poster 27
- Chronic Disease Self-Management Program 2012 29
- Chronic Disease Self-Management Program 2013 30
- Chronic Disease Self-Management Program 2015 31
- Peer mentoring 33
- Community Capacity, Faith Community Learning Collaborative 34
- CaregivingNOW 36

Introduction

Faced with evidence of dramatic growth in the older adult population in the next decade, Amherst H. Wilder Foundation identified caregiving as a strategic priority. A business plan was developed to strengthen home and community-based services for older adults that included a strong focus on supporting caregivers and strengthening the available resources to do this work. A CS/SD grant from the state of Minnesota, along with other private funding, catalyzed this effort, resulting in added capacity to existing services, a broader array of tools for engaging caregivers, and a strengthening of informal caregiver supports.

Despite increasing expertise and system capacity, research had revealed a decline in caregivers accessing or using caregiver services (information, education, consultation and coaching). Locally, while some funding existed, engagement with services was limited and Wilder's own research confirmed that a lack of caregiver self-identification and awareness was a significant challenge: if caregivers don't see themselves or their role as caregiving, they're less likely to seek help. Wilder's experience and research had shown that many people had carried out the role of caregiver in isolation, shouldering enormous burden, and often waiting too long to pursue available help. When crises occurred, caregivers were often burned-out and ready to find institutional solutions to care for loved ones. While our communities were changing to accommodate the needs of older adults, little attention had been paid to the needs of those caring for them.

This replication guide describes Wilder's activities to implement this initiative, the outputs achieved, resources necessary for launching each component, and the lessons learned in the course of the work.

The Caregiving Resource Center, on the Wilder Foundation website, is designed to provide a wide range of resources for caregivers in any role and at all stages. The main menu with common resources for caregivers is located at: http://www.wilder.org/Programs-Services/caregiving-resource-center/Pages/Common-Resources-for-Caregivers.aspx. Access to further information about Wilder Caregiving Services is located at: http://www.wilder.org/Programs-Services/caregiving-resource-center/Pages/Caregiving-Services.aspx

Background

In 2011 Wilder launched a five year program expansion of caregiver services with three goals:

- Increase caregiver identification
- Develop new services that are responsive to caregivers' needs
- Increase the number of caregivers accessing these services

Eight main programs and strategies were developed through CS/SD funding for caregiver support services:

- Outreach to create awareness of caregiver services
- Mobile outreach
- Chronic Disease Self-Management for caregivers
- Caregiver Café
- Peer mentoring—*P.S. I Understand*
- Building community capacity
- CaregivingNOW
- Social media toolkit

In the course of this work, partnerships have been initiated with the following organizations:

- Alzheimer's Association of Minnesota-North Dakota
- Alzheimer's Association—California Southland Chapter
- Faith communities in the Twin Cities metropolitan area
- Jewish Community Center of St. Paul
- Lyngblomsten
- Metropolitan Caregiver Services Collaborative
- Minnesota Board on Aging
- St. Joan of Arc & PFund
- Twin Cities Public Television (*tpt*)/ECHO
- United Way-United Front

The following section of this document outlines seven programs, initiated between 2012 and 2015, based on the following categories:

- Program description
- Outputs
- Resources needed for the program
- Lessons learned from program implementation

Programs

Outreach Awareness Campaign

Description

Amherst H. Wilder Foundation, the Alzheimer's Association, the Metropolitan Area Agency on Aging, and the Metropolitan Caregiver Services Collaborative and the Lifespan Respite Project of the Minnesota Board on Aging, worked together to create a campaign to raise awareness about identifying as a caregiver and increase access to caregiver supports. A 2001 AARP Caregiver Identification Study showed that only 19 percent of people actively caring for a friend, family member, or neighbor self-identified as a caregiver. Without recognizing this role, caregivers do not seek resources that could help them better take care of their loved ones and themselves.

The Caregiver Awareness Campaign began with a general goal of encouraging people to self-identify as caregivers, and expanded to include messages about getting support and resources for caregiving. Since 2011, four waves of the campaign used digital media, radio, outdoor media, transit media, and print media to communicate messages about caregiving. The CS/SD funding was used to replicate and expand the campaign statewide.

A website was created to direct caregivers toward community resources that are available to them. Four main areas of connection include links to:

- The Senior LinkAge® 1-800 333-2433
- CaregivingNOW website via Facebook
- https://www.minnesotahelp.info/
- Downloadable Caregiver Resource Guide
  The DVD toolkit (with Spanish translation) is available by contacting caregiving@wilder.org. The DVD contains art files in various formats, in English and Spanish translation for other organizations to use to create materials for their own programs.

Outputs

Since 2011, the campaign resulted in:

- Over 100 million media impressions across the state of Minnesota.
- The distribution of more than 700 toolkits by Wilder and its partners across Minnesota and nation-wide.
- The translation of materials into Spanish.

The second wave of the statewide campaign resulted in the following:

- 20,255 page visits and 24,185 page views.
- 83.4% were "new visitors" and 16.6% were "returning visitors."
- 53% of visitors entered with caregivinglink.org URL.

Other results:

- Two awards received by this collaboration: an Innovation Award from Aging Services of Minnesota, and a national award from the Family Caregiver Alliance and the Rosalinde and Arthur Gilbert Foundation for Policy & Advocacy.
- Organizations in Idaho and California, as well as ACT on Alzheimer's in Minnesota, are using materials developed for the campaign.

Resources

Many resources were required for the campaign, including:

- Partnerships with Area Agencies on Aging, Minnesota Public Radio (MPR), KFAI Radio, Twin Cities Public Television (tpt), ECHO, public transportation, community newspapers.
- Partnership with Kruskopf & Company, media expert and creative team.
- Funding for purchases of advertising for print media, transit, billboards, radio, and digital media access.
- Recruiting caregivers who were willing to be photographed.

Lessons learned

Lessons learned include the following:

- The power and success of the campaign lies in its simplicity and focus on increasing caregiver self-identification.
- Caregivers resonate more with the verb "caregiving" than with taking on a label of "caregiver."
- Stronger messages were implemented to engage caregivers and prompt them to seek information, find resources online, or join a support community, and included simplifying the existing copy; creating a new vanity URL for the landing page; and creating a user-friendly, mobile-responsive landing page to house the caregiver resources.
- Purchased media significantly drove "direct" traffic; referral links and social media made significant contributions.

Mobile outreach

Description

To proactively engage caregivers before a crisis, Wilder's Caregiver Services focused on outreach in areas where caregivers naturally gather. Called mobile outreach, this strategy encompassed engagement of caregivers at community health fairs and conferences, destination sites such as coffee shops, libraries, grocery stores, pharmacies, coffee and yogurt shops, and arts and cultural events. Individuals encountered during these events were asked to answer a brief quiz to assess whether or not they were caregiving.

Through these efforts, Wilder was able to connect with caregivers and gain their contact information for follow up. This helped raise awareness of Caregiver Services and allowed Wilder to proactively reach out to caregivers by phone and email at regular intervals (rather than waiting for caregivers to contact us) Wilder began to receive more frequent phone calls and increasing hits to the website. Program staff are still in contact with the majority of those we connected with during the outreach efforts, with seeking additional information or access to others services and supports.

Outputs

- Wilder staff and volunteers engaged with caregivers through 212 mobile outreach activities.
- More than 2115 new caregivers have information and support that has helped them with caregiving.

Resources

- Staff and volunteers wearing Wilder teal t-shirts working shifts of 2-4 hours
- Portable table, folding chairs
- Branded table cloth, caregiver quiz, clipboard, pens, candy
- Caregiver Information forms to be filled out
- Give-a-way tote bags filled with caregiver information and resources
- Connections in the community to conduct outreach in a variety of settings
- Rolling bin for transportation of supplies
- Portable tent for outdoor events

Lessons learned

1. Individuals who are caregiving are less motivated by seeking help/support for themselves and more motivated by being an effective caregiver for their care recipient.
2. Many caregivers do not want/need support right when they self-identify, but they are more likely to ask for support at the 3-month follow up.
3. Typical requests for support have been access assistance via phone – take something off their plates – versus more traditional forms of caregiver support such as coaching.
4. Community outreach (Mobile outreach) has been a successful strategy to engage caregivers in community settings to focus on self-identification and engagement however this strategy was not fully effective in engaging caregivers with available supports and services.

Chronic Disease Self-Management Program (CDSMP) for Caregivers

Description

The Community Center for Aging has been offering the evidence-based, health and wellness program, *Living Well with Chronic Conditions* since 2008. Offered as a six-week workshop[1] intended to assist those who are living with a chronic condition to learn a set of tools and skills to gain confidence in self-managing their symptoms, *Living Well with Chronic Conditions* has been offered in a variety of community settings.

While Wilder has always included caregivers in the *Living Well with Chronic Conditions* workshops, the expanded offering was intended specifically for caregivers. It was renamed *Caring for Someone with Chronic Conditions,* as these individuals may be coping with their own chronic conditions while caring for someone else. This expansion was intended to offer another layer of support to caregivers, as well as to connect participants with others involved in caregiving. Link: http://www.wilder.org/Programs-Services/Older-Adult-Services/Pages/Health-and-Wellness-Programs.aspx

Outputs

The following are results from *Caring for Someone with Chronic Conditions*:

- Eight workshops were scheduled during the time period from September 2012 through May 2015.
- One six-week workshop was completed in spring 2014.
- Participants rated their experience highly. All expressed gratitude for the opportunity and shared feelings of support for each other.
- Blog Post: Managing Your Health and Taking Control! http://www.wilder.org/Blog/Lists/Posts/Post.aspx?ID=55#.VnnKOvkrLcs

[1] The program was developed by Stanford University Patient Education Research Center.

Resources

Resources needed to provide Caring with Someone with Chronic Conditions include:

- Program licensure (provided by MAAA's program license which is purchased from Stanford University Patient Education Research Center) with the following fidelity guidelines:
  - Workshops must be held for six consecutive weeks, for two to two and one half hours each week.
  - Led by two trained leaders
  - At least eight participants for the workshop to begin (10-12 preferable, 16 maximum)
- Two trained leaders
  - Complete a four-day leader training, provided by certified Master Trainers
  - Agree to follow the curriculum as written
- Program materials
  - Leader manual must be followed and presented as written, with no additions or subtractions of any materials or subjects.
  - Program charts: chart paper, makers, easel, and time to create charts
  - Participant reference book: "Living a Healthy Life with Chronic Conditions"
  - Companion CD for leaders: *Pathway to Healing: Relaxation for mind and body* to be used for relaxation session.
  - Miscellaneous materials: name tags for participants and leaders, chart paper and easel or whiteboard, pens and markers, tissues
  - Participant paperwork for grant reporting
  - Healthy snacks and beverages
- Space that allows for privacy and confidentiality, is accessible, has parking available, and is accessible via public transportation.

Lessons learned

The following are lessons learned in the course of implementing and providing the program:

1. Attendance was limited, so additional efforts at outreach were implemented, including:
   - Listing the workshop details in various news publications, e-newsletters, and webpages
   - Person-to-person outreach through our caregiver services and mobile outreach opportunities
   - Providing information to our community contacts and partners
   - Writing a blog, published on Wilder's website: http://www.wilder.org/Blog/Lists/Posts/Post.aspx?ID=55#.VnnKOvkrLcs
   - Social Media posts through Facebook and Twitter
   - Internally in Wilder through the employee newsletter and calendar
   - Creating new outreach materials more aligned with Wilder's other Caregiving outreach documents
   - Changing the name to be more reflective of intended audience: "Caring for Someone with Chronic Conditions"
   - Offering the workshop in partnership with another community organization who could also market it to their community members.
2. It is important to have a clear message about the intended audience and benefits for participants.
3. Busy caregivers may have difficulty in committing to a six-week program; the program may be better suited for care recipients.
4. Caregivers may benefit from short term connections to learn about skills and tools for managing their care recipients' conditions.

Caregiver Café

Description

In response to caregivers' need for in formal supports and engagement with someone outside the family, Wilder launched the Caregiver Café in spring 2012. The Caregiver Café is a unique, four-part series of weekly gatherings for caregivers of older adults that differs from typical support groups. It was designed by caregivers for caregivers, in collaboration with Wilder's Caregiver Advisory Group. The series aims to empower caregivers to: ask for help; build connections between caregivers that result in opportunities for mutual support; and increase the support provided to caregivers by their families, friends, neighbors, and coworkers.

Each session focuses on a specific theme: caregiver story, caregiving vision, asking for help, and living your vision. Facilitated discussion occurs during the gatherings to keep the focus on the caregiver, and on meeting practical needs. Cafés were offered in community settings.

Outputs

The following are results from the Caregiver Cafés:

- 45 caregivers participated from Spring 2013 to Summer 2015.
- 12 sessions were held in a variety of community settings, including Black Bear Crossing-Como Park, Wilder's Community Center for Aging, Lyngblomsten's 551 Club, and St. Paul Jewish Community Center (as part of the Living Well program for people with early stage memory loss)

A CAREGIVER'S STORY

Jane Zappa has been taking care of people almost all her life. The oldest of nine children, she grew up taking care of younger siblings. She is a registered nurse and raised three daughters. When Jane's husband, retired military officer Pat Zappa, was diagnosed with a form of dementia in 2011, she had a lifetime of skills to draw upon.

She knew she needed to reach out for help. She and Pat ultimately found support through Wilder's Caregiving Services. "I think Wilder does just a fantastic job of finding new and different ways to help the person with dementia and to help their families," Jane says.

Pat and Jane joined the Living Well program for people experiencing early memory loss and their caregivers. Pat enjoyed exercise, creative arts and other engaging activities while Jane connected with other caregivers in a café-style atmosphere. "He just loved it," Jane says.

Because she knew to take advantage of services that reduce stress on the family, Jane eventually arranged for Pat to attend Wilder's Adult Day Health program one day a week. Pat says he enjoys the activities, particularly the men's group. He has maintained friendships with people he met at the Living Well program and has also made new acquaintances. While Pat attends the Adult Day Program, Jane has an opportunity for respite and catching up on things that need to be done.

Jane also knew she needed to seek support from others, so she joined a memory loss support group at Wilder. She appreciates the exchange of ideas among participants and the welcoming atmosphere at the Community Center for Aging. "The nice thing about the caregiver support group at Wilder is that it has been a great exchange of ideas between people," Jane says. "I think people get the idea that we're there to share and help each other."

Caregivers reported valuing meeting other caregivers, sharing their experiences, resources, and strategies that resulted in new social bonds with others in similar situations. Participants reported that the Cafés helped them realize they have shared challenges and experiences and can benefit from exchanging resources and strategies. Cafés also helped caregivers understand the importance of asking for help with caregiving tasks when needed and placing greater emphasis on self-care.

- Caregivers reported that their participation will make it easier to ask for help with caregiving in the future.
  - 63% Definitely Yes
  - 37% Probably Yes
- 87% reported that they planned to stay in touch with other caregivers after the group.

Resources

Resources required to provide Caregiver Café include:

- Two staff to facilitate the group
- Space that allows for privacy and confidentiality
- Coffee, tea, and food served in a café-style, informal setting
- Program supplies such as paper placemats, table cloths, markers, folders, nametags/ table tents, tea light candles

Lessons learned

Lessons learned about Caregiver Cafés include the following:

1. Shared problem solving facilitates connection, based on practical issues and real support.
2. Evening sessions are important in order to meet the needs of working caregivers and "sandwich" caregivers (for examples, persons caring older relatives and their own children simultaneously).
3. Stronger relationships are built when caregivers meet for more than four sessions.
4. The most helpful aspects of Caregiver Café are:
   - Connecting with other caregivers and learning that others have similar experiences and feelings
   - Sharing strategies and resources, having others listen, and exchanging ideas
   - Learning how to ask for help by focusing on problem solving and where to turn

Peer support—*P.S. I Understand*

Description

Caregiver Consultants at Wilder frequently heard from caregivers that opportunities to connect with other caregivers were a significant source of support—perhaps as valuable as professional support and yet distinctly different. Wilder researched various models of peer support and developed a unique caregiving model called *P.S. I Understand*. The program matches a current caregiver with a peer who is both a trained volunteer and a former caregiver, at least one year past their caregiving responsibilities.

The volunteer calls the current caregiver once or twice a month to provide emotional support as a peer who understands the caregiving experience. This program is ideal for caregivers who are unable to attend traditional support groups because of transportation or scheduling issues and/or those wanting the opportunity to talk to a peer about their caregiving. Peers provide an invaluable service to caregivers by breaking a caregiver's isolation and being an empathetic listener.

Training provided to peer volunteers includes learning more about caregiving and gaining skills to help peers develop helpful relationships with current caregivers. Training focused on education about caring for someone with memory loss, and empathy for understanding both the caregiver and care receiver's situation. Wilder staff remains connected with both the caregiver and the peer throughout the process.

Outputs

The following results were achieved:

- Developed unique model of support, including promotional materials and a training outline
- Developed promotional cards, adapting the caregiver awareness campaign message to include information about the program and contact information
- 9 volunteers trained, with six retained and matched, or available to be matched, with caregiver
- 12 caregivers total, with four retained and matched with volunteers
- 2 peer volunteers are matched with two caregivers each
- *P.S. I Understand* promoted by Roseville ACT on Alzheimer's, through 16 educational events

Resources

Resources required for the peer support program include:

- Volunteer mentors
- Time for interviewing and matching volunteers with caregivers
- Training materials focused on confidentiality and privacy rules, guidelines for vulnerable adults, and instructions for documenting conversations
- Promotional cards for recruiting volunteers
- HBO Memory Project videos and TED Talks used during training sessions

Lessons learned

The following are lessons learned about *P.S. I Understand*:

1. The program is time-consuming based on the following tasks:
   - Recruiting, interviewing, training volunteers
   - Recruiting caregivers
   - Coordinating matches between volunteers and caregivers
   - On-going monitoring of the matches
   - Paperwork documentation of volunteer and caregiver conversations
2. Guidelines for volunteers restrict the pool of possible peer partners. Recruiting is specialized, and traditional volunteer recruitment has not resulted in sufficient numbers of volunteers. Presentations at caregiving events and reaching out to former caregiver clients have been a successful model.
3. Determining and enforcing guidelines and boundaries for interactions between peer volunteer and caregiver pairs has been an on-going process. Guidelines include:
   - Two telephone calls per month
   - No in-person meetings
   - Texting or emailing to schedule times to talk is at the discretion of the matched pair
4. Training time was reduced from two days to one and a half hours. Volunteers did not require intensive training on empathetic listening, likely due to applying their own past experiences as caregivers to their new roles as mentors.

5. Completing one-on-one training as needed was more efficient than waiting for a larger pool of volunteers to be recruited, and it allowed for more immediate matching of pairs.
6. Caregivers and volunteers preferred matches based on similar caregiving relationships, gender, and diagnosed condition. Such matches were more effective and enduring.

Building community capacity

In response to findings reported in *Caregiving in Context*, a 2012 study completed by the Amherst H. Wilder Foundation, Wilder implemented several initiatives designed to build capacity of caregivers in Minnesota, including:

- Faith Community Learning Collaborative
- LGBTQ Caregiver Support
- National Night Out Outreach

Faith Community Learning Collaborative

Description

The *Caregiving in Context* study identified faith communities as a natural place for caregivers to turn for support. Yet when caregivers reach out to faith communities, only half received the support they were seeking. By 2013, building capacity in faith communities was recognized as a tremendous opportunity to leverage a key source for caregiver support. The resulting Faith Community Learning Collaborative is a gathering of lay people, faith community staff, parish nurses, and clergy from all religious traditions in the Minneapolis-St. Paul metropolitan area. Topics covered at quarterly meetings include sharing efforts to provide support and lessons learned; participating in shared training, skill-building, and learning opportunities; and building supportive, working relationships.

Outputs

The following are results related to the Faith Community Learning Collaborative:

- Quarterly meetings with members from 75 faith communities
- Development of over 20 new caregiving support programs or related activities, including educational opportunities, coffee conversations, prayers or blessings, sermons, or discussions with clergy

- Development of new partnerships that allowed collaborative members to strengthen informal relationships with other attendees, as well as become more familiar with local service providers

- Four Innovation Fund grants made to faith communities to develop/support caregiver programming. These grants were made possible through private grant funds.

Resources

The following resources are needed for the collaborative:

- Partnerships with organizations: Allina Faith Community Nurse Program, Lutheran Parish Nurse Association, Lyngblomsten, Saint Paul Area Council of Churches, Jewish Children and Family Services

- Innovation Funds for projects with at least one of the following characteristics:
  - Involving teams of faith community staff and lay people working together to support caregivers
  - Advancing the work of an Action Project identified through the Faith Community Learning Collaborative
  - Bringing together multiple faith communities in a collaborative effort that builds capacity and resources for caregivers
  - Demonstrating that the funds will build capacity that can be sustained by the faith community

Lessons learned

The following lessons were learned about the collaborative:

In 2014, 95 individuals who had participated in a Faith Community Learning Collaborative were surveyed. Thirty-one participants (33%) responded and provided the following information about the impact of their participation on them and/or their faith community:

1. **Sharing resources and information.** Respondents said they learned about new resources and information by participating in the collaborative. Some mentioned hearing ideas from other communities that they were inspired to try in their own communities.

2. **Feeling inspired and energized.** Respondents mentioned feeling energized after participating in the collaborative and inspired after meeting other people doing similar work.

3. **Connecting with like-minded individuals.** Respondents said they enjoyed the networking and social aspect of the collaborative, and felt that getting to know like-minded individuals and discussing topics that are not often talked about elsewhere was personally beneficial.

LGBTQ Caregiver Support

Description

According to the 2012 Twin Cities *LGBT Aging Needs Assessment Survey Report* by PFund, LGBTQ people are twice as likely to be caregivers as the general public. The same respondents indicated the need for a LGBTQ specific support group, not just a group that was welcoming. The LGBTQ Caregiver Initiative began in April 2013 when Wilder connected with a local LGBTQ caregiver through Wilder's online forum CaregivingNOW and recognized the need for increased supportive services for this population (as well as community conversations to raise awareness around aging).

Goals for LGBTQ caregiver support include: increasing access to an LGBTQ-specific caregiver support group for community members; decreasing isolation and burnout of LGBTQ caregivers; improving strategies for supporting LGBTQ elders and caregivers; improve connections between LGBTQ communities of color and white LGBTQ community; and increasing the voice of LGBTQ communities of color. The group expanded its focus to the creation of a multicultural, cross-class, intergenerational group. Link: https://www.facebook.com/lgbtqcaregiving

Outputs

The following results were achieved:

- Creation of the Twin Cities' only LGBTQ caregiving support group and network
  - Two facilitators recruited
  - Several Kitchen Table conversations held in the community
  - Monthly support group
  - Outreach at PRIDE
- New connections to faith-based organizations through LGBTQ participants who are members of area faith communities

Resources

Resources required for the LGBTQ Caregiving Network include:

- Community members across Minnesota who are or have been caregivers to their friends, partners, neighbors, and coworkers, biological and chosen families
- Additional funding through private grants
- Meeting space and caregiving expertise (provided by Wilder)

Lessons learned

The primary learning is that the success of the initiative was tied to its ownership within the LGBTQ community.

National Night Out Outreach

Description

Wilder piloted caregiving outreach at National Night Out (NNO) in 2013, engaging volunteers to attend NNO events across the Twin Cities to distribute postcards and magnets with information about supporting caregivers. The initiative was expanded in 2014.

Outputs

The following results were achieved:

In 2013:

- 277 information cards were distributed
- 151 caregiving conversations happened (in spite of severe weather that shortened or canceled events), and neighbor to neighbor outreach proved valuable

In 2014:

- 800 neighbors were engaged in caregiving awareness through the use of 13 volunteers attending 21 NNO events. Neighbors learned about who needed care and who was providing care in their neighborhood. Awareness of caregiving and resources was elevated in these communities.

Resources

Resources required for NNO events include:

- Recruiting and training volunteers
- An online training video: https://www.youtube.com/watch?v=epnOHBTVEsw&feature=youtu.be
- Postcards and magnets for distribution

Lessons learned

Lesson learned through National Night Out Outreach include the following:

1. It was difficult to recruit volunteers who did not already have a base level of knowledge about caregiving. The volunteers who were recruited, however, were very interested in the topic and went to multiple events each.
2. It may be more effective to recruit volunteers through partners and other organizations doing work with caregivers.
3. The best recruitment approach was reaching out to local churches already planning NNO events.

Caregiving Network On The Web (CaregivingNOW)

Description

CaregivingNOW is an online community and gathering place where caregivers can come for connection, information, support and friendship. It is geared toward caregivers who are isolated and looking to build connections with other caregivers, who would like to attend a support group but aren't able to get to one, or who enjoy online conversations and connections.

The online community was created in response to information collected through research about the needs of caregivers, which included a collaborative work group and caregiver listening sessions. Together a collaborative group created a customized online tool, recruited caregiver influencers to post relevant questions and respond to caregiving posts, and marketed of the online community. The group was launched on United Way's United Front platform in May 2013 in partnership with Greater Twin Cities United Way and Metropolitan Caregiver Services Collaborative. It later moved to Facebook.
Links: http://www.wilder.org/Programs-Services/caregiving-resource-center/Pages/caregiving-now.aspx and https://www.facebook.com/groups/caregivingnow

Outputs

The following are program accomplishments:

Between June 2013 and February 2014:

- 71 total members
- 11 topic threads
- 28 member posts
- 60 logins
- 29% completed member profiles

As a secure, closed group on Facebook in fall 2014:

- Expanded to 183 members

Resources

CaregivingNOW is a joint effort of the Wilder Foundation, the Metropolitan Caregiver Service Collaborative and the Greater Twin Cities United Way.

Other resources required for CaregivingNOW include:

- Recruitment of volunteer influencer caregivers
- Training for volunteer influencers
- Guest hosts, including Kari Berit, who engaged caregivers in a weeklong conversation on CaregivingNOW
- Platform to host the caregiving network
- CaregivingNOW Volunteer Community Manager
- Facebook advertisements

Lessons learned

Early lessons that formed the basis of CaregivingNOW include the following:
Caregivers are savvy members of online communities.

1. According to the Pew Research Center: "when all other demographic factors are controlled, being a caregiver in and of itself is independently associated with someone's likelihood to use the internet – fully 79% of caregivers have access to the internet."

2. Caregivers need support 24/7 – not just during regular business hours.

3. Caregivers want a secure community with logins and passwords, and an email digest of members.

4. Online communities can provide a space for conversation, asking and answering real and pressing questions. Participants learn from one another, and they don't need to attend support group scheduled at set times in a bricks & mortar locations.

5. Peer support is an invaluable resource for caregivers.

6. Often caregivers receive the most practical, useful and honest advice from others who have experience as caregivers.

Other lessons learned include the following:

1. There is some dissonance between partner expectations of "success" and caregiver needs.

2. Technology and tools can be barriers. The first platform required multiple logins. Moving the group to a secure, closed group on Facebook, with which caregivers were familiar, helped to increase membership.

3. Building online communities takes time.

4. Providing an online support network is a tool to offer proactive caregiver engagement,

5. Limited resources and capacity have an impact on recruitment and building vibrancy.

6. Existing uses of social media do not necessarily promote vulnerability. A closed, secure group has allowed caregivers to participate in the group and learn from other caregivers without needing to actively share their personal experiences.

Social media

Description

A study by the Pew Research Center found that 88% of caregivers look online for health information. Wilder realized that it needed to engage caregivers online in order to be effective in its outreach. Working with a local integrated marketing firm, Wilder conducted a landscape review to create a multi-channel strategy and developed a complete online social media toolkit to share with partners. Guiding the development of all platforms is the goal of providing emotional support for caregivers online.

Components of the strategy include:

Blog: Housed within Wilder's Caregiving Resource Center and featuring the stories, frustrations, and triumphs of caregivers.
http://www.wilder.org/Blog/Lists/Categories/Category.aspx?CategoryId=5&Name=Caregiving

Facebook: Located on the Wilder Caregiver Community's Facebook page, providing a supportive and emotional outlet, and featuring inspiring and relatable stories for caregivers seeking affirmation that they are not alone in their caregiving journeys.
https://www.facebook.com/WilderCaregiverCommunity/

Twitter: Created a Wilder Caregivers Twitter account that engages with targeted influencer networks by providing frequent updates, news, and resources.
https://twitter.com/wildercaregiver

Measurement techniques were implemented to gauge the degree to which posts connected with audiences, were shared with others' networks, and received approval from followers, using the following metrics:

- Conversation Rate: # of comments (or replies) per post to determine connection with the intended audience
- Amplification Rate: # of Retweets per Tweet
  # of shares per post
- Applause Rate: # of favorite clicks per post
  # of "likes" per post

Staff created a social media toolkit that contains:

- Wilder Blog Guide
- Blog Schedule
- Twitter Editorial Calendar
- Facebook Editorial Calendar
- Social Media Dashboard
- Editorial Calendar

Complete information can be found at:

http://www.wilder.org/Programs-Services/caregiving-resource-center/Pages/Social-Media-Toolkit.aspx

http://www.wilder.org/Programs-Services/caregiving-resource-center/Documents/Social_Media_Presentation.pdf

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  # of "likes" per post

Blog posts

Outputs

- 28 blogs posted in 39 months (10/12 to 12/15)
- 22 blogs from Wilder staff, interns and volunteers
- 6 blogs from guest bloggers

Resources

Resources required for social media initiatives include:

- Internet, computer or smart phone
- Tech-savvy person
- Toolkit (as mentioned above)

Lessons learned:

1. Engaging interns and volunteers strengthens the program.
2. Routine team brainstorming sessions are crucial for generating ideas, and maintaining an adequate supply of blogs.
3. Adhering to a blog schedule and reminding bloggers of deadlines is important.
4. Guest bloggers can be helpful in generating more contributions but must be monitored closely to assess alignment with Wilder's mission and values.
5. Blogs can be shared on other social media platforms such as Facebook and Twitter.
6. Hyperlinks to other websites and make the blogs easily readable.

Facebook

Outputs

- 831 page likes
- 1629 posts in 1636 days
- A paid boost ad generated 9049 impressions (displayed posts from the Facebook page), but did not yield any referrals.
- The number of fans (page "likes") online peaks at around 9:00 pm, with a steady and gradual increase from 3:00 pm to 9:00 pm.
- Most fans are women (86%) and are aged 45 to 64 years (50%).
- Nearly half of the fans are in the seven- county metro area (48%).

Resources

Resources required for social media initiatives include:

- Internet, computer or smart phone
- Tech-savvy person
- Toolkit (as mentioned above)

Lessons learned

1. Including pictures or videos generates more engagement than just status updates.
2. Scheduling posts on the weekends generates more engagement.
3. Determining when most fans are online and scheduling posts for those times may help reach more consumers.
4. Some trial and error with topics and formats may be necessary to determine what interests the community.
5. A variety of posts works best—external links, highlighting program, inspiring quotations and images, self-promotion, and interesting links.
6. Paid ads to boost a post do not necessarily generate more consumer activity.
7. Paid ads reach many people and can generate comments that will contribute ideas for responses or interventions.

Twitter

Outputs

- 1811 Tweets
- 1059 followers
- Used Hootsuite[2] to schedule 2 to 3 posts per day

Resources

Resources required for social media initiatives include:

- Internet, computer or smart phone
- Tech-savvy person
- Toolkit (as mentioned above)

Lessons learned:

1. It is helpful to develop commonly used hashtags in order to reach more followers, e.g. #caregiving, #caregiver, #dementia, and #alzheimers.
2. Engaging in pre-scheduled "tweet chats" can allow your voice to be present for specific topics.
3. Use the Twitter handles of other users to call them out can result in increased engagement when they become a new follower or Retweet.
4. Live tweeting at large events and conferences can promote your presence: Develop your own hashtag when hosting an event.
    - Be aware of the appearance of spending too much time on your phone.
    - Make sure you have a strong wireless connection so that you can successfully post.

[2] Hootsuite is a platform that allows multiple social media accounts to be managed from one place and for posts to be pre-scheduled.

Appendix

Campaign Poster

Chronic Disease Self-Management Program 2012

Chronic Disease Self-Management Program 2013

Chronic Disease Self-Management Program 2015

Caregiver Café

Peer mentoring

Community Capacity, Faith Community Learning Collaborative

National Night Out

CaregivingNOW

Campaign Poster

CAPACITY TO CARE

Improving the Systems of Support for Family and Friend Caregivers

AMHERST H WILDER FOUNDATION
Here for good.

Since July 2013 Wilder has improved the system of support for caregivers by:

- — Increasing the type and supply of caregiver services
- — Increasing public awareness of caregiving and support services
- — Increasing the capacity of informal networks to support caregivers as well as those individuals who may not have a family or friend caregiver

FOR MORE INFORMATION

Wilder Caregiver Services:
www.wilder.org/caregiving
651-280-CARE

Funding provided by a State of Minnesota CS/SD Grant, the Greater Twin Cities United Way, Older American Act funds, and private foundations

COLLECTIVE IMPACT THROUGH INNOVATION AND DISCOVERY:

AWARENESS AND CAREGIVER ENGAGEMENT

Two statewide caregiver awareness campaigns reaching 23 markets across Minnesota
—Fall 2013 and Winter 2014-2015
—170 Million impressions: online, print ads, and outdoor media
—Call to Action: Get Support & Resources for Caregiving at www.caregivinglink.org – Phone access via Senior Linkage Line; online support via MinnesotaHelp.Info and CaregivingNCW online community; plus downloadable Caregiver Resource Guide
—Dissemination of over 150 toolkits, including DVD version with Spanish translation

Mobile outreach: Staff and volunteers focused on engaging caregivers where they naturally gather in community settings
—Engaged 205 new caregivers through 120 Mobile Outreach events
—Quarterly proactive follow up with 1170 caregivers

Systems change - Partnered with clinics and agencies serving older adults to identify caregivers and gain consent for Wilder staff to contact caregiver
—Engaged 83 new caregivers through innovative fax referral programs with Lyngblomsten, 12 Entira Clinics, and 3 Optage House Calls Clinics

170 million media impressions
15 referring clinics

COMMUNITY CAPACITY BUILDING

Faith Community Learning Collaborative
—75 faith communities gathered to learn ways to build their capacity to identify and support caregivers
—Over 20 faith communities initiated new caregiver support groups, educational opportunities, sermons, etc.

LGBTQ Support Group
— Engaged Lesbian, Gay, Bisexual, Transgender and Queer community members to co-design a model of support for LGBTQ caregivers
— Launched Minnesota's only LGBTQ Caregiver Support Group in March 2015

National Night Out 2013 & 2014
— Recruited and trained 20 volunteers who reached over 800 neighbors with information about support for older adult and caregivers

75 faith communities
800 neighbors reached
Minnesota's only LGBTQ support group

INNOVATIVE PROGRAMS

Caregiver Café – support for caregivers through guided table talk facilitated by social workers, in a café-like environment
—Café incorporated into Living Well early memory loss dyad program; supporting care partners and building community.
—Opportunity for personal introspection topics ranging from changes in holidays, asking for help, and understanding transition points
—Cafes allow space for caregivers to begin future planning and problem solving; talking with others in similar situations.

***P.S. I Understand* – former caregivers matched with current caregivers for monthly phone based peer support**
—7 volunteers trained and matched with 9 caregivers
—Empathetic support especially suited for isolated caregivers
—Quarterly volunteer gathering; to learn, share and support one another

Caring for Someone with Chronic Conditions Pilot – opportunity for caregivers to come together, discuss and practice a variety of health and wellness skills for their own self-care
—Offered 7 evidence-based series; six cancelled despite varied marketing and scheduling strategies, due to low enrollment

NEW peer support program
7 volunteers trained and matched with 9 caregivers

SOCIAL MEDIA CHANNELS

National exposure and influence through Twitter; sharing innovative ideas and pertinent caregiving content
—Audience primarily other providers, organizations
—@WilderCaregiver engaged 847 followers through 1369 tweets

Wilder Caregiving Facebook Community engaged 393 caregivers
—Keep caregivers connected to upcoming classes
—Sharing resources, information, tips, other "feel good content"
—Audience primarily caregivers

Caregiving blogs: Monthly blogs giving voice to caregivers, and caregiving influencers; providing encouragement and sharing information.

CaregivingNOW: Network on the Web offering caregivers a platform for discussion 24/7

WilderCaregiverCommunity
CaregivingNow

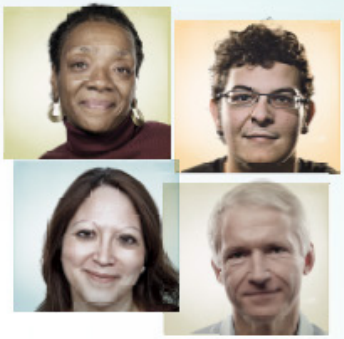
@WilderCaregiver

847 followers
393 caregivers

CAPACITY TO CARE

Improving the Systems of Support for Family and Friend Caregivers

Family and friend caregivers form the backbone our community's long-term care system. In Minnesota, 92% of long-term care is provided by family and friend caregivers, and every one percent decline in family caregiving costs the state $30 million dollars annually.



The challenges facing caregivers combined with the impending "age wave" of older adults who will need support demands that we create new, cost-effective solutions that successfully engage and support caregivers before they are in crisis.

Wilder's goal is to improve the system of support for caregivers by achieving the following objectives:

OBJECTIVE 1

Increase the type and supply of caregiver services

1. Chronic Disease Self-Management Program
2. Caregiver Café
3. Caregiver Peer Support Program

OBJECTIVE 2

Increase public awareness of caregiving and support services

1. Public awareness campaign
2. Outreach events
3. Connections and referrals with healthcare
4. Proactive follow-up
5. Social media

OBJECTIVE 3

Increase the capacity of informal networks to support caregivers as well as those individuals who may not have a family or friend caregiver

1. Faith Communities
2. Cultural Communities
3. Online Communities
4. Neighborhood Communities

Funding provided by a State of Minnesota CS/SD Grant, the Greater Twin Cities United Way, and private foundations.

IMPROVING THE SYSTEMS OF SUPPORT FOR FAMILY AND FRIEND CAREGIVERS

FOR MORE INFORMATION

Wilder Caregiver Services:
www.wilder.org/caregiving

Join the CaregivingNOW community:
www.unitedfrontmn.org/new-account

Wilder Online Caregiver Community:
facebook.com/WilderCaregiverCommunity
Wilder Caregiver Services
twitter.com/WilderCaregiver

Chronic Disease Self-Management Program 2012

Do you or someone you care for have diabetes, arthritis, chronic pain, heart disease, a cancer diagnosis or any other chronic health condition?

Then the Pathways to Better Health Program is for you!

During this six week course, get the skills, information and motivation to live a more healthy, active and enjoyable life!

You Can:

- Become more physically active
- Improve your diet
- Manage symptoms more effectively
- Cope better with difficult emotions
- Improve communications with family, friends and the health care providers
- Learn many other tools and techniques!

Caregivers are encouraged to attend this session!

Thursdays, September 13th, 20th, 27th, October 4th, 11th, and 18th

2:00-4:00PM (includes a break & a healthy snack)

Wilder Foundation-Community Services for Aging
650 Marshall Ave
St. Paul, MN 55104

You will be provided with a reference book:
Living a Healthy Life with Chronic Conditions

Fee is based on income and a sliding fee scale is used. No one is turned away for an inability to pay.
This program has been designed by the Stanford University Patient Education Research Center.

For more information or to register call:
Melissa Gibbs, Health and Wellness Coordinator, 651-280-2515

Sponsored by the Wilder Foundation, and funded under contract with the Metropolitan Area Agency on Aging Inc. as part of the Older Americans Act Program funding.

METROPOLITAN AREA AGENCY on AGING

AMHERST H. WILDER FOUNDATION
Here for good.

Chronic Disease Self-Management Program 2013

Do you or someone you care for have diabetes, arthritis, chronic pain, heart disease, a cancer diagnosis or any other chronic health condition?

Then the Living Well with Chronic Conditions Program may be for you!

This Chronic Disease Self-Management course is tailored to caregivers and provides a toolbox of management skills. Sessions run for 6 weeks.

Topics Discussed:

- Ways to manage symptoms more effectively
- Problem Solving
- Healthy Eating and Weight Management
- Better Breathing Techniques
- Managing Pain and Fatigue
- Future Planning
- Coping with difficult emotions
- Improve communications with family, friends and health care providers
- Many other tools and techniques!

We are hosting this workshop for Caregivers!

Tuesdays, March 19th, 26th, April 2nd, 9th, 16th and 23rd
1:30-3:30PM (includes a break & a healthy snack)

Wilder Foundation-Community Services for Aging
650 Marshall Ave
St. Paul, MN 55104

You will be provided with a reference book: *Living a Healthy Life with Chronic Conditions*
Sliding fee scale is used to determine fee for the program. No one will be turned away due to financial constraints.

For more information or to register call: Melissa, Program Coordinator, at 651-280-2515.
Respite Care is available for a fee through Wilder's Adult Day Health Program-please call Melissa for more information.

This program has been designed by the Stanford University Patient Education Research Center.
Sponsored by the Wilder Foundation and funded under contract with the Metropolitan Area Agency on Aging Inc. as part of the Older Americans Act Program funding. This workshop is also supported, in part, by a CS/SD grant from, Department of Human Services (DHS).

METROPOLITAN AREA AGENCY ON AGING

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Chronic Disease Self-Management Program 2015

Caring for Someone with Chronic Conditions

If you or someone you care for needs help managing an ongoing health condition, this program can help!

This six-week workshop is designed to give you the skills, information, and motivation to live a healthier, more active lifestyle while managing symptoms that most chronic conditions have in common, such as: fatigue, depression, stress/ anxiety, poor sleep, physical activity and pain. The program builds on your existing strengths and provides new tools to take control of your health in a welcoming and supportive environment!

Caregivers can manage these symptoms by:

- Learning tips and techniques for better breathing, communication, healthy eating, physical activity and dealing with difficult emotions
- Obtaining support in problem-solving and making decisions
- Setting manageable goals

Mark your calendars and please join us for one of our next workshops being held in 2015!

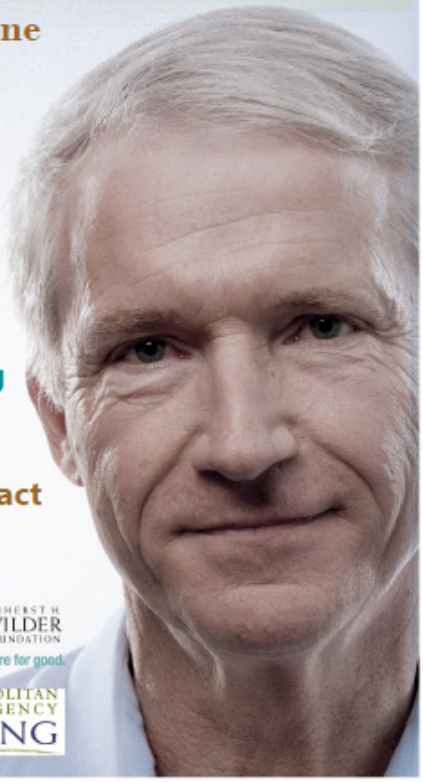
Wednesdays, January 7th—February 11th
10:00am-12:00pm

Or…

Saturdays, April 11th—May 16th
10:30am-12:30pm

Being held at:
Wilder Foundation-Community Center for Aging
650 Marshall Ave., St. Paul

To register or for more information, please contact Wilder Foundation's Caregiver Services at:
651-280– CARE (2273) or caregiving@wilder.org



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METROPOLITAN AREA AGENCY ON AGING

Caregiver Café

CAREGIVER CAFÉ— support for caregivers through guided table talk, in a café-like environment

Cafés offer caregivers the space for personal awareness and the opportunity to build connections with others in the group, gaining mutual support.

Holiday Traditions

OBJECTIVE:

- To find possible new traditions that may be able to be implemented now that caregiving.

FACILITATED DISCUSSION QUESTIONS:

- There is a difference between memory and traditions. How have they played out in our life?
- What is your favorite family holiday tradition?
- How will that tradition change this year?
- Lost traditions
- Setting new traditions
- What could be one change you could implement that would release some holiday stress?

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For more information email caregiving@wilder.org

Funded in part, by a CS/SD grant from the MN Department of Human Services

CAREGIVER CAFÉ— support for caregivers through guided table talk, in a café-like environment

Cafés offer caregivers the space for personal awareness and the opportunity to build connections with others in the group, gaining mutual support.

Asking for Help

OBJECTIVE:

- Learn why and how to ask for help
- Know the Warning Signs of Burnout

FACILITATED DISCUSSION QUESTIONS:

- Share an experience of asking for help with your caregiving
- When you ask others to help you in your caregiving role, what gets hard?
- Choose one person to ask for help between now and our next week's Gathering.

GROUP DISCUSSION:

- Family Meetings
- Online resources (Caring Bridge, Lotsa Helping Hands)

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For more information email caregiving@wilder.org

Funded in part, by a CS/SD grant from the MN Department of Human Services

CAREGIVER CAFÉ— support for caregivers through guided table talk, in a café-like environment

Cafés offer caregivers the space for personal awareness and the opportunity to build connections with others in the group, gaining mutual support.

Caregiving Vision

OBJECTIVE:

- To develop their caregiving vision for the person they are caring for and provide space to create their ideal vision of a support team for themselves.

FACILITATED DISCUSSION QUESTIONS:

- What is your vision for the kind of care the one you're caring for receives?
- What is your vision of the ideal caregiving support team for yourself?

GROUP DISCUSSION:

- Education Opportunities in the community

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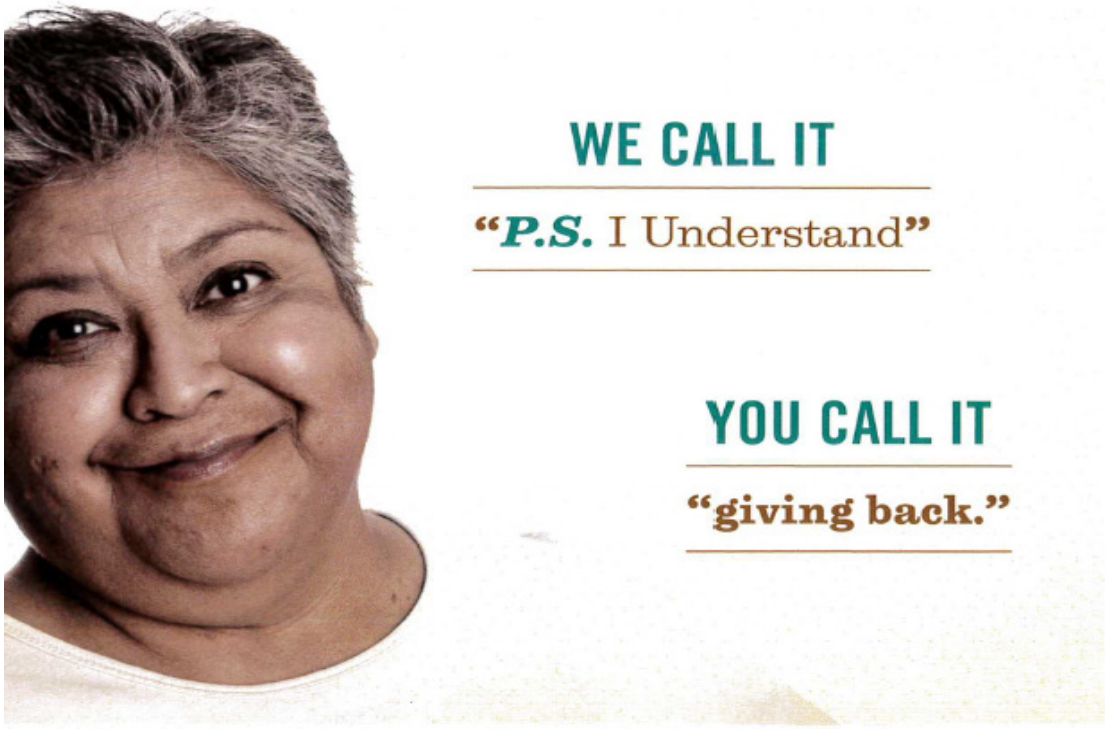
For more information email caregiving@wilder.org

Funded in part, by a CS/SD grant from the MN Department of Human Services

Peer mentoring



Peer Support Program:
CONNECTING CURRENT AND FORMER CAREGIVERS

AMHERST H WILDER FOUNDATION
Here for good.

You've been a caregiver: you understand.

Now you can support a current caregiver while joining a community of former caregivers.

Volunteers connect with a current caregiver by phone once or twice a month to check in and listen.

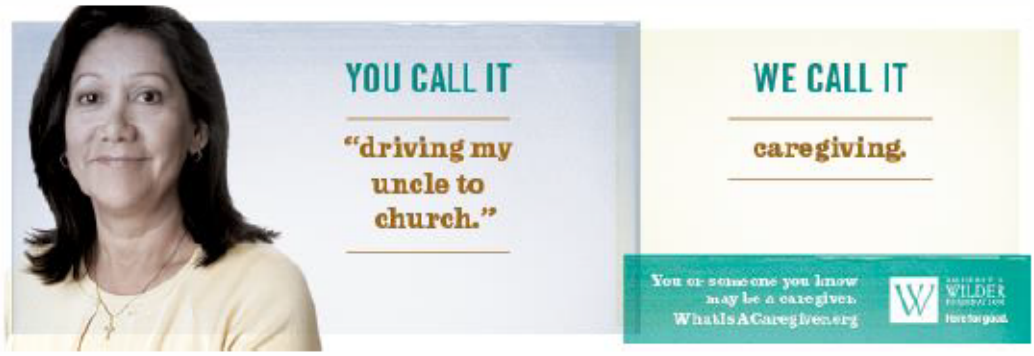
Volunteers can call from wherever they are!

To learn more, contact the Wilder Foundation at:

651-280-CARE (2273)
caregiving @wilder.org
www.wilder.org/Caregiving

Funded in part by a CS/SD grant from the MN Department of Human Services and offered through Eldercare Partners, funded by the Metropolitan Area Agency on Aging Inc. as part of the Older Americans Act Program funding.

Community Capacity, Faith Community Learning Collaborative



Faith Community Learning Collaborative:
Building Faith Communities' Capacity to Support Caregivers

What is the need?

More than 65 million people in the US are currently caregiving. Family members, friends, neighbors and faith community members provide over 90% of long-term care to elders in Minnesota, these caregivers are the backbone of our long-term care system.

In a 2012 study by the Amherst H. Wilder Foundation, Caregiving in Context a number of questions were asked about the role of faith communities in caregivers' networks of support. The study found that caregiver saw faith communities as a natural place to turn for support in their caregiving journey – even those who didn't belong to a faith community saw them as a trusted source of information. However, when caregivers reached out to faith communities only half received the support they were seeking.

Faith communities have a tremendous opportunity to serve as a key source of support in the caregiving journey – how do we build our capacity to meet the need when caregivers reach out?

What is the purpose of the Learning Collaborative?

In response to the findings in Caregiving in Context a group of faith communities in the Minneapolis – St. Paul metropolitan area began coming together on a quarterly basis to support one another in taking action to build capacity to support caregivers.

The Learning Collaborative is a space for lay people, faith community staff, parish nurses and clergy to gather. Together we are working to better understand what support caregivers need and want from faith communities. When we gather each quarter, we focus on:

- Sharing our individual efforts to provide caregiver support and the lessons we've learned
- Taking part in shared training, skill-building and learning opportunities
- Building our relationships and supporting one another to launch new caregiver support efforts

When does the Learning Collaborative meet?

The Faith Community Learning Collaborative meets on a quarterly basis at the Saint Paul Area Council of Churches at 1671 Summit Avenue, St. Paul MN 55104. Faith communities of all religious traditions are welcome and encouraged to attend. Below is our meeting schedule for 2015:

Friday, April 17th 2015 – 10am-Noon
Friday, August 28th 2015 – 10am-Noon
Friday, November 13th 2015 – 10am-Noon

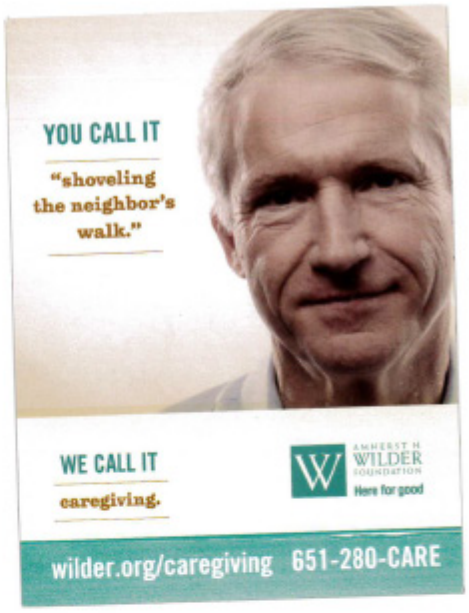
National Night Out

CAREGIVING
is happening in your neighborhood

1 in 6 adults in Minnesota are **caregiving** for an elder

Caregiving is a tough job.
Neighbors can help make it doable:

- pick up a few groceries
- rake the lawn
- visit an elderly neighbor



If you or your neighbors need additional resources, contact the Merriam Park Living at Home Program at 651-646-2301.

I was caring for my husband with Alzheimer's. It was a 24/7 job. My neighbor said if I left my garbage and recycling on the back step he would get it to the curb.

I was doing all of the yard work and heavy chores at my Grandmother's house across town. When I mentioned this to my neighbor he offered to mow my lawn each week for the rest of the summer.

My neighbor insisted on having my kids and I over for dinner once a month. She knew we were juggling parenting with caring for my aging parents.

My neighbor had often chatted with my mother when she was out gardening in our yard – they always connected over their love of mystery novels. As my mother's vision declined, the neighbor offered to come over and read out loud to her.

It is hard to ask for help.
Make the first move—help a caregiver in your life.

tpt

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Here for good.

CaregivingNOW