Dementia Capable Southern Arizona – Empowering Caregivers Implementation Manual

Dementia Capable
Southern Arizona
Anchored at PCOA

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Program Background and Rationale

Pima Council on Aging (PCOA), established in 1967, was one of the first Area Agencies on Aging (AAA) in the country. Founded before the establishment of the national network of AAAs under the Older Americans Act, PCOA provides expert services, advocacy, and unbiased information for older adults and their families.

PCOA initiated a comprehensive Community Needs Assessment of older adults in 1975 – an ongoing initiative that identifies evolving needs and informs goals, objectives, and activities for the organization. This feedback has led to innovative programs and partnerships including Dementia Capable Southern Arizona (DCSA), a community collaborative anchored at PCOA, that provides services to those living with Alzheimer's disease and related dementia (ADRD) as well as their caregivers.

This collaborative effort, launched with generous funding provided through the Administrative for Community Livings Alzheimer's Disease Programs Initiative, supports people with dementia and their caregivers through coordination and availability of resources, community education, and effective policy change. Anchored at PCOA, DCSA aims to increase our community's understanding of ADRD. Working alongside local governments, DCSA is creating a dementia-friendly communities plan to make Southern Arizona a better place for people living with dementia and those who care for them.

Southern Arizona is home to a rapidly aging population, most of whom express a desire to age in place. Supportive services are required to keep individuals in their residences and out of institutionalized settings, particularly when diagnosed with chronic, long-term conditions like ADRD.

According to the Alzheimer's Association[i] 11% of adults over the age of sixty-five, or 151,500 individuals are living with Alzheimer's disease (AD). Over 290,000 caregivers are providing 483 million hours of unpaid care on their behalf. Our workplaces are filled with these caregivers. More than 1 in 6 Americans working full or part time are also the caregivers of an elderly or disabled family member, friend, or relative. Employees attempting to balance the responsibilities of caregiving and work are more likely to experience chronic health issues (66.7%), stress and depression (27.7%). Care partners spend an average of 34 hours per week caregiving, miss an average of 12 hours per month of work, and 40% leave their positions altogether. Employees balancing work and caregiving cost U.S. businesses an estimated $33.6 billion per year in lost productivity.

It is important to note that there are additional challenges for caregivers of individuals living with ADRD:

- Isolation
- Constantly evolving needs of the care recipient
- Increasing severity of symptoms as the disease progresses
- Higher cost of care due to complicated needs
- Difficulty finding respite or in-home assistance
- Need for routines and consistency
- Scarcity of dementia friendly community services
- Lack of public understanding, awareness, and empathy

One of the goals of DCSA is to create a collaborative and cohesive system to support individuals with ADRD and their families, including those balancing work and caregiving. Working caregivers require dementia education, mental health support, peer interaction, and access to resources. *Empowering Caregivers* is a low barrier workplace program developed in response to these challenges. The goal is to increase the availability of support and the care partners' ability to safely provide assistance to their loved one through an accessible workplace initiative.

Impact

The COVID 19 pandemic elucidated many aspects of employees' psychological well-being and elevated the need for more comprehensive workplace support. Factors noted to strongly influence employee resilience include adaptability, work-family conflict, organizational support, and job stress. *Empowering Caregivers* was designed to fill a gap in employee needs.

Qualitative feedback from participants suggested positive impact from the program:

> *“The support of each other was a high value that developed.”*
>
> *“It's always good to be with others who are willing to share about their experiences, you realize you are not alone.”*
>
> *“Excellent experience! It was valuable to meet once a week with a sympathetic group and talk about subjects I wouldn't ponder on my own. Lots of great information.”*
>
> *“I got to know everybody and see how common being a caregiver is and really appreciated the support and friendship through the series.”*

Program Description

The *Empowering Caregivers* program was created to support working caregivers by offering education, resources, and specific training to arm employees with the necessary tools to be successful both in their job and personal journey as a care partner. Designed to meet caregivers where they are (onsite at their place of employment or virtually while at work), *Empowering Caregivers* leverages the fact that programs within the workplace are an enticing benefit shown to increase productivity, retention, and employee satisfaction. These programs build trust with the workforce and business offering flexibility to caregivers reap a return on investment of $1.70 - $4.45 for every dollar spent.

Empowering Caregivers includes employer leadership engagement, identification of caregivers within the company employee pool, management and staff orientation, series delivery and ongoing support. Forward thinking employers may elect to offer the series on an ongoing basis as part of a benefits package and new staff onboarding.

The program consists of eight weekly 90-minute classes that combine the 6-week evidence-based Powerful Tools for Caregivers[ii] with two additional modules. These supplementary sessions are tailored to the needs of participants and are conducted in the hands-on learning environment of Pima Council on Aging’s (PCOA) Caregiver Skills Lab. Envisioned as a lunch and learn, the mode of delivery is flexible and can be adapted at each employer's request.

Empowering Caregivers was influenced by the United Way of Southwestern Pennsylvania’s *United for Caregivers@Work*[iii] Program. The local version was created in partnership with the United Way of Tucson and Southern Arizona who served as a liaison to the Pennsylvania agency, assisted with recruitment of local employers for the program and co-created materials. All coursework is delivered by trained DCSA instructors.

Program Interventions and Trainings

DCSA utilized *Powerful Tools for Caregivers (PTC)* as the evidence-based intervention for the *Empowering Caregivers* program. PTC was developed over three years of pilot testing in Portland, OR and has been offered in communities since 1998. Six class sessions held once a week are led by certified, experienced Class Leaders. PTC was adjusted so that it could be delivered virtually or in person but is not available in a hybrid model.

Delivery of PTC requires interventionists to become licensed as a PTC Class Leader. A licensing course is available through PTC and encompasses a detailed, scripted curriculum that is built on "The Caregiver Helpbook." PTC is a train-the-facilitator program. Through the program Class Leaders are fully prepared to team-teach PTC and the curriculum is currently available in English, Spanish, French, and Korean. The class is delivered to caregivers either in person or virtually. Two co-leads are required to deliver each session in the PCT curriculum.

Program Recruitment

In partnership with the United Way of Tucson and Southern Arizona, DCSA created a list of agencies that both entities had previous connections and collaborations with. Two nonprofit organizations were approached to launch the workplace program and provide feedback. Ongoing plans include recruiting employers through the United Way of Tucson and Southern Arizona Workplace Campaign network and our local SHRM of Greater Tucson. In addition, an *Empowering Caregiver* flyer was created to aide in employer recruitment (Appendix A).

Once an employer is engaged, a second level of recruit is required to identify staff members who have an interest in caregiver support programming. A survey, ideally distributed via the Human Resources Department or staff supervisors, is conducted to determine caregivers within the company workforce.

Program Delivery

Once an organization is identified and leadership agrees to implement the *Empowering Caregivers* program, employers are provided the *Empowering Caregivers Guide for Companies* (Appendix B) to assist them in seamlessly implementing the series in their workplace. Program delivery encompasses 5 steps:

STEP 1: Conduct the Survey

- Review the sample surveys
- Schedule the surveys and reminders
- Meet with PCOA to discuss the results
- Schedule a 12-month follow-up survey

STEP 2: Announce the Program

- Send the intro emails
- Send out overview of 8-week series

STEP 3: Orient Employees

- Add it to your print/online materials for employees
- Send out FAQs to all staff

STEP 4: Host the Empowering Caregivers Series

- Schedule the 8-week series
- Promote events

STEP 5: Ongoing Support

- Provide additional trainings available by PCOA
- Customize the training based on feedback from the survey

Surveys are administered to all staff, allowing identification of working caregivers. In addition, content for communications, social media tool kits, newsletters, website posts and FAQs are provided to the employer to help promote the program and pinpoint staff who are willing to participate. While the series is ideal for a lunch and learn model, sessions can be scheduled in alignment with agency specific workflow and obligations of staff.

Content for *Empowering Caregivers* consists of an 8-part series covering the topics below. Required material includes the hard copy "Caregiver Helpbook" which is provided to participants.

- Class #1: Taking Care of You
- Class #2: Identifying and Reducing Personal Stress
- Class #3: Communicating Feelings, Needs, and Concerns
- Class #4: Communicating in Challenging Situations
- Class #5: Learning From Our Emotions
- Class #6: Mastering Caregiver Decisions
- Class #7: PCOA Overview of Services to Caregivers
- Class #8: Interactive Tour of the Caregiver Skills Lab at PCOA

Working caregivers have unique needs and every effort is made to reduce barriers to participation and to increase positive impact of the program This includes the following features:

- Meeting employees where they are, either in person or virtually.

- Providing a space for peer support and comradery.
- Utilizing an evidence-based intervention, Powerful Tools for Caregivers.
- Offering hands-on experience at the Pima Care at Home Caregiver Skills Lab.
- Extending opportunity to receive supplemental educational modules based on caregiver interests.
- Providing tools for caregiving (e.g., Healthy Brain Kits).

Program Outcomes

Assessment of *Empowering Caregivers* was provided by our third-party independent evaluator and addresses our objective to offer support and information for these working caregivers:

> *"Increase availability of support and caregivers' ability to safely care for their loved one through implementation of workplace initiatives."*

Description: Workshops were offered to teach working caregivers self-care skills, to better understand behaviors of individuals experiencing ADRD, and to provide information about resources and other supports. Workshops were designed as eight one and one-half hour sessions based on the model provided by evidence-based program Powerful Tools for Caregivers. Workshops were provided online to accommodate worksite and participant's schedules.

Outputs: 2-3 employers; 45 working caregivers across multiple employers; One 8-week session per quarter.

Outcomes: Improved caregiver quality of life and reduced caregiver burden.

Measures: The pre-post- surveys (Appendix C) were designed by the DCSA team and evaluator by identifying items on the CGQOL and the QOL-AD that were likely to be influenced by new information and resources. Specifically, four of the five "Time spent in caregiving" items from the CGQOL were used (excluded was "Were limited in the kind of activities you did") and scored on a five-point scale ranging from Some of the Time (1) to All of the Time (5). Also included was one item from the CGQOL burden scale ("How often did you worry that you might be unable to take care of your relative with dementia in the future?"). This item was scored so higher scores reflected more burden (also negative). Four items from the QOL-AD Scale ("Energy," "Mood," "Ability to do things for fun" and "Life as a whole") were also used and scored on a five-point scale ranging from Poor (1) to Excellent (5). These items were summed, and high scores reflected better quality of life. Finally, one item reflecting self-efficacy ("Do you feel you are able to meet your loved one's needs?") scored on a five-point scale was included and a high score was positive reflecting higher self-confidence.

Data collection methods: Data were collected before and after the series of sessions using a University of Arizona online collection portal. Participants were given a link to the website prior to and after training sessions and encouraged by the trainer to complete the survey.

Results: Because of the pandemic, the Empowering Caregivers program launch was delayed, and participation was negatively impacted. One complete series was completed involving two employers. There were eleven unique individuals in the data set but only five had matched pre-post data for the CGQOL and four had matched data for the QOL-AD. All were females and non-Hispanic white. Two cared for an individual with memory impairments and two cared for individuals with IDD/DDD.

QOL-AD

For the four items from the QOL-AD Scale, there were increases for scores for all and two were significantly improved:

"Mood" (t = 2.28, df = 4, p = .05)

"Ability to do things for fun" (t = 2.28, df = 4, p = .05)

Although the total score was also improved the result was not significant

(t = 1.67, df = 4, p = .08).

For the confidence item there was a significant decrease in confidence between pre and post:

"Do you feel you are able to meet your loved one's needs?"

(t = -2.45, df = 4, p = .03).

CGQOL Scale

For the four items from the CGQOL scale that measured time spent, there were significant differences for two. Scores for "putting your own needs aside to take care of your loved one" were significantly lower (more positive) after the sessions. Scores for "had difficulty performing at work or other activities" were significantly higher (more negative) after the sessions. There was no difference in the summed scores for the four items. There was no significant difference in pre-post scores for the one burden item from the CGQOL or the four items from the CGQOL scale that measured time spent, there were significant differences for two.

Scores for "Putting your own needs aside to take care of your loved one" were significantly lower (more positive) after the sessions

(t = -1.84, df = 5, p = .05).

Scores for "Had difficulty performing at work or other activities" were significantly higher (more negative) after the sessions

(r = 3.165, df = 4, p = .02)

There was no difference in the summed scores for the four items. There was no significant difference in pre-post scores for the one burden item from the CGQOL.

Conclusion: Qualitative comments were generally positive about the curriculum and the experience and there were some promising trends to explore further (e.g., increase in mood and decrease in putting aside own needs). There were also some concerning trends to be explored in the future (e.g., decrease in confidence). These findings must be interpreted with caution as the output targets were not met for either number of participants or number of offerings. No significant conclusions can be drawn from these data, given the tiny sample sizes – additional program series and feedback will be required to further elucidate benefit.

Challenges and Lessons Learned

Identifying Workplaces and Caregivers

The sheer number of individuals experiencing ADRD, and the number of working care partners makes it probable that there are many workers in need of support. Despite this likelihood and literature endorsing the effectiveness of workplace programming, the cost of working caregivers to employers, and care partners' stated need for education and resources, it was difficult to find agencies that would offer the program. Casting a significantly wide net will be necessary to find organizations inclined to participate. Our Pennsylvania partners noted that outreach to twenty organizations resulted in only five agencies being onboarded. For our local efforts, high-level leadership outreach (CEO to CEO) was required to make inroads. This was not attributed to lack of willingness or recognition of potential benefit, but instead to lack of time and capacity. In addition, every agency has unique workflows, processes, and policies. While the delivery *Empowering Caregivers* was designed with flexibility in mind, PTC has requirements for administration and implementation by employers and it is recommended to allow sufficient time for planning. Combining sessions with multiple agencies, while efficient, may not allow for enough organizational autonomy to be successful.

Program Length

Powerful Tools for Caregivers is 90-minutes per session and 6 weeks in duration and cannot be adapted due to its evidence-based nature. While supplementary modules were seen as beneficial, this extended the series an additional two weeks. This timeline was a barrier for some employers and participants.

Training Staff

PCOA had the benefit of an in-house staff member licensed in Powerful Tools for Caregivers. However, additional staff required training as Licensed Class Leaders to team-teach to groups of 8-15 caregivers. In addition, within a year after training completion, PTC Class Leaders must teach two caregiver class series to maintain licensure. These requirements may be a burden for some agencies.

Unanticipated Benefit

After the initial cohort completed the PTC series, the group continued to meet weekly via zoom. This space became a peer-to-peer support group and, while not part of the initial plan, was rated as highly advantageous for participants. Organizations hoping to implement a workplace caregiver support program might encourage ongoing employee resource groups.

Considerations for Replication

Program Flexibility

Offering *Empowering Caregivers* in a way that maximizes access for employees is critical. This will vary depending on specific agency needs and assets. Powerful Tools for Caregivers can be delivered in person or virtually, but not as a hybrid model. In addition, agencies and workers must dedicate a significant commitment of time. If in-person delivery is chosen, adequate private space must be available on site. While virtual programming is a feasible option, many participants feel a diminished sense of connection with peers. Individuals also require a degree of technological savvy to take part virtually.

Program Cost

Powerful Tools for Caregivers requires licensure for instructors which is $200 per person for training. Class Leader training is two full days plus travel time if attending in person, or five days of 3-hours sessions if attending virtually. In addition, the "Caregiver Helpbook" provided to participants costs $30 per copy. These expenses are ongoing and could be offered to employees for a fee to recoup costs.

Conclusion

Over forty million Americans serve as unpaid caregivers, mostly for parents and grandparents. Eleven million people provided unpaid care for those with ADRD, with a total cost of 360 billion dollars in 2024. While unpaid caregiving is nothing new, the need spans generations. Nearly one quarter of today's caregivers are from the Millennial generation[iv]. They are full and part time workers and are struggling with the costs and burden of balancing care for older loved ones, young children and job responsibilities. All indicators point to the need for support in the workplace for these individuals.

Due to many factors including the pandemic, the objective to "Increase availability of support and caregivers' ability to safely care for their loved one through implementation of workplace initiatives" was the most challenging program area to successfully plan and execute under this grant. Output targets were not met, making conclusions about the benefit of a workplace caregiver support program difficult to draw. Nevertheless, data from analogous programs like *United for Caregivers@Work*, anecdotal reports from partners, and qualitative comments from our participants lead us to believe additional initiatives of this kind will be fruitful in positively impacting our quickly growing population of older adults and their family care providers.

Appendices

A. Empowering Caregivers Program flyer
B. Empowering Caregivers Guide for Companies
C. Empowering Caregivers Pre- and Post-Series Survey

References

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[i] Alzheimer’s Association (2024). *2024 Arizona Alzheimer’s Statistics*. Alzheimer’s Impact Movement Report for Arizona

[ii] Home - Powerful Tools For Caregivers

[iii] United for Caregivers@Work - United Way of Southwestern Pennsylvania (uwswpa.org)

[iv] Dodd, Chris, et. al. (2019). *The Sandwich Generation's Financial Strain: How Caregivers Balance Family and Finances.* Bipartisan Policy Center.