CAREGIVER FRIENDLY COMMUNITIES ASSESSMENT

Best Practices: Caregiver Social & Emotional Support

Social and emotional supports provide needed outlets to share the struggles of caregiving with others who understand the challenges – these supports can be tremendously helpful in providing strength and support to help caregivers continue in their role. In a study of 246 caregivers 45% indicated that emotional support was one of the top caregiver needs (Black, 2013).

> "The demanding work of caregiving can put caregivers at risk of engaging in harmful behaviors toward their care recipients, particularly among caregivers of persons with cognitive impairments. Depressed caregivers are more likely to harm their spouses. Caregivers who are at risk of depression while caring for spouses with significant cognitive or physical impairments are more likely to engage in neglect or abusive behaviors, such as screaming and yelling, threatening to abandon or use physical force, withholding food, hitting, or handling roughly." Susan Reinhard, National Center for Biotechnology Information

The Caregiver Friendly Communities Assessment scores this section on two primary factors: group support and individual support. Below, you'll find the scoring factors along with recommended practices**.**

1. Group Support

Group support for caregivers offers multiple benefits, including improved emotional well-being, reduced stress, increased self-efficacy, a sense of feeling understood and validated, and improved problem solving as a caregiver. As with all domains within this Assessment, access to services was a guiding principle. Scoring for this element focused on: 1) availability of group support and flexibility of group connection options (including in-person, telephonic, and video conferencing); 2) illness-specific support, and 3) culturally relevant support.

o **Availability and Flexibility of Connection.** In the shadow of the 2020 COVID-19 pandemic, flexible connection options became critically important and also bridged a challenge many faced even before the pandemic - access to group support without

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leaving one's home. Online caregiver support through video conferencing support groups has been shown in multiple studies to result in caregivers being able to relate to each other's struggles, feeling understood, validating each other, and producing more effective problem solving and coping strategies. (Damianakis, 2018). ***Recommended Practice: ensure at least one caregiver group support program is in operation to serve residents of your community, at a minimum through video conference.***

Suggested programs:

- The online **iCare Stress Management Training Program** for family caregivers may be effective at significantly reducing caregiver stress levels and improving their information retention, as compared to more traditional training programs (Kajiyama, 2013). https://www.amazon.com/Stress-Management-Training-Dementia-Caregivers/dp/B00816NTLM

- The six-part video series "**CareAware: Help and Hope for Family Caregivers**" features interviews with local subject matter experts and real-life caregivers who provide insights and practical advice on how to take care of yourself while also caring for loved ones. Topics covered in the series include: the journey of caregiving; key legal documents and advance directives for end-of-life care; dealing with negative emotions; preventing caregiver burnout; physical, emotional and financial abuse; and available community resources. Based in Indiana, services are available free online: https://cicoa.org/services/caregiver-support/

o **Illness Specific Support.** While generalized caregiver support is helpful, caregivers have noted that they needed additional information and support around the specific condition that their loved one is facing and that connecting with others also coping with caring for someone with the same condition has proven very helpful. ***Recommended Practice: seek to offer at least 3 condition-specific group support options.*** Examples of illness-specific support are found in the General Resources section.

Suggested programs:

o The **New York University Caregiver Intervention** (NYUCI) was studied with a group of 228 caregivers of those living with dementia and found decreased depression and better coping with the care recipient's behavior in a four-month follow-up assessment point (Mittelman, 2014). https://ttdc.hcinteractive.com/content/program-overview

o **Best Practice Caregiving**, developed through a partnership between Benjamin Rose Institute on Aging and Family Caregiver Alliance, is a free online database of proven dementia programs for family caregivers. It offers a searchable,

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interactive, national database of vetted, effective programs that offer much-needed information and support. https://bpc.caregiver.org/

o **Culturally Relevant Support.** Many group support options fall short for people who identify with different cultures due to cultural norms related to how they care for loved ones (such as Chinese American, Arab American, or other communities), their level of safety in sharing private information in group support (such as LGBTQ community members), and their ability to effectively communicate with the group (such as those speaking a different primary language such as those who are deaf or do not speak English well). *Recommended Practice: identify the primary marginalized groups in your region and seek to offer at least 3 group-specific support options.* Examples of culturally relevant support are found in the General Resources section.

> "Caregivers who are also spouses of the care recipient tend to need more emotional support and respite care, while adult children of care recipients tend to need more informational support" (Peeters, 2010).

2. Individual Support

Individual support is another useful resource for caregivers. Offering counseling services online can be more accessible and effective for caregivers managing busy schedules and is particularly useful for regions that don't have this service available locally for in-person assistance (Augar, 2014; Cameron, 2008).

Ensuring there are a range of types of individual support available is important. Do those providing individual support cover specialities such as caregiving concerns, aging, chronic illness, dementia? Do you those providing individual support include helping caregivers navigate issues such as having difficult conversations, navigating family disputes, making end-of-life decisions, coping with driving cessation and dealing with potential caregiver abuse? *Recommended Practice: Identify at least three providers who collectively cover the specialty areas listed above.*

Recommended practices from research:

o In one study, caregivers recommended that having access to a 24 hour a day phone or online support would be helpful, providing more access to professional support groups, financial assistance and informational support (Gan, 2010).

Sample Programs:

o Westchester County Department of Senior Programs and Services developed the **Livable Communities Caregiver Coaching** program, which trains volunteer coaches to

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provide one-on-one telephonic to caregivers. The amount of time each coach devotes to a family caregiver varies depending on the needs and situation. https://seniorcitizens.westchestergov.com/

o Westchester County Department of Senior Programs and Services (DSPS) Caregiver Collaborative developed the **Livable Communities Care Circles of Westchester Program** to help caregivers effectively manage daily responsibilities. The program trains caregivers how to seek assistance from volunteers by creating Care Circles of individuals who help them accomplish such daily tasks as preparing meals, walking the dog or simply providing companionship. https://seniorcitizens.westchestergov.com/

o Caregiver Action Network's offers a free **Caregiver Help Desk**, staffed by caregiving experts, to help find the information needed to help navigate complex caregiving challenges. https://www.caregiveraction.org/

o **AARP Caregiving Support Line**. Connects you directly with an information specialist who can talk with you about services and support available in your community. 1-877-333-5585. En espanol: 1-888-971-2013. Mon-Fri, 7am-11pm EST.

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