



Involving Caregivers in the CHA Process

A caregiver extends beyond a doctor, nurse or therapist; a caregiver is anyone who regularly provides assistance with activities of daily living for someone who needs it. The person receiving care might be a sick spouse or partner, a child with a disability or an aging friend or relative.

The demanding nature of providing care places significant emotional and physical stress on caregivers, a reality that can lead to depression, anxiety, stress and burnout. For professional and family caregivers alike, balancing caregiving responsibilities with work, family, personal life and self-care poses a time-management challenge, while the financial strain of caregiving can be substantial, possibly affecting personal finances and career stability.

It is crucial for caregivers to receive emotional and practical support for them to effectively navigate such challenges. Understanding these challenges will help hospitals, health systems and community stakeholders more fully involve family caregivers in the CHA process.

Before You Begin

Communication is the key to meaningful engagement with caregivers. The caregiving experience can be one of fragmented relationships with multiple health care professionals, social service agencies, and family and friends who may or may not be involved.

It is important to remember that family caregivers may be caring for multiple people with varying needs, as well as caring for their own families, holding down a job, attending school and more.

Keep in Mind

Common challenges for family caregivers include financial stress, isolation, lack of resources and emotional burden:

Financial Stress

Access to professional, affordable and available in-home caregivers is a challenge for many, if not most families. Placement of a loved one in a residential care facility may not be financially feasible, regardless of insurance coverage or income levels. This is even the case when it is no longer safe to care for a family member in the home, or when someone's needs exceed what a family member can provide.

Many people end up paying out of pocket for care costs, adding financial hardship to an already stressful situation, and many end up taking on some or all of the caregiving responsibilities themselves.

Isolation

Many caregivers feel isolated due to a lack of support from family, friends or their communities. Their unique experience is difficult for others to understand, which can lead to further feelings of alienation.

Some may not even realize that they are family caregivers, while others may not identify as caregivers, a reality that effectively makes their role invisible to communities, their own families and even themselves.

Lack of Resources

Existing programming tends to focus on caregivers who provide care for older adults, while fewer support systems exist for families who care for children and teens who have health conditions that are rare, difficult to diagnose and complex to manage, such as rare genetic and chromosomal disorders, disruptive substance use disorders or mental illnesses.

Emotional Burden

The uncertainty of making difficult decisions and navigating health care or bureaucratic government systems further adds to the complexity of caregiving.

The emotional toll of witnessing a loved one's decline, coupled with the challenge of maintaining a balance between providing care for the individual and preserving their independence, contributes to the multifaceted nature of caregiving challenges.

As a result of these challenges, caregivers may struggle with sleep deprivation, poor nutrition and/or limited time for exercise. They may neglect their own medical needs as they focus on the immediate ongoing needs of those they care for.

9 CHA Toolkit Steps and How to Engage Caregivers



STEP 1

Map Development

As a starting point, speak with your team to map the caregiver-oriented services that already exist within your hospital, community and relevant area agencies. Discuss who will collect what data, what information will be used and how it will inform your ability to sustain your program. Your team also might want to consider the following questions:

1. Which organizational departments need caregiver-oriented services?
2. What are the existing caregiver service delivery barriers?
3. Which departments and personnel should be involved in the planning process?

Lastly, assess existing collaborations with any local organizations that touch family caregivers' lives. This includes partnerships with home health service agencies, caregiving agencies, skilled nursing facilities, food banks, services for people experiencing homelessness, local behavioral health clinics, hospices, and police, sheriff and fire departments.



STEP 2

Build Relationships

Family caregivers may be unable to leave the home or take a break from their role as caregiver to attend to their own needs. In these cases, services aimed at providing caregiver relief are beneficial.

Consider working with community partners who are engaged with the caregiver population, such as home health agencies, skilled nursing facilities, health systems and community-based organizations.

Give caregivers in your community the opportunity to provide insights. When caregivers recognize that their interests and needs are heard, they may be more likely to attend and become involved.

Keep in mind: A simple phone call is a time-efficient and effective way to connect with caregivers helping someone who cannot be left alone. It also relieves the caregiver of the need to keep track of additional appointments.



STEP 3

Develop Community Profile

Caregivers enter their roles in many ways and come from different geographic, cultural and financial backgrounds, bringing with them a broad range of experiences, assets and challenges.

- When working with caregivers who provide care for older adults and people with dementia, developmental disabilities, mental illnesses or substance use disorders, consider allowing them to act as the "experts," since they are most familiar with the patient.

- Remember, caregivers may experience feelings of resentment due to prior difficulties in the relationship, while others care for their loved ones out of a sense of duty or expectation. Some may enter the role hoping that relationships can be mended through provision of care, while others may relish the experience of being a caregiver, as the role gives them a sense of purpose and a mission in life.
- Although difficult, assessment of suicidality, harm to others or neglect should be part of ongoing services, particularly when the caregiver has a history of trauma or conflicted relationship with the patient.

It is important to consider the ways in which the caregivers assumed their role, as well as understanding why they are providing care.



STEP 4

Increase Equity with Data

Consider using tools such as [Patient Health Questionnaire-9](#), [General Anxiety Disorder-7](#), [Zarit Caregiver Burden Scale](#) and the [Connor-Davidson Resilience Scale](#) to gain insights into caregiver needs and help assess factors that directly track wellness. These tools are free to use and can be accessed in different languages. Connect with your family practice and behavioral health care team for more information.

Once programming is in place, data should be gathered at regular intervals to track improvement markers such as anxiety, depression and confidence levels, caregiver burden and the relationship with the family members' primary care providers.



STEP 5

Prioritize Needs and Assets

Caregiver programming should fall under the behavioral health services umbrella due to the mental health variables that are part of the dynamic for both family member and caregiver.

While caregivers should be involved in the design and planning of supportive programs, it is important to keep in mind that caregivers may not be able to fully participate in their own lives, let alone community activities, due to their obligation to the loved ones they care for.

Tools and programs intended to serve caregivers must have demonstrated knowledge and sensitivity to cultural factors, an ability to provide services in participants' native language, flexible outreach and program timing, and a command of diverse communication channels.



STEP 6

Document and Communicate Results

Relying strictly on electronic delivery may be a barrier for some individuals and groups, making it important to communicate with caregivers in a variety of formats.

Information should be provided in native languages to a particular regional area whenever possible.

Communicate with transparency, warmth, caring and compassion as caregivers may have difficulty communicating effectively with health care providers' offices, pharmacies, social service agencies and more.



STEP 7

Plan Equity Strategy

Continue to focus on the way staff training is conducted, enabling staff to have an adequate sense of equity, cultural knowledge and humility.

When possible, include those reflective of the caregiving population, as well as from the group being cared for. Prioritizing this can help ensure an understanding and respect of cultures and customs that relate to caregiving roles and responsibilities.



STEP 8

Develop Action Plan

Collaborate with caregivers who have the expertise and availability to support the implementation of an action plan. In addition, it is vital to collaborate with providers who specialize in serving this population. These two groups can leverage their connections and experiences to drive the work forward, while also making important contributions to implementation subcommittees.

The action plan should also involve connecting with other organizations serving caregivers, including local [Area Agency on Aging](#) branches, behavioral health centers and community-based organizations with missions to serve patient populations. It also may be beneficial to explore existing networks such as the American Hospital Association's [Hospital Community Collaborative](#) for online training and tools that can help provide a road map for working alongside these organizations toward a common goal.



STEP 9

Evaluate Progress

When identifying metrics to measure success, it is important to remember that caregiving is a nuanced and often emotional environment dealing with diverse demographic groups. Caregiver issues involve people of all ages caring for loved ones who may have physical or behavioral health needs or both, substance use disorders, developmental disabilities or dementia. When gathering data, aim to reflect this complexity.

Progress evaluation must include caregiver input, which can be collected in various ways, including an in-person home visit, on-site doctor visit, telehealth, through the mail, email or various forms of social media. Offering a stipend or other giveaway may encourage participation. Evaluations should be conducted by staff that understand the needs and issues of caregivers. The evaluators would ideally include other caregivers, caregiver mentors and those from the caregiver's cultural and ethnic group and language.

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