

# THE IMPORTANCE OF CAREGIVERS

## WHAT IS A CAREGIVER?

“A CAREGIVER provides regular care or assistance to a FRIEND or FAMILY MEMBER with a health problem or disability.” Most often the caregiver is unpaid but sometimes a paid professional helper or institutional employee. While the term “caregiver” is the word used in the U.S., be aware that the term “carer” is more commonly used elsewhere.

In the context of dementia and Alzheimer’s, the caregiver helps organize and manage daily tasks, as well as assist with personal care. As these diseases progress, the caregiver has to help with increasingly basic needs brought on by memory loss, time & place confusion, and inability to solve problems. The caregiver gradually becomes the “memory keeper” and “active do-er” of the couple.

In 2019 in the U.S., about 18.6 billion hours of unpaid caregiver time was exerted in support of those with dementia and Alzheimer’s. This roughly averages out to about a 20-hour workweek year-around.

## WHO ARE THE CAREGIVERS?

For all forms of dementia:

- Two thirds of caregivers are women.
- 60% are spouses or long-term partners.
- One third are daughters.
- 30% are over the age of 65.
- 25% are “sandwich generation” – generally an adult child caring for a parent while also having their own children at home.

For all forms of disabilities:

- 1 in 4 women are currently caregivers.
- Caregiving is a challenging commitment – over half of caregivers have provided care for over two years; nearly 1/3 provide care for 20+ hours per week.

The majority of caregivers are active adults living with the cared-for person. With the demands and concerns related to their caregiving role, they themselves often have higher levels of anxiety and an increased sense of isolation. Studies have shown the need for “respite” programs for caregivers – giving them “a break” from the many demands they shoulder.

## WHAT DOES THIS MEAN FOR BASEBALL REMINISCENCE PROGRAMS?

Include considerations for the caregiver in the development and delivery of baseball reminiscence programs. It's important to keep the caregiver engaged. They are key to getting the participant to the sessions and keeping them involved. This applies to online sessions as well, as the caregiver will likely need to help with scheduling and setup.

- Discuss with the sponsoring host (ex. local Alzheimer's Association chapter) if caregiver attendance should be a requirement for participant attendance. In general, this is good policy, although exceptions might be made for early stage/high functioning participants.
- Recruit women volunteers. As the majority of caregivers are women, they likely will feel more comfortable engaging with, and even confiding in, other women. The opportunity to socialize will provide some respite as well.
- Be aware of the "Sundowning Effect" - a symptom of dementia and Alzheimer's also called "late-day confusion". The participant may exhibit increased levels of confusion and agitation as the day goes on. As these symptoms are usually less pronounced earlier in the day, it's best to schedule reminiscence programs for late morning-lunchtime. If lunch can be included, that provides additional respite for the caregiver.
- Many caregivers may not be baseball fans. Keep their interests in mind when developing the program agenda. Other reminiscence topics that are effective and complementary to baseball might include: music/singing/dancing, cinema/movies, period TV shows, cultural/lifestyle topics, etc. Ask the caregivers about this and experiment to find out what might appeal to those in your group.
- Keep in mind the caregiver's role as the memory-keeper for the couple. Be attuned to their prompting the participant to reminiscence about a pertinent memory. Allow time for prompting and response. Consider sending out agenda topics (along with potential prompting questions) to caregivers in advance of sessions, so they're prepared to help their partner participate.

This document was written by Linda Ann Cely, a retired R.N. and baseball reminiscence volunteer. Sources used include documentation and research from The World Health Organization (WHO), the National Institute on Aging within the National Institute for Health (NIA/NIH), the national Alzheimer's Association, and the Center for Disease Control.