

# CGP CONFERENCE



## Stewarding Donors with Dementia

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NATIONAL ASSOCIATION of  
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### **Author Note**

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## **Stewarding Donors with Dementia**

Dementia is a group of symptoms characterized by memory loss and reduced cognitive function that can have a devastating impact on individuals, no matter the person's socio-economic background (Alzheimer's Association, 2017; ASHA, 2017). The most common cause of dementia, Alzheimer's disease, is progressive, irreversible, has no cure and few treatment options (Alzheimer's Association, 2017). Dementia affects more than 5.5 million people in the US, including about ten percent of individuals aged 65 or older. However, the cognitive decline associated with dementia may begin a decade before diagnosis and early onset dementias may affect individuals well before the age of 65 (Alzheimer's Association, 2017; ASHA, 2017; NIH & NIA, 2016).

### **What is Dementia?**

Dementia is not a "disease" that is diagnosed by an x-ray or a blood test (Alzheimer's Association, 2017). Dementia is a term that is used to label a condition characterized by a collection of symptoms. These symptoms include problems involving memory, attention, language, communication, planning, judgment, decision-making, problem solving, sensory systems, and more (Alzheimer's Association, 2017; ASHA, 2017). Not all persons with a diagnosis of dementia will have all of these symptoms, but all will have some of them.

By contrast, Alzheimer's is a disease; it is a pathology that attacks the brain (Alzheimer's Association, 2017). Not everybody who has Alzheimer's has dementia and not everybody who has dementia has Alzheimer's disease. However, Alzheimer's disease accounts for somewhere between 50% to 80% of dementia diagnoses, making it the most common cause of dementia (Alzheimer's Association, 2017). Other causes for dementia include Pick's disease, Parkinson's

disease, AIDS, vascular problems, and metabolic problems (Alzheimer's Association, 2017; ASHA, 2017; Bayles & Tomoeda, 2013). Generally, the symptoms involved in dementia vary depending on the cause of the dementia. But it is important to know that dementia and Alzheimer's are not the same thing, so professionals should not assume that people who have dementia have Alzheimer's or use the terms interchangeably.

As mentioned, over 5 million Americans have dementia. One in every 10 people who are 65 years of age or older have dementia, and this percentage increases with age. About 50% of all people 85 or older have dementia (Alzheimer's Association, 2017; Lubinski, 2006). The number of Americans with dementia is expected to double in the next 30 years (ASHA, 2017). This may be due to improvements in physical medicine, longer lifespans in general, and an aging baby-boomer population. These numbers add up making persons with dementia among the fastest growing clinical populations for speech-language pathologists, the professionals who diagnose and treat communication disorders (Bayles & Tomoeda, 2013). This same population, those who are 65 years of age or older, are also a population of donors with whom many professional fundraisers routinely interact. In fact, a recent pilot survey project found that most fundraisers reported that half of their major gift donors were 65 years of age or older (Cyr, Collins, & Hyppa-Martin, 2015). Consequently, for some fundraisers, the population prone to higher rates of dementia is also frequently their donor population.

### **Dementia and Professional Fundraisers**

Professional fundraisers adhere to strict ethical standards and should never engage in soliciting from persons with dementia. However, some professional fundraisers may find themselves in a position where they need to continue to steward a respectful, professional

relationship with a donor who is experiencing memory loss, while also working with the donor's appointed representatives. At the same time, individuals with dementia should be respected and socially included—not isolated. Consequently, it would also be problematic, and inconsistent with donor-centered methodology, if professional fundraisers ended relationships with individuals who have dementia in favor of only interacting with the individuals who now represent the donor's financial interests. Professional fundraisers need to have the ability to continue to steward respectful, inclusive relationships with this population. As such, professional fundraisers need to know what to do when encountering donors who exhibit signs of dementia, how to recognize the signs of dementia, and how to navigate relationships with donors who experience this condition.

This paper, and the corresponding presentation, will explore findings from a survey of professional fundraisers that examined fundraisers' understanding of dementia, their ability to recognize its signs, and their familiarity with communication strategies that are useful when interacting with individuals with dementia (Cyr, Collins, & Hyppa-Martin, 2015; Habben, Hyppa-Martin, Mizuko, & Collins, 2014). Implications of the findings from their survey study will be reviewed with the goal of helping professional fundraisers ethically steward positive relationship with donors who experience dementia.

The authors' interest in this topic is motivated by personal experience. Both Dr. Jolene Hyppa Martin and Rob Hofmann, have family members who had or are currently living with dementia. However, it was a specific donor engagement experienced by Rob Hofmann that led to his motivation for investigating what can be done to steward donors who have dementia.

**Rob's story: A visit with Mr. and Mrs. Smith.** It was a very cold winter day when my new dean and I had our meeting with long time university donors Don and Carol Smith (pseudonyms). This was the first time my new dean had the opportunity to meet with these two very generous patrons of the arts, with whom I'd had a long relationship. The Smiths were often assisted by a care partner who supported them in many ways such as driving them around the community. I made arrangements with them and their care partner to meet at Don and Carol's favorite Mexican restaurant for lunch. Our objective for this meeting was to introduce them to the new dean and to provide updates on programs within our school. Unfortunately, the visit did not go the way I had anticipated.

I had been aware of memory issues my donors had been having, but I was not prepared for what transpired during our visit. Don Smith was well into his 80s and had been a very conversant fellow in the past, always ready with a story and a joke. But on this occasion Don was very quiet. His wife Carol, also in her 80s, was her usual warm and friendly self but looked much more tired than the last time we visited.

Our server took our initial beverage orders and left us to peruse the extensive menu. My first indication that something was amiss occurred when Don stated he didn't recall what he liked to eat. Carol then pointed to a combo meal that she stated was his favorite. He didn't seem to remember the selection, but agreed to it. Their care partner then suggested a soup for Carol.

When I shared an update about my pet dog, who was friendly with Carol and Don's dog, Don became conversant and related a story about growing up in the depression with a family dog named "Fella" and how funny it was when he would call out "Fella, Fella!" and people in the vicinity turn their heads thinking he was addressing them. We all laughed. However, a strange

thing occurred shortly after Don shared this story; shortly after he finished the story, he told the story for a second time, almost verbatim. An uncomfortable silence of a few moments followed until I changed the subject to a recent concert event in our famous music hall. Following this, Don could not recall attending such an event, nor did he recall the music hall. After that, Don remained very quiet for the rest of our visit. Meanwhile, Carol was having great difficulty swallowing her soup. The care partner escorted Carol to the ladies' room, leaving my dean and I with Don, who was silent, for more than ten minutes. Carol and her care partner returned, but the incident was not addressed. We completed our meal but Don ate very little, Carol did not finish her soup, and everyone seemed uncomfortable for the duration. Finally, in our final minutes together, I tried to share updates about projects that had been important to the Smiths in the past, and had some materials to share, but my donors did not seem engaged. When the visit was over and my dean and I were on our way back to campus, I explained that this was the most challenging donor visit I had ever experienced – assuring my dean that it was not a typical donor call.

I reflected on my visit with the Smiths for days and wished I had known what to do in that situation. My initial research found little to no policies or guidelines helpful for professional fundraisers to navigate this issue. I found this troubling due to the pervasiveness of dementia. To address this lack of information I sought the expertise of Jolene Hyppa Martin and a graduate student research team to facilitate a survey among a small population of professional fundraisers to examine (a) whether fundraisers want or need to steward relationships with people with dementia, (b) whether they feel prepared to do so, and, (c) if not, to identify the types of training that these professional fundraisers may find beneficial. With my consultation, a survey was

developed and piloted (Cyr, Collins, & Hyppa-Martin, 2015; Habben, Hyppa-Martin, Mizuko, & Collins, 2014).

### **Survey Results**

During the development and pilot process, a total of 42 professional fundraisers responded to the survey, though not all respondents answered every question. Consequently, the findings must be interpreted with caution due to the small sample size and limited geographic region in which respondents were employed (Indiana, Michigan, Minnesota, Ohio, or Wisconsin).

The professional fundraisers who responded to the survey represented a highly educated group of individuals. Ninety-one percent were college graduates, 55% held graduate degrees, and 33% had specialized certifications. They also tended to be quite experienced in that nearly half had been professional fundraisers for 11 to 20 years. Most respondents (93%) were fundraisers in higher education.

With respect to the research questions, the following data was revealed by the professional fundraisers' responses:

- 52% indicated that more than half of their major gift donors were over the age of 65 years.
- 89% reported that they worked with a donor that they knew or suspected had dementia.
- 36% encountered at least three major gift donors who had dementia.
- A majority of professional fundraisers stated they felt uncomfortable managing relationships with donors who had dementia, and indicated that they lacked the skills to communicate effectively with individuals who have dementia.



- 91% indicated they would benefit from additional training designed to help them maintain respectful and effective relationships with current or past donors with dementia.
- 70% indicated they would elect to complete training about how to communicate more effectively with persons with dementia if it was offered, and about 30% had some interest in the training, with one respondent indicating s/he would not complete training on this topic.
- Preferred formats for this training about this topic were varied and included interest in face-to-face workshops, pre-recorded online webinars, and written materials.

Consequently, the results of this pilot study suggested that professional fundraisers routinely work with a population whose age places them at risk for dementia, and also suggested that it may be relatively common for professional fundraisers to encounter people with dementia in their work. Training tailored for professional fundraisers on how to more effectively communicate when stewarding relationships with persons with dementia is needed, given the frequency with which fundraisers reported discomfort with and lack of skills to interact with persons with dementia. This circumstance places speech-language pathologists, professionals who have expertise in the communication disorders related to dementia, in a special position to collaborate with professional fundraisers to address this need.

### **Strategies for More Effective Communication**

As an initial step to provide professional fundraisers with tools to navigate meetings with donors who have dementia, we suggest 10 simple communication strategies, or “tips,” that are based on several sources on this topic to which the reader is referred for more detail (e.g., ASHA, 2017; Bayles & Tomoeda, 2013; Jootun & McGhee, 2011; Lubinski, 2006; Ripich, Wykle, &

Niles, 1995). The first five strategies help to prevent a communication breakdown, while the last five help to repair a communication breakdown.

**Tip 1: Manage the environment.** Managing the environment means that one needs to take responsibility to proactively reduce background noise and other distractions, ensure adequate lighting, and face the person with dementia so they can see your “body language” and facial expressions. These are important cues that will help them process your message.

**Tip 2: Orient and introduce.** Orient and introduce means one needs to introduce oneself and others. Don’t assume that a person with dementia will remember your name or organization. Next, introduce the topic, then repeat key information to aid the individual with dementia in maintaining orientation to the conversation. For example, you might say, “Hi Bob, I’m Steve Jones from City College. I want to thank you for your support of the Collins Art Museum. The Collins Art Museum acquired this sculpture last month.”

**Tip 3: Reduce pronouns.** To understand a pronoun, you need to remember its referent. That taxes memory and attention. So, “Susan Long sends her regards. Susan is meeting with architects today. The architects are designing a new wing at the Collins Art Museum.” This is better than, “My partner sends her regards, she’s meeting with the architects who are designing a new wing at the museum.”

**Tip 4: Provide non-transient cues.** Our speech is transient. It is here for a moment, and then gone. To understand speech, you have to remember what was said long enough to process it. Non-transient cues can help person with dementia comprehend conversation more effectively, because these cues are more permanent. We all benefit from non-transient cues. For example, the PowerPoint you see during our presentation helps you remember our last key point. Non-

transient cues that can be very helpful in the previous examples can include our fundraiser wearing a name tag that lists his name and affiliation. Another helpful non-transient cue might be the latest brochure featuring a photo of the Collins Art Museum, as well as the recently acquired sculpture.

**Tip 5: Reminisce about the distant past.** Talking about the here-and-now is great, especially when there are non-transient cues, conversation pieces, and a context to support the discussion. But when you want to talk about the past, reminisce about the distant past. Generally, more recent memories are harder for people with dementia to recall, so when talking about the past, ask about growing up on the farm, not about last week's shopping trip. Avoid questions like, "What did you have for lunch today?" or "Have you had other visitors lately?" or "what did you buy when you were Black Friday shopping?" Instead, reminisce about the distant past, like this: "Bob, you grew up in the Mankato area right? I bet you have wonderful memories of Mankato...Did you enjoy fishing on the rivers in the Mankato area?"

**Tip 6: Validate the underlying feeling or intent.** Don't correct a person with dementia if they repeat themselves or say something that is not entirely correct. This can highlight their frustrations and shortcomings and cause embarrassment. Instead, think of the underlying intent of what they said and validate it, one may follow it up with a redirection into a productive conversation, too. For example, if the person with dementia says something that you know is not true, like saying, "I was at my son's house in Tampa this morning." You might say, "Your family has always been important to you. I bet your grand kids are growing fast! And how are Bob Jr. and Mary doing?"

**Tip 7: Help by providing a starter phrase.** We all occasionally “lose our train of thought” but it happens more often to a person with dementia. When it happens, give them a “boost” by casually and naturally rephrasing where they left off. For example, if Bob begins telling you about a visit to Vail and then stops, one might say, “Your visit to Vail...” then pause. Often this will “restart” the conversation.

**Tip 8: Ask choice questions.** “Would you like coffee or tea?” is better than “What would you like to drink?” because the open-ended question requires the listener to remember the words for possible drink options. The choice question, relies on recognition rather than recall.

**Tip 9: Keep your non-verbals positive.** A person with dementia receives a lot of important information from your facial expressions and body language, so don’t let any discomfort or tension show through. Stay relaxed, positive, and attentive in your facial expressions and body language, even if the conversation encounters a challenge or two. Also, don’t yell, just speak in a clear voice, at a normal pace and loudness. Slowing way down and talking much louder does not often help the exchange.

**Tip 10: Dignity and respect.** Even though your donor has dementia, it does not mean they want to be forgotten. It is still important that they feel valued, dignified, appreciated, respected, and included. It is important that they know that their wishes and well-laid plans are being honored and that they are still important, contributing members of society.

### **Using these Strategies in Practice**

Earlier, we shared Rob's challenging donor visit where faithful donor Don repeated a story about his dog, "Fella." Don's repeated story provides a perfect opportunity to apply tip #6 and validate Don's underlying feeling or intent. Instead of ignoring Don's second iteration of the same story about this dog, a response could have been, "Don, I can tell that you've always had a kind heart for dogs! I've always enjoyed your stories and jokes. Gosh, Fella is a funny name for a dog." This would help Don know that Rob heard his story, appreciated Don's love of pets, and would have avoided the awkward silence that followed when this happened during their meal at the Mexican restaurant.

When Don could not recall his recent visit to the concert hall, tip #2 to orient and introduce would have been helpful in setting up that discussion more effectively. For example, saying something like, "Say, Don, I enjoyed seeing you and Carol at the holiday concert in the Weber Music Hall in December." Here we also use tip #3 when we reduce pronouns by providing the full name of the attendees, event, and location. Additionally, this would be a perfect time for an effective communicator to produce a brochure of the concert hall with pictures to support Don's memory, thus using tip #4 to provide non-transient cues. Finally, a nice way to conclude this portion of the discussion may be to apply tip #8 and ask choice questions, like "What do you enjoy more, music concerts or live theater?"

You may also recall that a contributing challenge to Rob's visit with Don and Carol was Carol's choking episode and subsequent ten-minute absence. People with dementia happen to have a heightened risk for swallowing disorders (ASHA, 2017). An important thing to remember when planning visits with individuals who have dementia is to engage in one agenda item at a time. Trying to do two things at once (i.e., eat *and* talk) can be more challenging for a person

with dementia. As such, it may be best not to include food as part of some visits. If you do include food, plan time before or after eating to talk and share materials. Keep the conversation while eating friendly, but light and minimal. We all know that even the best-laid plans can encounter a few bumps. When and if that occurs, be mindful of tip #9 to keep your non-verbals positive, and remember that our goal is always to apply tip #10 and make our visits, and our stewarded relationships, ones that regard individuals who have dementia with dignity and respect.

### **Conclusion**

Professional fundraisers pursue their work with a donor-centric methodology. It is in the best interest of our profession that practitioners of donor-centered fundraising become better trained to recognize the signs of dementia and embrace communication strategies that promote stewarding this vulnerable population of donors.

With proper training, accompanied by industry leading standards, practices, and policies, we will be better equipped to serve our donors in sensitive and ethical ways, while also protecting the institutions we serve. The authors of this paper will continue to work toward furthering research in this area, as well as finding effective methods of applying existing research for the betterment of our professions. It is the hope of the authors that this exploration will result in policies that protect the vulnerable population we steward, while supporting respectful, inclusive relationships with donors who have dementia.

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