



Stewarding Donors with Dementia

By Lani McCollar, BWF Associate

Imagine one of your top-tier major donors whom you already have a 7-figure ask out to privately discloses to you over lunch that they knew they were having trouble with their memory, have seen multiple specialists, and were recently diagnosed with dementia. How do you proceed with this new information about your major donor? Dementia affects more than 5.5 million people in the U.S. This number is expected to double to approximately 16 million people in 30 years. This may be due in part to longer lifespans and/or improvements in physical medicine. Dementia affects about 10 percent of individuals aged 65 or older and in just 15 years, 78 million people will be 65 and older. Additionally, reported in 2017 by the Alzheimer's Association, approximately 50 percent of all people 85 or older have dementia. It is also important to note that cognitive decline associated with dementia may begin ten years before the diagnosis, and early onset dementia may

affect individuals well before the age of 65. According to an article published in the *Nonprofit Times* (Hyppa-Martin & Hofmann, April 2018), donors aged 60–79 comprised 47 percent of major donors, and those 80 years or older comprised 30 percent of top gift donors in 2016. The intersection between a growing population and donor demographic greater emphasizes why all nonprofit organizations must become better aware of the ways in which their reputation, legal standing, and financial infrastructure could be impacted now and into the future by this issue.

There is no question this rising concern should focus a spotlight on how organizations and their fundraising professionals will handle this delicate and expanding demographic of prospects and donors potentially affected by dementia and the way in which they communicate with and approach them. In a recent study conducted

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by researchers at the University of Minnesota Duluth, (Rufer, Olson & Hyppa-Martin 2018), 419 fundraising professionals across 45 states were surveyed on whether they had a need or desire to steward relationships with previous donors who now have dementia. The study found that 83 percent of fundraising professionals had worked with a donor with dementia, 67 percent reported lacking skills to effectively communicate with those donors, and 60 percent felt uncomfortable managing the relationship. Furthermore, that same study reported 94 percent affirming they would benefit from training to maintain respectful relationships with donors with dementia. It is clear from the initial study that dissemination of information about dementia and best practices for professional fundraisers on how to steward donors with dementia is greatly needed.

Before learning what to do and how to appropriately interact with donors who are either diagnosed with or suspected to have dementia,

it is important to first understand what dementia is and what it is not. Dementia is symptomatic (not a disease) and is defined by a collection of the following, but not necessarily all need to be present in its diagnosis: deficits in memory, language, attention, planning, communication, decision-making, problem-solving, sensory perceptions, and others. It can be caused by the diagnosable diseases of Alzheimer's, Parkinson's, AIDS, vascular problems, Pick's disease, and metabolic problems.

There has been some publicity in recent years on this important topic of stewarding donors with dementia for professional fundraisers and organizations, but not enough. A trailblazer on the topic, Robert P. Hofmann, MA, CFRE, senior development officer at the University of Minnesota Duluth School of Fine Arts, along with the dean of the school, had his first very uncomfortable donor encounter years ago when the donor, his wife, and their professional caregiver met for lunch. It went from bad to worse when everyone knew

the restaurant was the donor's favorite, yet he could not remember his preferred menu item that he always ordered. Later, the donor's wife started choking on her food and had to be assisted by the caregiver. (Swallowing difficulties are more common among individuals who have dementia.) After the unfortunate experience, Rob knew he could not be the only one who had experienced that type of donor visit and had to do something about it.

Moved by the experience, Rob has worked closely with Jolene Hyppa-Martin, Ph.D., CCC-SLP, assistant professor of Communication Sciences and Disorders at the University of Minnesota Duluth College of Education and Human Service Professions, to determine ways in which professional fundraisers can safely and effectively steward donors with dementia. Preventing communication breakdown and helping repair communication, if a breakdown does occur, are

equally important to think about when working with this special population. Their work together is showcased through these top 10 tips in how to best visit and communicate with donors with dementia.

It is particularly important to note that their work has been strictly focused on raising awareness of dementia, how former donors with dementia can be (and why they should be) stewarded, but never solicited.

Ensuring continued social engagement with the organization is important, but never, ever is soliciting appropriate.

Preventing Communication Breakdown

Tip 1: Manage the environment.

Managing the environment means that you need to take responsibility to proactively reduce background noise and other distractions, ensure adequate lighting, and directly face the person with dementia so they can see your "body language" and facial expressions well.

Tip 2: Orient and introduce.

First, introduce yourself 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. For example, you might say, "Hi Sarah, I'm John Smith from State College. I want to thank you for your support of State College. A new education program was started at State College last month."





Tip 3: Reduce pronouns.

To understand a pronoun, you need to remember its reference; that taxes memory and attention. So, “Susan Long sends her regards. Susan is meeting with architects today. The architects are designing a new student center at State College today,” is better than, “My partner sends her regards, she’s meeting with the architects who are designing the new student center at the college.”

Tip 4: Provide non-transient cues.

Our speech is transient. To understand speech, you have to remember what was said long enough to process it. Non-transient cues can help a person with dementia comprehend conversation more effectively. We all benefit from non-transient cues. Consider wearing a name tag that lists your name and affiliation. Visual brochures with photos are also very helpful.

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. When talking about the past, reminisce about the *distant* past. Avoid questions like, “What did you have for lunch today?” or “What have you been up to lately?” Instead consider, “What were your school days like?” Or, “What were the best parts about growing up on a farm?”

Repairing Communication Breakdown

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.

Instead, think of the underlying intent, validate it, and follow up with a redirection into a productive conversation. For example, if the person says something that you know is not true like, "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 William Jr. and Sally doing?"

Tip 7: Help by providing a starter phrase.

Losing our train of thought happens to everyone, but more often to a person with dementia. Help the conversation by casually and naturally rephrasing where they left off. For example, if Christina begins telling you about her visit to Vail and then stops, one might say, "Your visit to Vail..." then pause. Often this will help to restart the conversation.

Tip 8: Ask choice questions.

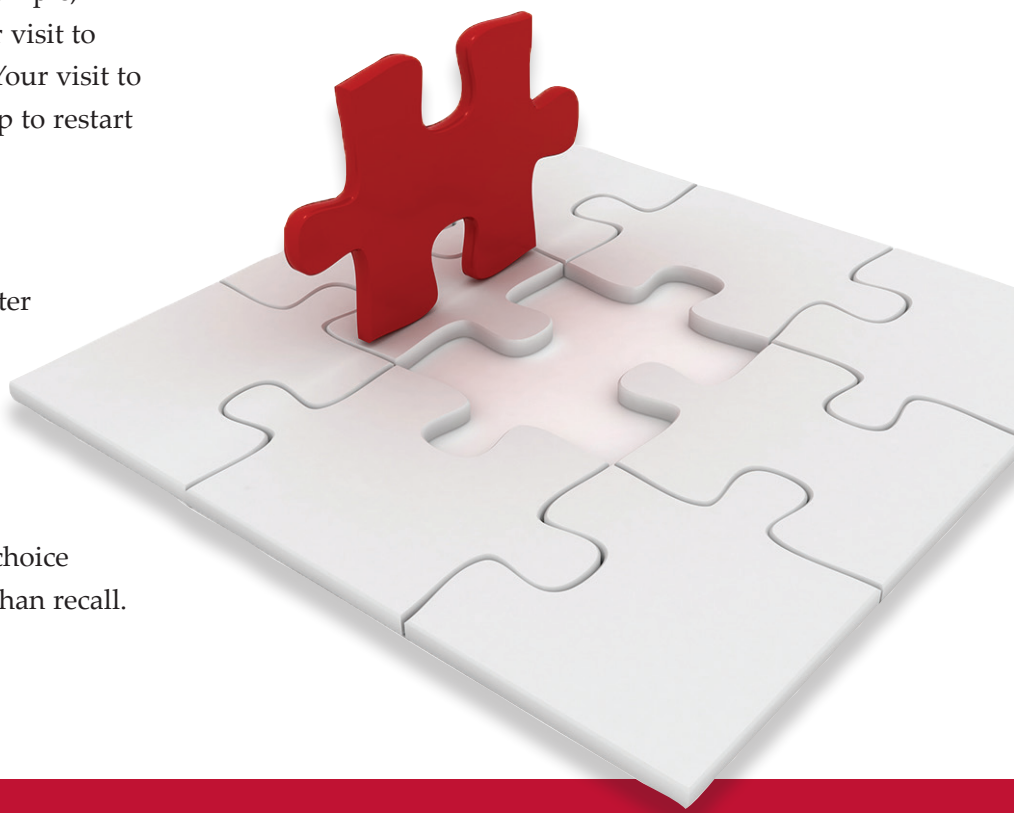
"Would you like coffee or tea?" is better than "What would you like to drink?" because an open-ended question requires the listener to remember the words in the sentence string and then have to consider possible drink options. The choice question relies on recognition rather than recall.

Tip 9: Keep your non-verbal communication positive.

A person with dementia receives a lot of important information from your facial expressions and body language. Stay relaxed, positive, and attentive in your facial expressions and body language, even if the conversation encounters a challenge or two. Also, do not increase the volume of your voice, just speak clearly, at a normal pace and volume. Slowing down and talking louder often does *not* help.

Tip 10: Dignity and respect.

Even though your donor has dementia, they still want to engage with you and your organization. It is important that they feel valued, appreciated, respected, and included. It is important they know their wishes and plans for your organization are being honored.



What **NOT** To Do

As important as it is to learn how to prepare for and be able to facilitate conversations while stewarding donors with dementia, it is equally important to know what *not* to do. Here are some important tips for fundraising professionals and organizations to consider which could impact their ethical, legal, and financial status or infrastructure.

Third-Party Solicitors

If an organization decides to engage in hiring a telemarketer, they need to make sure there are strict policies in place which the telemarketer understands and follows in the possible case that a donor they reach on the phone has potential signs of dementia. For example, The Fundraising Standards Board, a British watchdog group, upheld complaints against a professional telemarketing company which claimed they went too far in pressing a woman with obvious signs of dementia to make a gift.

Use Caution

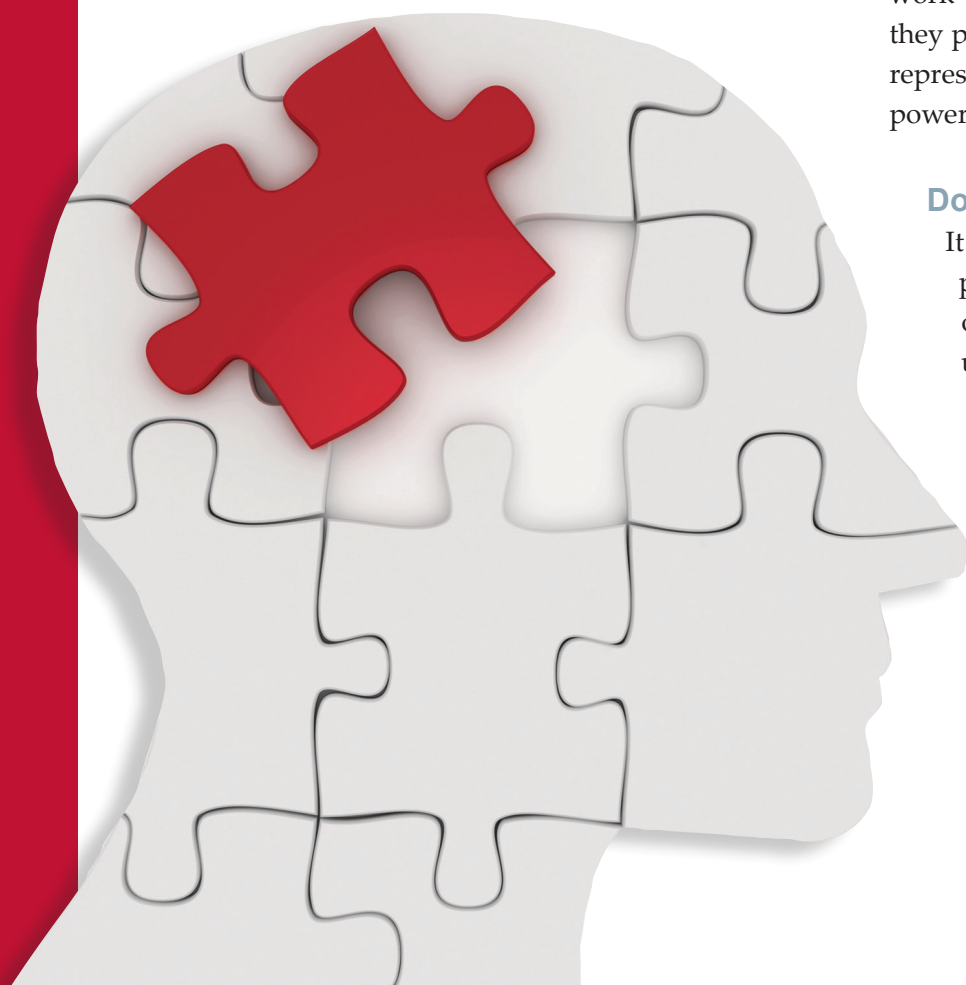
Err on the side of sensitivity and caution in your conversation when stewarding a donor who is either diagnosed with dementia or is showing signs as such. While fundraisers always have the best interest in mind for an organization, it is easy to become over-zealous when your donor has high gift potential. Such was a case where a great-niece of an 89-year-old woman filed a lawsuit against many organizations that issued several charitable gift annuities to her aged aunt in exchange for hundreds of thousands of dollars. The great-niece alleged that the financial well-being of her aunt was compromised.

Gift Conversations

Certainly, if a donor is suspected to not have mental capacity and/or that information has been made explicitly known to you, a gift solicitation made directly with the donor with dementia is completely off the table. If you do need to work with a donor in such a state for a pledge they previously made, make absolutely sure a representative from their family and/or durable power of attorney are present for the conversation.

Documentation

It is good practice for all donor visits, but particularly for those who have signs of or are diagnosed with dementia, to follow up with correspondence notating what was discussed at the visit and thanking them for the valuable time you spent together. If during your stewardship visit conversations included any kind of exchange about the donor's charitable plans, make sure to send a copy of your correspondence to all parties necessary, which could include a family member, financial advisor, and/or durable power of attorney.



Gift conversations with a donor who has dementia are off the table,

but you can and should continue to involve the donor in stewardship activities.



Are Gift Conversations Ever Still an Option?

The question still remains, with a growing aged population who comprise approximately 75 percent of top-gift donors, coupled with projected growth in those who are and those who may be diagnosed with dementia in the future, is there any possibility to still involve these sensitive and fragile individuals in gift conversations? The answer is yes and no. As mentioned before, if the donor shows signs of and/or you are privy to them being diagnosed with dementia, then the gift conversation is completely off the table and should be moved to one that is strictly about stewardship. You can and should continue to involve the donor in your organization by inviting them to events and/or provide other stewardship benefits such as free tickets to a concert or lecture series, for example.

While continuing to professionally steward the donor with dementia, attempt to develop relationships with other members of their family, possibly their financial advisor and/or their durable power of attorney. Establish a connection with them through written communications which acknowledge your recent and past

conversations with the donor and, at the same time, showcase your organization, its mission, and future plans for growth. Encourage and invite them to participate in the stewardship events you have already invited your donor to, expressing how their side-by-side participation will enhance your donor's overall continued life-experience with your organization and those it serves.

While this form of communication is not directly soliciting the donor with dementia nor those closest to them, by opening the lines of communication and sharing your organization's mission with those around them, you perhaps may be opening a new donor door. Often family members will start to see signs of dementia developing in their loved one before you do and will make sure to review estate plans and wills with their loved one along with their various professional advisors. Cultivating relationships with those who are related to and/or know the donor's past and current love and wishes for your organization may help to maintain and/or uncover new gifts to your institution.

Staying Current

Both Rob Hofmann and Dr. Jolene Hyppa-Martin at the University of Minnesota Duluth continue to speak and write on this topic. They will be speaking at the upcoming AFP ICON 2019 conference to raise greater awareness. Dr. Hyppa-Martin and her team will continue to research the necessary skills and other traits which fundraising professionals need to know in stewarding donors with dementia. Both are working on publishing a future book on the topic.

Devoting time to publication on the most current and important topics for philanthropy professionals is paramount to BWF's mission. BWF will continue to follow the work of Dr. Jolene Hyppa-Martin and Rob Hofmann and publicize any new information or research on this topic.

BWF is a full-service philanthropic consulting firm serving clients across the country and globally. For more information on developing specific strategies for your organization in stewarding donors, contact Lani McCollar, BWF associate, at lmccollar@bwf.com.

The Time Has Come

It is hard to ignore the changing landscape of the top-tier major donor population. The numbers speak for themselves, and fundraising professionals have reported that they are ill-equipped to navigate these unstable waters. The time is definitely ripe for consideration of amending the current AFP Code of Ethics, which was last updated 15 years ago, and possibly the Donor's Bill of Rights as well. By doing so, it will both raise the awareness and conscience of organizations and fundraising professionals as to how they should consider working with donors with dementia and also provide a platform where education around current issues will become more widely disseminated.

Rob Hofmann is considering convening a think tank of possible key stakeholders such as University of Minnesota gerontologists, the Alzheimer's Association, other professional fundraisers, estate attorneys, and financial advisors to explore these issues with the outcome of drafting a policy statement and recommended best practices for the field.

To be sure, organizations whose mission reflects serving aging populations certainly cannot ignore these important issues. One such organization, Santa Fe Senior Living Foundation, has developed their own set of ethical fundraising guidelines and standards of practice. It serves as a formalized guideline for the seniors they serve, the families that support them, and the fundraising professionals who interact with their prospects and donors. It is detailed, thorough, and heavily backed by research in its formulation, which could also serve as a starting basis for developing such amendments. ■

