

Tips on Communicating About Brain Donation

Talking to potential donors about brain donation is never easy. Use these tips, based on expert experience and practice, to help ease the way forward. These tips were developed to help dementia researchers communicate with their study participants about brain donations, but may also be useful for health care professionals and community organizations who discuss brain donation with their patients or community members. The tips are broken out by conversation style and audience demographic to best fit the needs of your organization and donors. They can be used along with the Brain Donation FAQs at www.nia.nih.gov/alzheimers/brain-donation-resources-adcs#faq.

Communicating One-on-One

Start the conversation early. The decision to donate one's brain can be difficult. It often requires more than one conversation. Don't wait for a medical emergency or until it's too late to talk to potential donors.

Include loved ones. The opinions of family and friends can play a critical role in a person's decision to donate. Invite everyone to be a part of the conversation. If family members seem reluctant about brain donation, try to have a separate conversation with them without the potential donor present. Provide potential donors with information about how to start the conversation at home.

Set aside time to talk. Don't wait until the end of a lengthy annual visit to talk about brain donation. Make the conversation a priority; schedule a specific time to talk about it during an appointment.

Touch base regularly. At each appointment, ask potential donors how they feel about brain donation. Ask them to identify as ready to enroll; open to but still thinking about donation; or not open to donation, now or ever. Let their response guide your conversation.

Emphasize the benefits. Among brain donors, the most common reason cited for agreeing to donate is to help researchers find a cure for Alzheimer's disease and related dementias. Another factor is that family members often want to confirm, by autopsy, whether their deceased loved one had Alzheimer's



or if something else caused their dementia. Although some tests can help a doctor or researcher see biological signs of the disease in a living person, by examining the brain after death under a microscope, signs of Alzheimer's disease, such as amyloid plaques and tau tangles, or other brain diseases can be identified. When donating as part of a study or by donating to the NIH NeuroBioBank, there is no cost to the family for the donation procedure or the autopsy report. Make these benefits of brain donation a central part of your conversation.

Share stories. Use materials that share the stories of people who have decided to donate. Hearing why others have chosen to donate their brains or the brains of loved ones may be useful for someone who is still unsure. Include stories of people from populations that are underrepresented in research in the materials.

Be specific. Offer the potential donor a clear, detailed description of the donation process. This includes brain autopsy and donation procedures, as well as specific information researchers can learn from donated tissue. Reassure the potential donor and their family that donation will not interfere with plans for funeral services. Regularly share any new research findings and potential implications with possible donors.

Make every staff member a resource. Ensure that all potential donors receive accurate, detailed information. Hold regular staff meetings and training to help staff become well-versed in brain donation procedures, including autopsy and tissue-processing procedures. Make participation mandatory.

Involve the principal investigator. Involving the principal investigator in early conversations with potential donors may promote trust and encourage participation.

Showcase your facility. Offer tours of your brain bank. It's an opportunity to show potential donors what will happen after their brain is donated and how carefully and respectfully scientists treat donated tissue.

Communicating With Diverse Communities

Encourage group discussion. Group discussions can be a constructive format. They encourage peer-to-peer interaction; offer people a chance to hear a variety of perspectives; and allow people to communicate in a familiar, comfortable way. For example, some studies suggest African Americans listen to and trust their peers more than hospital and medical staff. Offer facilitated group discussions among cultural subgroups.

Appeal to your audience. Many people want to know how brain donation will positively affect their community. Emphasize that involvement of diverse communities in research and clinical trials can help scientists discover why some populations are disproportionately affected by Alzheimer's and related dementias. For example, you might explain that although African Americans and Hispanic Americans are more likely to develop Alzheimer's than whites or Asians, our knowledge about why this happens and how these diseases affect their communities is limited because these groups are underrepresented and understudied in research.

Build relationships first. Volunteer at community events, such as health fairs, on a regular basis. This involvement can build the personal connections and trust needed when asking someone to consider brain donation. Maintain these connections throughout the year with regular phone calls, newsletters, and cards for special occasions like birthdays and holidays.

Meet your audience where they are. If possible, conduct annual evaluations in donors' homes. Getting to and from your center may be a major barrier to participating in the brain donation program.

Communicate using a variety of methods. To maximize your reach and impact, present information in multiple ways. For example, potential donors with low literacy levels might not benefit from a written brochure.

Use videos, infographics, and easy-to-read materials. Ensure materials are available in the languages spoken in your community.

Involve religious leaders from the community. People from different cultural and religious groups may be concerned about the religious implications of brain donation. Discuss brain donation with religious leaders and other prominent people in the community. Ask them to consider being part of your brain donation education program.

Promote cultural respect among staff. Provide regular cultural respect training for team members. An ethnically diverse staff may encourage open, honest communication with donors.

References

- Boise L, et al. [Will my soul go to heaven if they take my brain? Beliefs and worries about brain donation among four ethnic groups](#). *Gerontologist*. 2017;57(4):719-734. doi: 10.1093/geront/gnv683.
- Boise L, et al. [Willingness to be a brain donor: A survey of research volunteers from four racial/ethnic groups](#). *Alzheimer Disease and Associated Disorders*. 2017;31(2):135-140. doi: 10.1097/WAD.000000000000174.
- Chan RJ, et al. [Patient attitudes towards brain donation across both neurodegenerative and non-neurodegenerative neurological disorders](#). *Cell and Tissue Banking*. 2020. Epub March 5. doi: 10.1007/s10561-020-09819-2.
- Gamboa CJ and Julion WA. [Proactive recruitment of older African-Americans for Alzheimer's research with brain donation: A cohort case study of success](#). *Journal of Racial and Ethnic Health Disparities*. 2021. Epub June 25, 2020. doi: 10.1007/s40615-020-00803-w.
- Lin MJ, et al. [Why people donate their brain to science: A systematic review](#). *Cell and Tissue Banking*. 2019. Epub Sept. 19. doi: 10.1007/s10561-019-09786-3.
- Montoya Y, et al. ['My parent's body is sacred': Perspectives from adult Latino children about brain donation for Alzheimer disease research](#). *Alzheimer Disease & Associated Disorders*. 2021;1;35(1):88-90. doi: 10.1097/WAD.0000000000000377.
- Striley CW, et al. [Community perceptions related to brain donation: Evidence for intervention](#). *Alzheimer's & Dementia*. 2019. Epub Oct. 23, 2018. doi: 10.1016/j.jalz.2018.09.005.