Sharing our best patient-centric practices from extensive experience in Alzheimer's Disease.

At Fortrea, we're committed to advancing research in Alzheimer's Disease (AD) and other dementias. Learn about our best practices and recommendations developed from years of experience advancing these complex studies.

We're listening to the voices of patients and caregivers:

"Right now, this is complicated. My mother avoids the word [Alzheimer's]. It is shameful for her, and she doesn't want anyone to know."

— Caregiver

"The word 'Alzheimer's' she won't admit to. She just says she has depression. She is afraid she will be like her sister (who has AD), and doesn't want to believe that she has AD. She will only say she has small memory problems."

— Caregiver

"I would be happy to do that (test for a new drug). I would ask my doctor, my psychologist, daughter, husband."

— Patient living with AD

1. Recognize the differences in cultural attitudes about memory loss and dementia

We have found there are varying levels of awareness of Alzheimer's and other dementias as medical conditions versus normal aging. It's important to understand the targeted audience's awareness and provide accessible education, as needed.

2. Know that most study partners do not consider themselves "caregivers" at the early stages of the disease

Instead of targeting specialist caregiver publications, it is better to direct caregiver-directed outreach toward the demographic of spouses/adult children.

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3. Acknowledge the burden of a study for both patients and study partners/caregivers

Many potential clinical trial participants fear study-related assessments, especially lumbar puncture. Other assessments, such as PET/MRI/PK, can also be time-consuming. Pre-assessment day reminders and education about procedures can support these assessments, while take-home reminder cards can document what happened during the visit and what to expect.

4. Consider the fear of side effects and/or disease progression in a study

We recommend providing easy-to-watch and/or repeatable videos in plain language to support study education. Allowing extra discussion time with the study nurse also helps patients and caregivers understand their options.

5. Understand that not all patients will be known to sites

High screen failure rates are common in these studies. Most sites need support with outreach methods to augment recruitment from their databases. The use of diagnostic cognition instruments through an awareness campaign as well as patient advocacy group collaboration and patient ambassadors can help find more eligible patients.

6. Incorporate patient- and caregiver-centric accommodations

In terms of logistics, more attractive studies may consider several accommodations, such as travel support, patient-specific study plans to ease any worries or informal “Tea and Conversation” meetings with care partners.

7. Explore methods to promote protocol compliance and PRO data collection

A focus on education and repeating support calls/meetings along with take-home reminder flowcharts, videos or even refrigerator magnets, can help promote protocol compliance and patient-reported outcome (PRO) data collection. Automating drug accountability can also help care partners, while decentralized and home nursing opportunities can support compliance.

Our neuroscience team is here to help navigate a complex clinical landscape and increase the likelihood of your trial’s success.

LEARN MORE: at fortrea.com/scientific-expertise/by-therapeutic-or-specialty-areas/neuroscience.html

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