

Hello,

Thank you for joining the I-MEASURED research study at the University of Pennsylvania! Last September, we shared the [first paper](#) from this study with you. We have continued to look at the information from the interviews, and we want to share more about what we've learned with you.

We have published the second paper from this study. We have included the paper as a pdf attachment. You can also read it by clicking [here](#). This part of the research study focused on how patients and their families feel about treatments for Alzheimer's disease.

**During interviews, we asked:** Imagine a new treatment was to come out for memory problems. What would you hope it might achieve?

**We identified the following themes** based on participants' answers.

### **Theme 1: Patients and their families wish that new treatments could cure memory problems, but these hopes often feel unrealistic.**

[I wish] I wouldn't have the memory problems, that it would ameliorate that, that it would be gone, I would be without that.

So, it's—will there ever be anything for Alzheimer? Who knows? That could say, take this and you'll be fine? I doubt it.

I mean, realistically, I don't think they're gonna fix this. I mean if they could, yay, but I don't see that happening.

Person with mild dementia

Spouse of a person with mild cognitive impairment

Spouse of a person with moderate dementia

### **Theme 2: Some patients and their families would find it helpful if a new treatment could slow down or stop the worsening of memory problems.**

Well, if I could see that I was plateauing out, it would be wonderful.

You know, when I think back to where we were 2 years ago, if we could have even just halted it there, that would have been lovely. So I would say anything that would halt progression would be amazing. Anything that, obviously, could turn it around would be even more amazing, but that seems a lot to ask of a drug.

Stabilizing where he is right now, stopping progression. That would probably be the biggest gift.

Person with mild cognitive impairment

Child of a person with moderate dementia

Spouse of a person with mild dementia

**Theme 3: But, some families worried about slowing down or stopping the worsening of their loved one’s memory problems. They felt this could extend their loved ones’ suffering or cause distress for family members.**

If you would have asked me this 2 years ago, I would have said just stop it at that point. You know, you don’t have to bring all his memories back because you can—you could make new ones at that point. But today I don’t think there’s any there, so today if it happened, I would want it to be able to reverse it.



Spouse of a person with severe dementia

Well, pie in the sky. Reverse it. Ain’t gonna happen ever. Well, if there’s something that could—do I even wanna slow it down? That’s such a hard question. Do I want to? ... I don’t know.



Spouse of a person with mild dementia

Well, I hate to be Debbie Downer, but if it would keep him the same as what he is, I wouldn’t let him have it... If it’s not gonna change you and make you better and back to how you were before you had it, then it’s wasted on him.



Spouse of a person with moderate dementia

**From these interviews, we learned** that researchers need to continue studying better treatments for dementia. Researchers also need to study the unique experiences that can cause patients and their families to have different feelings about dementia treatments. Researchers and doctors should talk to individual patients and their families to understand when it is appropriate to use treatments for dementia.

**Next, we will** continue looking at participants’ answers to the interview questions. We plan to write one more paper based on the interviews and share what we’ve learned with you.

**For more information about the study,** you can read the attached paper. You can also read it by clicking [here](#).

Please contact us with any questions at [catherine.auriemma@penmedicine.upenn.edu](mailto:catherine.auriemma@penmedicine.upenn.edu).

All the best,

Katie Auriemma, on behalf of the I-MEASURED team